



healthwatch York

Making York work for people with dementia



March 2017

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A note about language

Language shapes our reality. The words we use not only illustrate our thoughts and feelings, but also play a role in either reinforcing or challenging stereotypes.

At Healthwatch York, we follow the social model of disability and therefore use the term disabled people as a political one. People may have physical or sensory impairments, mental health conditions, or learning difficulties, but they face barriers in daily life because of the way society has developed. They are, in essence, disabled by society. For example, a wheelchair user may have a physical impairment, but if buildings are developed with ramps and lifts, they are not 'disabled'. Similarly, if we provide sign language interpreters at meetings, Deaf people who use signing are not disabled. But if we do not, they are.

We feel it is important to use terminology that reflects our belief in empowering people and removing barriers to their inclusion. We have worked closely with a number of disabled people who are passionate campaigners for a greater understanding of the social model. We believe this applies equally to how we talk about and describe the experience of living with dementia. Never has there been an illness where so little support is aimed at those living with the illness. To change this, we must shift the emphasis, focussing much more on people with dementia.

In this report when we use the term 'people with dementia' or 'people living with dementia' we are talking only about those with a dementia diagnosis, or experiencing symptoms of dementia. We are not using it about people caring for those living with dementia. We believe it is important to identify separately the needs of those with dementia, and those caring for them. We heartily endorse the work of both the Dementia Engagement and Empowerment Project and the Dementia Friends programme in challenging the words we use to talk about dementia.

For more information see:

<http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>

<https://www.dementiafriends.org.uk/>

Making York work for people with dementia

Introduction

The purpose of this report is to build on the work already done through the Joseph Rowntree Foundation, to consider how we can make York work for people with dementia, their carers and families.

Dementia Facts & Figures

Dementia is caused by a number of diseases that affect the brain. The most common is Alzheimer's but diseases also include vascular dementia, dementia with Lewy bodies and Pick's disease. Different types of dementia affect the brain at different rates and in different ways, but other things like someone's personal circumstances, the people around them and the environment in which they live, will affect their experience of dementia. Dementia progresses in a way that is unique to each individual.ⁱ In 2014 the Alzheimer's Society published their findings on the impact of dementia in the UK and they suggested that by 2015 there would be over 850,000 people with dementia. They also predicted this figure would increase to over 1,000,000 by 2025. Whilst dementia is often talked about as an issue affecting older people, there are over 40,000 people diagnosed with early onset dementia (before the age of 65).

In 2015, approximately 2,700 people in York aged over 65 were predicted to have dementia.ⁱⁱ This number is expected to rise to over 4,000 by 2030. Of those currently living with dementia in York, roughly half will have a diagnosis. Two thirds live in the community, with a third in residential care. Around half of those living in the community live alone. The Government's dementia diagnosis target – wanting 67% of people with dementia to have a formal dementia diagnosis - is not yet being reached within the city. Despite a recent increase, NHS Vale of York Clinical Commissioning Group reported the rate stands at 55.3%.ⁱⁱⁱ

Why is Healthwatch York looking at dementia?

Since Healthwatch York began in April 2013 until April 2015 we had contact with over 20 individuals raising concerns about support for people living with dementia. Usually these are one-off signposting queries, where people have struggled to get the information they need. The enquiries received indicate:

- People still struggle to get diagnoses, with significant variation in practice between GPs.
- People are not being routinely signposted to sources of support by GPs or social care providers.
- People have poor access to information about available support, particularly at times of crisis.
- People who approach us have often already made contact with up to four other agencies, but have been unable to get the information they need.
- There are serious concerns about the availability of suitable care homes and care homes with nursing support for people with living with dementia.

Each year Healthwatch York surveys the public to identify areas of concern and in our latest survey, 58% of respondents felt that we should look at dementia services. Comments regarding why this should be a priority included:

- You should look at dementia. I've spoken with a number of people about dementia services, and we don't have a good strategic approach in the city to make sure people's needs are met and concerns responded to.
- Dementia is an increasing problem - with 50% of over 80s affected. This will increase in the community.
- It would make a huge difference to Carers if there were more 'day care' opportunities. We all want to keep people at home, but it is exhausting without regular breaks.

We secured funding from Joseph Rowntree Foundation which made it possible for us to take on this work, which we hope builds on their excellent reports:

- Evaluation of the York Dementia Friendly Communities Programme^{iv}
- Developing a national user movement of people with dementia^v
- How can we make our cities dementia friendly?^{vi}

What we did

We worked with York Minds & Voices dementia forum. We invited both people with dementia and their supporters to be involved with this work. We met monthly for a year. At the first meeting, we identified topics that the Forum were keen to explore, using the JRF Evaluation of the York Dementia Friendly Communities Programme as a starting point. At each subsequent meeting, we then took a topic in turn and discussed people's experiences. In some meetings, we split up into two groups – people living with dementia and people caring for those with dementia. This allowed space to explore sensitive topics freely.

We also ran a survey. We made this available electronically and in paper form. We shared copies of the survey with the key dementia support organisations in York. We received a limited number of useable returns. We also had our highest ever number of returns where only the first question was answered – 32 people began the survey without going beyond the first question. Although only from a small sample, it gives an indication about the potential challenges of a digital-by-default approach for people living with dementia.

Key findings

Key themes emerged from our work. These are:

1. Everyone's experience of dementia is unique

It is one of the 5 key facts about dementia that the Dementia Friends programme promotes, but it is still not universally understood.

2. The need for genuine engagement with people with dementia.

People living with dementia in York are keen to share their experience. They can help organisations understand what it means to be dementia friendly. However, engagement opportunities need to move beyond tokenistic representation. Assumptions about what people with dementia can and cannot do limit our abilities to collectively create a dementia friendly York. Many education initiatives are delivered in the absence of people living with dementia.

If you want to know what people with dementia think about something, talk to people with dementia.

3. Diagnosis is vital, but experience of this is inconsistent.

In the Vale of York we are falling short of the national target of making sure 67% of people with dementia have a formally recorded dementia diagnosis. We miss this target by 13%.

The importance of diagnosis was identified repeatedly as an area where improvement is needed and is possible. It was clear that the quality of experience of the diagnostic process varied dramatically.

This tallies clearly with Wendy Mitchell's experience, which she blogged about for JRF:

My GP asked me, "Why would you want a diagnosis?" I wanted a diagnosis to put an end to the uncertainty and give me the ability to start focussing on what I could do. Early diagnosis offers you the opportunity to talk to your loved ones about what you want and develop strategies to give all those around you a more positive experience.^{vii}

People with dementia were very keen to support GPs to understand the importance of diagnosis. They also had examples of how to share this news in a supportive manner. Diagnosis can also be a gateway. Where people are effectively signposted to other support services, this can allow them, and their carers, to get information, advice, support, and access activities, all of which can reduce the need for statutory health and care interventions.

As part of this work, we began developing a guide to dementia support. This was initially based on some work by Salford Dementia Champions. We hope to launch this guide early in 2017, and hope that this can support GPs in their signposting role.

4. Being active and involved, being heard, and helping change things has positive health benefits

Those involved in our sessions repeatedly highlighted how important this was for them. Alongside the well-documented benefits of volunteering^{viii}, particularly for older people^{ix}, positive meaningful activity for people living with dementia helps them maintain their skills, feel connected, and most importantly continue to enjoy life. Some in the group talked about how challenging it was initially before they were aware of activities they could be involved in. They talked about a sense of ‘prescribed disengagement’, of being “sent home to fade and die”.

5. Everyone has a role to play in making life better for people with dementia and can help create communities that are better for us all

The work to address stigma, improve understanding, and enable people to be dementia friendly is vital. However, this work is not just about being dementia friendly, it’s about being friendly to all. Underpinning dementia friendly communities are some fundamental ideas – being patient, slowing down, taking time, being supportive of each other, giving good customer service, providing clear signage and information – all these things not only improve the lives of those with dementia, but help create a society that is better for us all. Simple things like fixing wobbly pavements have a positive impact, not just for people with dementia and for people with mobility challenges, but also for all of us going about our daily lives.

What we found out (in more detail)

Participants

Twenty people took part in the monthly meetings. These were for Minds & Voices forum members and supporters, but ran as ten separate focus groups in a local community venue. Of these 20 people 13 were people with dementia. The remaining seven were carers. The members of the focus groups had been invited through Minds & Voices to take part in the study.

Symptoms

Participants were asked to recall the signs and symptoms that they or their partners were experiencing which suggested there may be a problem. The symptoms of dementia appeared to present themselves in a variety of different ways.

Many raised issues of forgetfulness:

Participant [Carer, Male] ***“My wife came to me and said that she was having some problems forgetting things. I hadn't really noticed.”***

Participant [Carer, Female] ***“He started to put a notice beside his bed to say it was Wednesday. I thought it was a bit odd and wasn't like him.”***

Participant [Carer, Female] ***“He simply didn't know where the dishwasher was, yet he had always been totally aware.”***

Participant [Carer, Male] ***“If you took her out of the house she would lose her sense of direction. Gradually at home she couldn't work out where the bathroom is.”***

Comments were also made that the symptoms go beyond memory, and public awareness of this is limited. Many had experienced comments from friends along the lines of:

“Oh, I should come too! My memory is shocking!”

The group confirmed that denial is a factor:

Participant [Person with dementia, Male] ***“The fear of finding out you may have dementia is worse than the reality of having it.”***

Participant [Carer, Male] ***“It was our daughter who started to worry about her mum, I was in denial. She started the ball rolling.”***

Participant [Person with dementia, Female] ***“We need to challenge the fear of dementia to stop denial.”***

The time before diagnosis can be difficult for the person facing a dementia diagnosis, and for those closest to them.

Participant [Carer, Female] ***“He would forget the answers to questions and accuse me of not answering or telling him lies.”***

Diagnosis

Despite approaching health professionals with their symptoms, for many the process of getting a diagnosis was drawn out, fraught and beset with difficulties.

Participant [Person with dementia, Male] ***“It is cruel and it took years for the doctors to say you have early onset dementia. The process of getting the diagnosis was the worst. It felt really hard when trying to get a diagnosis.”***

Participant [Carer, Female] ***“I had to fight for two and a half years. One of the doctors came to visit us but nothing happened. Eventually one of the doctors said to me ‘Well what do you think is wrong with [husband]’ and I said ‘he has Alzheimer’s’ and then she said ‘but you knew that all along didn’t you?’”***

Participant [Carer, Female] ***“We were told initially that he [my husband] didn’t have dementia when he went for tests at Bootham. However, when Bootham closed. He was sent to Limetrees and was then given the diagnosis of Alzheimer’s disease and Vascular dementia.”***

However, some did report a more positive experience of the diagnosis and subsequent treatment and care service.

Participant [Carer, Male] ***“Gillygate surgery sent her to see the consultant, but that GP has gone now.”***

Participant [Carer, Female] speaking about how her husband was diagnosed and it appeared more straightforward than for some ***“It was a lumbar puncture that pinpointed the markers.”***

Participant [Carer, Female]: ***“We were lucky really. We went to the GP and then everybody [health professionals] came to see us.”***

Participant [Person with dementia, Female] ***“I agree, my getting a diagnosis was also quite straightforward but I think it was because my daughter works in mental health and she was very good, she just did it all.”***

There was an acknowledgement between these two ladies that it may have been easier for them because a family member works in health care. This meant they had support from someone who understands the process and helped them get appropriate medical intervention. The process of assessment and subsequent diagnosis didn't appear a 'one size fits all' for all the participants in the study. One of the participants described the way in which he was assessed for having dementia by a local clinician:

Participant [Person with dementia, Male] ***“She (GP) just chucked a pen on the floor and asked me to pick it up.”***

A couple of members had initial diagnoses that were incorrect.

Participant [Person with dementia, Female] ***“I kept being told that I had labyrinthitis.”***

Participant [Carer, Female] ***“He (speaking about partner with dementia) was treated for depression.”***

One of the participants in the group gave his rationale for why he believed there may be such variation in getting a diagnosis.

Participant [Carer, Male] ***“There is perhaps a lack of a pathway or protocol for people displaying problems with memory or cognition some clinicians are perhaps reticent about diagnosing too early as there is such a lack of treatment options.”***

Treatment / Continued Professional Support

Many of the forum members spoke about the lack of help and support from health and social care professionals since their diagnosis. Despite lack of treatment options many people reported feeling abandoned and unsupported. It appeared that for some gaining a diagnosis was the end of any professional involvement and they felt they were largely left to cope alone.

Participant [Carer, Male] ***“I have been caring for my mum for over three years but we have had only one visit from the health services. Initially you cope alone but as things progress you do need help, support and social activities.”***

Participant [Carer, Male] ***“My wife was diagnosed over ten years ago and we have had very little support by the health and social services during this time.”***

Participant [Person with dementia, Male] ***“I was discharged from Bootham and told that someone would come and see me from somewhere in Acomb, but no one ever did.”***

Participant [Carer, Female] ***“We saw no one in six years.”***

Some reported a belief that the general message being communicated was that there is nothing that can be done. There is no effective treatment, it is progressive and you are going to die.

Participant [Carer, Female] ***“Many people were told to go home, put your affairs in order, and basically wait to die.”***

However, one carer spoke about how at a local General Practice they had employed a 'dementia champion'. This had positively impacted on the service that people received at the practice. There was a greater understanding of the disease, signs and symptoms and the importance of subsequent 'signposting' to further services. In addition, one of the carers reported that one of the local GP practices has strong links with a nursing home for people living with dementia and they visit weekly to check on the residents.

The needs of people with dementia are not always considered when changes to services they need are brought in:

Participant [Person with dementia, Female] ***“I used to get blister packs from (name of pharmacy). They won't do them any more as they've ‘got too much on.’ I get lots of different medications, but if I call my previous pharmacy for any of them I am now told I have to ring (different branch of same pharmacy). They will only deliver medication when the blister pack is due, so anything outside of these has to wait. I take some medication which stops me from passing out. At the moment I only have three of these tablets left, but the pharmacist will not deliver more until the next blister pack is due in a week. I'm worried that this puts me at additional risk of falls. It is all so confusing - why are our medical services making it harder for people to look after themselves?”***

Some of the study participants discussed how when drug manufacturers change their tablet design and packets. They felt that this can have a big impact for someone with dementia because of the issues around learning new information and coping with visual changes.

Participant [Person living with dementia, Female] ***“When tablets change it is really confusing. They used to be all red but now they are all yellow.”***

Participant [Carer, Female] ***“It totally throws you when they change the boxes. He used to recognise the packaging.”***

Participant [Carer, Female] ***“They don't realise the confusion it causes. We used to have to halve his long pills but now they have changed and substituted them for small round ones.”***

Family and Relationships

Many of the participants spoke how important family and friends are in order to cope as there were such lack of support from health services.

Participant [Carer, Male] ***“You need a good family around you and we have.”***

Participant [Person with dementia, Female] ***“I can't go into town any more as I get lost. But I have a friend who goes with me once a month. I have someone to talk to, someone who is different to your husband or carer.”***

Participant [Person with dementia, Male] ***“I have friends that I have always had and we still go out together regularly”.***

However, telling family and friends could be problematic. Group members believed this was because of the lack of understanding and awareness around what it means to have dementia. For some this meant that friendships had ended and family relationships became difficult or had broken down completely. The idea that being diagnosed with dementia means immediately becoming incapable of functioning was a source of huge annoyance for some. The group talked of the importance of recognising that people are still the same person they were before the diagnosis was made:

Participant [Person with dementia, Male] ***“My children can drive me around the bend, because they say Dad you can't do this or that 'cos you have dementia.”***

Participant [Carer, Female] ***“Our daughter-in-law comes every week not every day and starts saying to me you should do this or do that. They are not here for us, they don't see what is happening every day and they don't know what it is like.”***

Participant [Person with dementia, Female] ***“My brother can't cope with my dementia. My son thought I should be in a mental home.”***

Participant [Person with dementia, Male] ***“Friends I had have now gone. I don't know if it is the dementia or they have just backed off.”***

Participant [Carer, Female] ***“We have lost friends you know, good friends, friends that we have had for a long time. I don't think they could handle it, his diagnosis.”***

Sometimes the loss of memory associated with dementia impacted upon how much that person remembered about those individuals, the friendship and what it had been and meant to them throughout their life.

Participant [Carer, Female] ***“We went to friends one lunchtime. These people we have known for over twenty years. When we left he (person with dementia) asked me ‘Are they good friends of ours?’ He forgot he knew them.”***

York’s Dementia Friendly and Dementia Unfriendly Places and Spaces

The forum members were asked about what they understand by the term 'Dementia Friendly'

Participant [Person with dementia, Female] ***“People helping you who understand how you feel and that you are not as quick as you might be.”***

They discussed what makes an environment dementia friendly and what the requirements would be to receive 'dementia friendly' status. If dementia is a disability what are the equivalent requirements for those with dementia that handrails, ramps, or lifts are for wheelchair users? What should people expect to be in place in order for someone with dementia to access services and facilities? There was a suggestion that some of the group’s members could carry out audits into the suitability of places for people with dementia. Members of the group felt this was an important idea.

Nearly all the participants described experiences where they felt that a place, space, individuals or organisations were not being 'dementia friendly'.

Participant [Person with dementia, Female] speaking about her experiences in a well-known department store in York ***“A few years ago I asked for a nightdress. They said use your eyes they are over there.”***

Participant [Person with dementia, Male] ***“I went into a shop in town and the staff were stood chatting. I asked for a book and he pointed to a mass of books but he wouldn't come and show me.”***

However, the difficulties experienced weren't confined to shopping. Many of the forum spoke about frontline staff providing health or social care support who were not dementia aware. The group felt this was surprising as they had an expectation of greater understanding of what dementia is and how that impacts upon an individual amongst health and care professionals.

One participant living with dementia spoke of a situation which caused him upset and confusion. He was involved with a local housing trust. They were encouraging him to move out of his home into other accommodation:

Participant [Person with dementia, Male] ***“They give you 24 hours to decide if you want it. If you don't (make a decision) then in 24 hours it is gone. I couldn't cope, they were very abrupt. I said if I live there I will need three buses to get to places which would be a problem as I have dementia.”***

The physical environment of an establishment could also present challenges for someone living with dementia. The group spoke about the hospital and how the layout, signage, long corridors, lack of wheelchairs, poor lighting and at times lack of staff available to help support people to access where they needed or wanted to be.

There were also problems reported using public transport. These included issues getting on and off the buses, accessing seats for disabled and older people. One of the participants recalled a time when she took the wrong bus in confusion.

Participant [Person living with dementia, Female] ***“The driver wouldn't stop but a young man on the bus was really helpful and made the bus driver stop and wait for him whilst he showed me what to do.”***

Similarly, when organisations like banks, building societies and even GP surgeries introduce touch screens these can become prohibitive to people

living with dementia. When humans are replaced with technology and machines this can be devastating for someone with dementia as they rely on human engagement in order to access services etc. and to retain their independence as much as possible.

Participant [Carer, Female] speaking about how dementia has affected her husband's ability to use technology ***“He can't do anything with technology, not even the telephone or TV controls.”***

Participant [Person living with dementia, Male] speaking about a high street banking branch, ***“Faced with the machines, I have given up with the banking machines.”***

Participant [Person living with dementia, Male] speaking about the railway station and the ticket machines ***“I used the machine once but now go to the desk.”***

However, there were many examples given by the forum members of how people and some local organisations were 'getting it right' for people with dementia. Often it simply came down to the attitude and the approach of the staff members.

Participant [Carer, Male] ***“There was this cashier at (Name of shop) who was wonderful with this guy who was confused over his money.”***

Participant [Person with dementia, Female] ***“(Name of shop) are wonderful, a friend told a member of staff that I had Alzheimer's, so the lady said she is still a human being and took me by the arm and chatted to me.”***

Even when the physical environment or the layout of a business or store can appear to be the most 'awkward' for a person living with dementia, it was again the attitude and approach of the staff working within it that turned a seemingly 'dementia unfriendly' environment into a 'dementia friendly' place. One very well-known local family business in York was highly praised by several members because despite the chaotic layout, the many entrance and exit doors, the several flights of stairs, and the lack of a lift, the staff were always helpful and for one of our members who lives with dementia they

allowed her dog in the store too. Similarly, with another local department store, they too were recognised by the participants as being supportive.

Many of the participants insisted that the key is to tell people that you or your partner is living with dementia because it can often lead to greater understanding and a better service.

Participant [Carer, Female] ***“Once people know, most will fall over themselves to be helpful.”***

Participant [Carer, Female] ***“There are pockets of good practice, lots of good stuff out there already. You just have to tell people and often they will be only too willing to help if they know. My husband tells people you have to bear with me as I have dementia.”***

Another of the participants who is living with dementia also believes that the best way to cope is just to tell people that you have dementia

Participant [Person living with dementia, Male] ***“I go and play bingo. Daughter went to the desk and explained that Dad has dementia. That's (Name of Bingo) they are marvellous really.”***

Participant [Person living with dementia, Female] talking about her local pharmacy ***“You know since I have told them that I have Alzheimer's, they have been great and now they have my medication ready for collection.”***

Coping and Caring - Living with Dementia

Without exception, the carers discussed the initial shock that they or their loved one felt when either they or their partner was diagnosed with dementia and how they coped with the news.

Participant [Carer, Male] ***“She (person with dementia) was devastated, she was in shock when she got diagnosed.”***

Participant [Carer, Male] ***“When my wife was diagnosed I was in denial but she came to terms with it – it took two years to tell people that she [my wife] has dementia.”***

Although there was the acknowledgement that dementia does have an impact on one's life and independence, the idea that it was inevitably the end of the useful happy, fulfilling part of your life was not a view held by any of the group. The participants shared with the group the strategies and routines they had introduced to help them cope and the activities they were now participating in since diagnosis.

Participant [Person with dementia, Female] ***"We are all normal. We just have an impairment. Like any other disabled person."***

Participant [Person with dementia, Male] ***"Going on the panel for JRF grants really reminded me of being a parish councillor. It links to who I am, what I do. I felt useful again."***

Participant [Carer, Female] ***"He has coped well with it, there were lots of tears and now we said so let's get on with living, so we went to Australia and that was six years ago. We have long silences and sometimes he doesn't answer if I speak to him. He is happy with his life, it is as full as possible."***

Participant [Carer, Female] ***"He (person with dementia) will sit, but he is always doing something and if I ask him he will go and do it."***

Participant [Carer, Female] ***"We are brilliant at going out for coffee."***

Participant [Carer, Female] ***"Once a month we go to a carers group in the village (Haxby). We learn such a lot talking to each other."***

Participant [Carer, Female] ***"You do have fun, we have fun at our singing group." (speaking about Vocal Flourish)***

Participant [Carer, Male] ***"She (partner with dementia) likes doing crafts, especially making cards."***

Participant [Carer, Female] ***"We still like to get away. Went on holiday with Shearings to Torquay. Went on a few trips with them, had a good experience with them."***

Participant [Carer, Male] ***“We go on holiday with Diamond holidays to Scotland, they are good.”***

When asked what it was that made those holidays successful:

Participant [Carer, Female] ***“Ah they are just very good, they just treat you like you are all normal and look after you from door to door.”***

Participant [Carer, Male] ***“It doesn’t seem to matter that she’s got dementia like, they just are good and everything is done for you.”***

The participants spoke about some of the difficulties they experienced at times being cared for or caring for someone with dementia as the disease appeared to affect people in a variety of different ways and with most relationships there are challenges. Before dementia, couples would not usually be with each other 24 hours a day, but pursuing their own work, hobbies or interests. There is a need for more opportunities for both people living with dementia and carers to spend time apart, as well as activities they can take part in together.

Participant [Person with dementia, Female] ***“There is friction between people with dementia and carers. Always wrong assumptions about what you can and can't do.”***

Participant [Carer, Female] ***“I do the best I can but sometimes I say to (my husband) that you can't speak to me that way. He can sometimes use really bad language [he didn't swear before diagnosis] and I tell him, I am not standing for that.”***

Participant [Carer, Female] ***“He (husband with dementia) just sits and closes his eyes. It drives me mad.”***

Participant [Carer, Female] ***“It’s very restrictive when you can't leave them alone.”***

However at times, and like most relationships, the group confirmed the need to have space and time apart.

Participant [Carer, Female] ***“You cope best when you get time away.”***

Participant [Carer, Female] ***“I like the theatre festival as I need to keep up my independence.”***

Participant [Carer, Female] ***“I am glad I am away from him for those five hours. I love my day at the hospital.”***

Participant [Carer, Female] ***“It is essential to have time away. He (person living with dementia) goes to his club (day centre) he loves it and I just go phew and breathe a sigh of relief. I can go to the hairdressers or meet with friends or family for coffee.”***

Participant [Carer, Female] ***“My husband (person with dementia) loves to go to the Gym once a week, they all know him in there so he is fine.”***

Moving On - 'York a Dementia Friendly City'

The group were asked what they felt could be done to help York become a great city for people with dementia. These are the key suggestions that were made:

Education/Raising Awareness

Education was seen as the most important step in raising public awareness. The group felt that with prevalence and incidence of dementia on the increase, it is likely that most people will know someone with a dementia now or in the future. However the group don't want a 'doom and gloom' scenario like the media describes. They want very clear factual information about dementia. This should cover what it is and how it can affect many aspects of people's lives. They wanted to be clear it does not just affect memory but how people can tolerate crowds, social situations, colours, lighting, and noise levels. Many of the forum wanted to highlight that since and in spite of their diagnosis, they are living full and interesting lives. Some now take part in and enjoy more social activities than ever before.

Participant [Carer, Female] ***“We need to talk to people because I think people are frightened by dementia.”***

Participant [Person with dementia, Male] ***“I’ve never had such a good social life till I got dementia. My diary is full now!”***

Participant [Person with dementia] ***“The public have to be taught, they don't know what to say.”***

One of the couples in the group became involved in making a film. This aims to raise awareness and dispel some of the stereotypical views about living with dementia.

Participant [Carer] ***“We made a film, sharing normal life, he (partner with dementia) doing what he likes (playing the piano).”***

Several members of the group are actively involved in giving talks to people to help raise awareness of what can be achieved with a diagnosis of dementia.

Participant [Carer, Male] ***“She (wife with dementia) gave a talk in London. She has never done anything like this before. She was brilliant.”***

One of the group discussed a talk that they went to about a dementia study, attended by many health professionals. The study findings were that there was a low level of dementia awareness amongst clinicians. Many lacked knowledge about dementia and how it affects and impacts upon people. The person attending the conference felt these statistics were worrying. Others agreed because, as one of the participants who lives with dementia suggests, ***“If clinicians are not informed and educated about dementia what will happen to us? We rely on them to refer us for diagnosis and further support.”***

Participant [Person living with dementia, Female] ***“There is a need to get levels of awareness in clinicians up as they act as the gateway to services.”***

Participant [Person living with dementia, Female] ***“No-one gives us a manual. We need help and support to know what to do.”***

One of the members suggests that there may also be a reluctance to diagnose too early due to lack of effective treatments available. They felt that it can be 'scary' for clinicians to give the diagnosis because of the perceived 'doom and gloom' scenario around the condition.

All participants stressed the importance of raising awareness within the wider population. They felt that where people were informed and aware this has a positive impact on those living with dementia. Awareness of dementia was often delivered through the 'Dementia Friends' programme. This has been created by Alzheimer's Society, usually delivered by volunteers within the community. The group felt these awareness raising sessions provide significant benefits for those working with or offering a service to people who may have dementia. However, they felt these sessions could be improved through the direct involvement of people with dementia. Other awareness raising opportunities in this area have been provided by Dementia Forward.

Participant [Person with dementia, Male] ***“We need people to know that Alzheimer’s is not just one thing. Not everyone is GaGa.”***

Participant [Carer, Female] ***“I think that any of the groups that have had people in to explain, I think anyone who has learned are more aware of it.”***

Participant [Carer, Female] ***“We are lucky in Haxby, nearly all the shops are dementia friendly”.***

Participant [Carer, Female] ***“He (husband with dementia) loves to go to Aroma cafe in Haxby. All staff are 'Dementia Friends'.”***

There was a feeling things are improving with the wider public. Many appreciated the ***“unexpected kindness of strangers.”***

Participant [Person with dementia, Male] (speaking about a situation when he became confused) ***“A young lady sat on the doorstep and said ‘are you OK, you look a bit confused’ and I said ‘I am.’ She helped turn me round and as soon as she did I knew where I was.”***

Participant [Person with dementia, Female] ***“A person I did know stopped when I had a funny turn. Another person who I didn’t stopped in their car. They took me home, the other person took my walker home. They were lovely.”***

There was also a view that it is never too early to educate young people about dementia as it likely that either now or in the future children will experience a family member, friend or neighbour with dementia. One member recalled that 'Joseph Rowntree School' showed their pupils a film about people with dementia and this is what they had to say about it.

Participant [Carer, Female] ***“One of the pupils reported ‘we realised that they are still people inside’ which was brilliant.”***

Several suggested that dementia awareness for all people working in the health and social care services should be mandatory and not optional as it appears to be at the moment. This awareness raising activity could be extended to everyone who deals with the public so that all people have a greater understanding of the disease and implement changes in their organisations to accommodate people with memory impairment. The idea is that more places could become more accessible for people with dementia and perhaps there could be a 'ten step' action plan to have some sort of accreditation.

Work/Employment

For many of the group a diagnosis of dementia meant the end of their careers and working life. The group discussed whether this was an inevitable consequence of the disease. There was discussion about what people should expect and want from employers. Should reasonable adjustments be made to accommodate their needs? What are the employment rights of people with dementia? Should work be done to challenge the expectation that people with dementia become immediately unable to work?

Participant [Person living with dementia, Female] ***“I went to work and told them I had been diagnosed with dementia. I never went back again.”***

Participant [Person with dementia, Male] ***“I was in the police and they just tell you ‘You can’t do your job so off you go.’”***

However, one of the forum members with dementia did continue working after his diagnosis. His employers agreed to a “sideways shift”. They worked with him to understand what was challenging within the role and made reasonable adjustments.

There was hope that things are beginning to change. Recently, another one of the group has been approached about doing some form of employment appropriate for his needs and with the correct support. As another member commented:

Participant [Carer, Female] ***“Shops like Sainsbury’s have been doing it for ages taking on disabled people.”***

Participant [Carer, Female] ***“Aroma Cafe in Haxby are special and they have a person with dementia working alongside someone else.”***

Participant [Carer, Female]: ***“We were employed by Tees Esk and Wear Valleys NHS Foundation Trust to interview staff, as part of the recruitment panel. We really valued this opportunity, but had a lot to contribute too.”***

Clubs/Organisations

There was a recognition that York has lots of clubs, classes, cafes, and events that are suitable for people with dementia. Some of the forum members have never been so busy.

Participant [Carer, Female] ***“There are pockets of good practice, lots of good stuff out there already”.***

However for many this hadn’t always been true. Some of the group spoke about the impact that being part of 'Minds and Voices' had made in their lives. The support and company that they had since joining the group was significant.

Participant [Person living with dementia, Female] ***“After all these years our lives have come back once meeting up with this group.”***

Participant [Person living with dementia, Male] ***“It’s a good life and since coming to these forums it has been really great.”***

Many reflected on the positive benefits of involvement:

Participant [Person with dementia, Female] ***“My family said ‘you’ve really improved since you got involved in activities.’”***

Participant [Carer, Male] ***“It’s great when I look at their diary, it’s full of things she wants to do, and she’s better when she’s involved in things.”***

When discussing what prevents people getting involved with activities, transport was identified as a significant barrier. As one participant stated ***“the success of an activity depends on making sure I can get there”***. The main barriers identified were:

- Money (taxis are expensive)
- Difficulties using public transport
- Making sure everything was arranged
- No longer driving
- Family or friends being unable to drive you at the time of activities

Several of the group are concerned that there are still many more people isolated at home with dementia. As this is quite a small group given that there are over 2,700 people with dementia in York, they are keen to know the circumstances of these other people. Considering how challenging many of these people found accessing good information, they worried that isolated people are even less likely to be able to access some of the groups etc. which support people with dementia. They questioned how different organisations can work together to identify how they get information to these people who need it most. They suggested a task force to reach out and identify those people with dementia who are not connected with any support or social activities.

Participant [Person with dementia, Male] ***“I just want to go round and bring people out.”***

Participant [Person with dementia, Male] speaking about himself getting out there and talking to people about living with dementia ***“If you have got it, flaunt it.”***

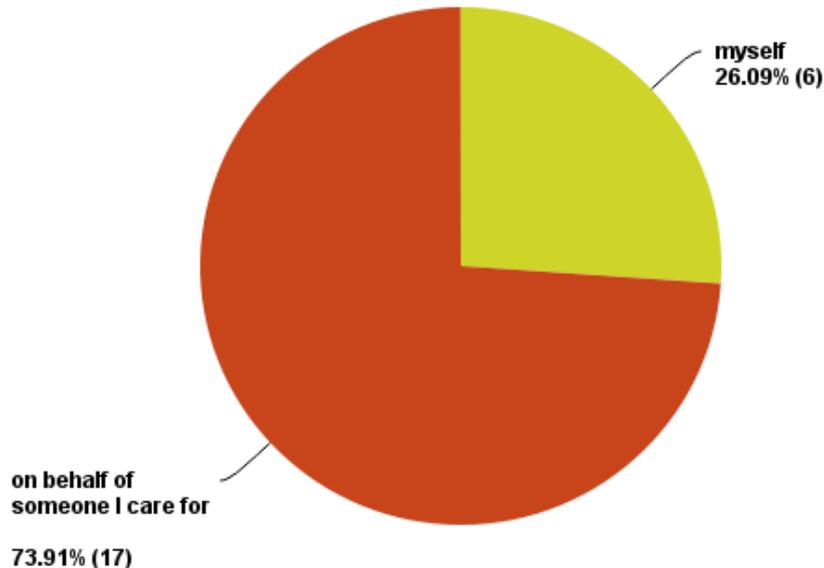
The group discussed where people look for information when they receive a diagnosis. The group felt people usually look for it at health services. From their experiences, quite often they have found very little or no information available. One member of the group suggested there is demand for information for people with dementia – he had recently placed some leaflets in his GP surgery and by the next day they were all gone. However, it is possible that staff simply moved it.

The group were asked to think about information. What did they need to know and how do they want it? Many suggested the need for information at diagnosis. This way they can move forward in their lives - come to terms with their diagnosis and live life the best way possible for them. Not having appropriate information can make them feel more isolated and less able. The group felt having a dementia support service that helps people navigate and access relevant support and information is vital. Dementia Forward are contracted to provide this support in York. Some of the group had been signposted to them, but experience of being signposted was inconsistent. They felt that improved signposting by clinicians to this service was vital. They also felt information needed to be available face to face, in writing, and through peer support.

Survey results

Q1 Who are you answering this survey for?

Answered: 23 Skipped: 1



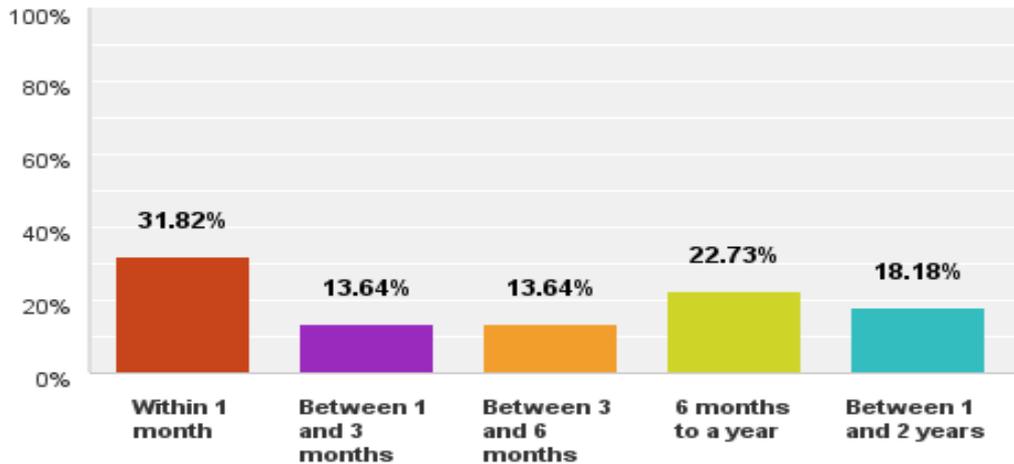
Q2 Can you tell us what made you think that there might be a problem with your memory?

Answers included:

- I started forgetting my children's names 8 years ago
- Lack of co-ordination and general confusion rather than forgetting facts
- General forgetfulness, leaving oven on, hand / brain co-ordination slightly affected
- I didn't, my doctor realised it
- Relations said I was not myself and I kept getting lost and forgetful
- Previous family members have had dementia and so as it can be hereditary I always knew that it was a strong possibility for me. I started forgetting things occasionally in my early 70s and it gradually was getting worse. I decided to phone the doctors surgery for an appointment to have a test

Q3 How long was it before you contacted your GP to discuss your symptoms?

Answered: 22 Skipped: 2

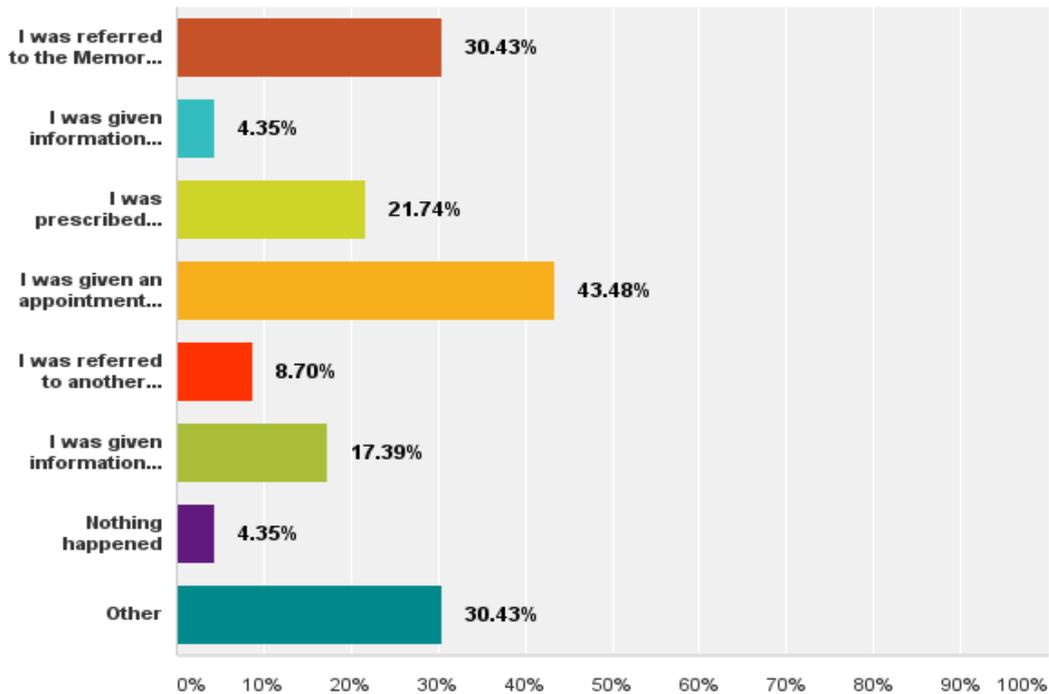


Comments included:

- Maybe more
- Hard to say as I don't think my mum herself contacted the GP, she simply carried on and adapted to life with my dad gradually taking over more tasks. Only as I became more concerned did I go to the GP

Q5 What happened following your conversation with your GP?

Answered: 23 Skipped: 1

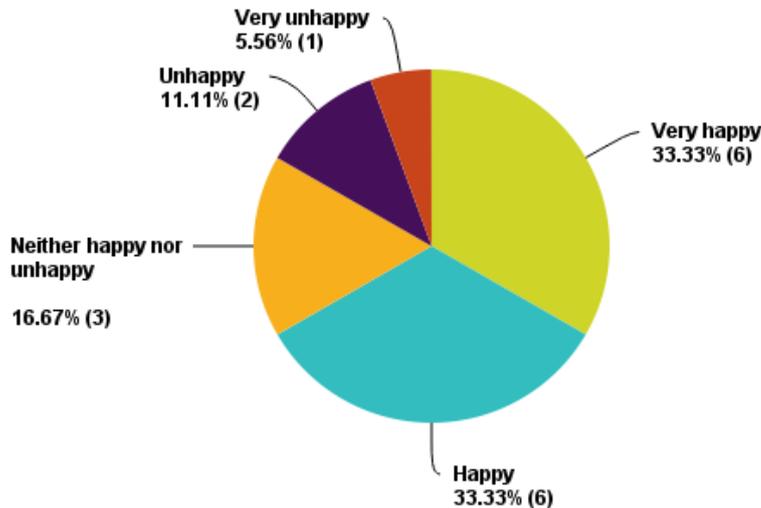


'Others' included:

- I went to a private hospital and consulted a neurologist
- Nurse at surgery was excellent. She asked me several questions. Blood was taken for various tests and then we had a talk about family history of dementia. This was followed with a CT scan then an appointment with a doctor at Bootham Park
- I have attended the GP twice and am waiting for further help which is in the pipeline
- I was asked 4 questions to which I did not know the answers and was told I had pre-senile dementia!!!
- Referred to CMHT
- Did a quick memory test which was ok
- Having taken the standard memory test, initial score 28/30 was recommended to repeat the test in 6 months

Q6 Overall, how happy or unhappy were you with your GP's response?

Answered: 18 Skipped: 6



Comments included:

- Happy after the second consultation, ignored at first consultation
- Been over long period sometimes good, sometimes not so good
- Didn't believe him

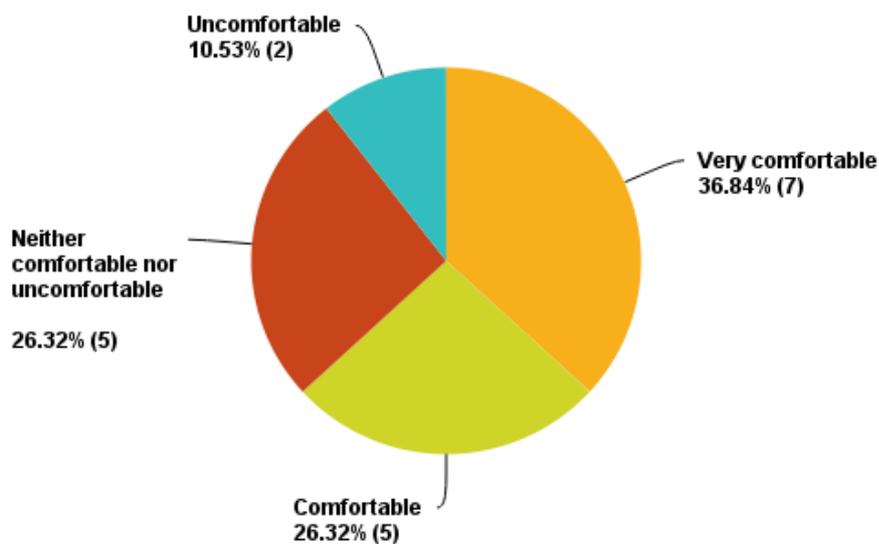
Q7 Please tell us in your own words about your experience

- The GP handled it in a friendly and efficient manner
- It was scary
- Told to come back "when dinner down your shirt" by GP. 2nd visit with another GP made immediate referral and prescribed daily tablets.
- 4 questions to determine dementia, I was totally disgusted. I was then left to my own devices to try and get something done about it.
- On arrival in York I was referred to a consultant. One year later I saw a memory nurse
- Prescribed medication for Parkinson's – referred to Parkinson's clinic. No further information given
- It took several repeat tests at which each score got progressively lower and it took pressure from carers to finally get referral to a consultant after 2 years

- I had some difficulty in getting to speak to the GP on my mum's behalf to express my concerns and request assessment, hence time passed further and symptoms progressed. Eventually I managed to get a home visit by the GP to assess my mum but only because I knew what to say. I used my professional knowledge and experience to do so. I think if my father had done this himself without my support he would have struggled to achieve this.
- First I wasn't happy with this response as he didn't believe me. Then went a second time and he did something.

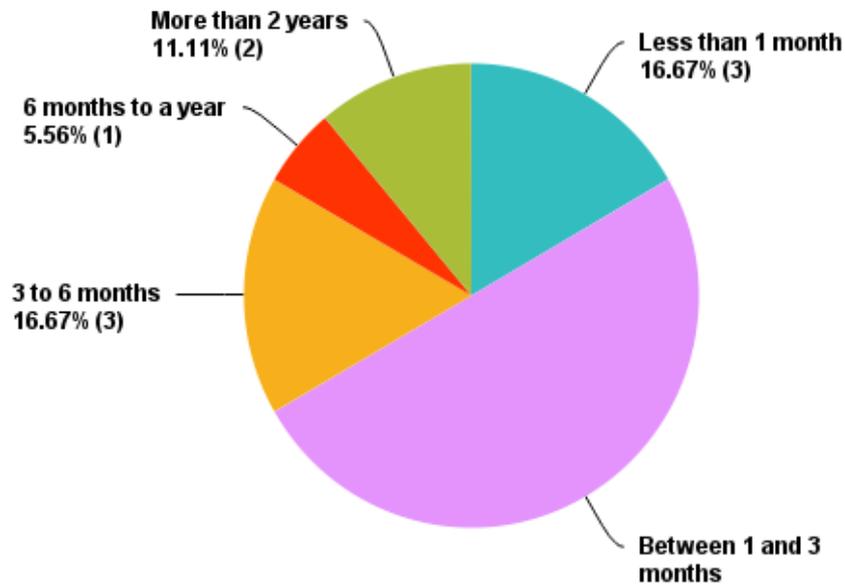
Q8 How comfortable do you think your GP was in talking about dementia with you

Answered: 19 Skipped: 5



Q10 How long did it take before you were given a diagnosis of Dementia?

Answered: 18 Skipped: 7

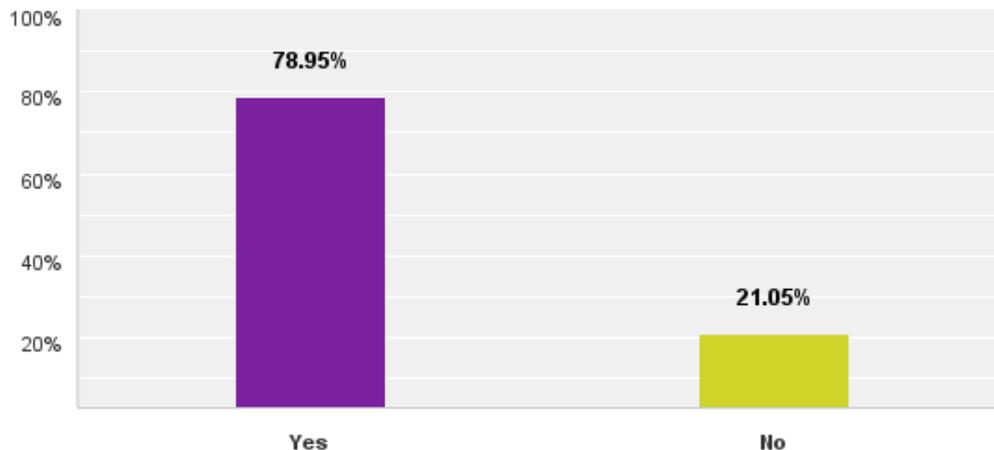


Comments included:

- The consultant never actually said that I had Alzheimer's. I was told I had some short term memory problems. I found out years later that she had diagnosed me as having Alzheimer's
- Initially 2 years with GP before referral to consultant, then about 6 months for consultant to confirm

Q11 Are you receiving any treatment for Dementia?

Answered: 19 Skipped: 5

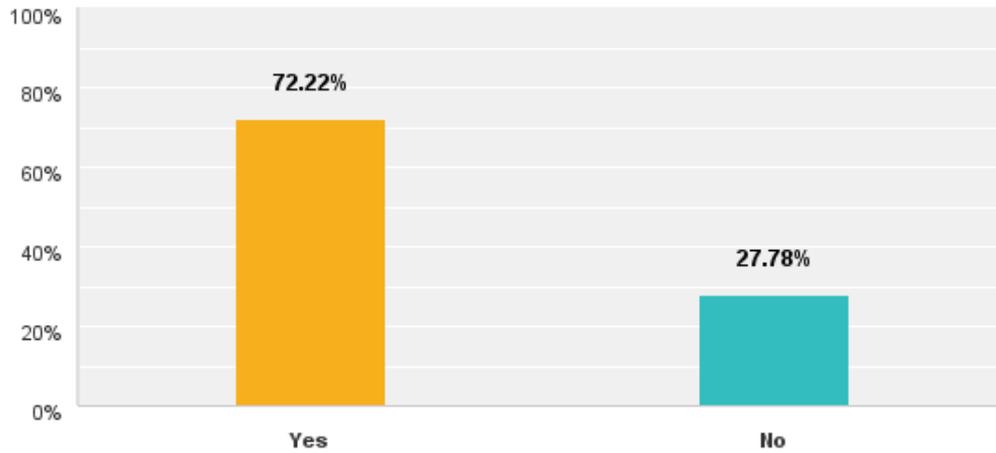


Comments included:

- Nurse used to come and visit. Not much support, found it difficult in the community
- Eventually after seeing 2 more GPs knowing they would not contradict the original GP I went to see a very RUDE psychiatrist. “I think you have Alzheimer’s” was his diagnosis. My husband had to ask for medication for me. “What did you have in mind?” was the reply from the psychiatrist.
- I receive a monthly injection
- Donepezil
- Voleze transdermal patch
- Aricept (+ trial drug via Alzheimer’s Society dementia research)
- Consultant gave treatment for drugs within a month
- Not Doneprizil as this didn’t suit, had side effects. Memantine

Q12 Do you know what type of dementia you have?

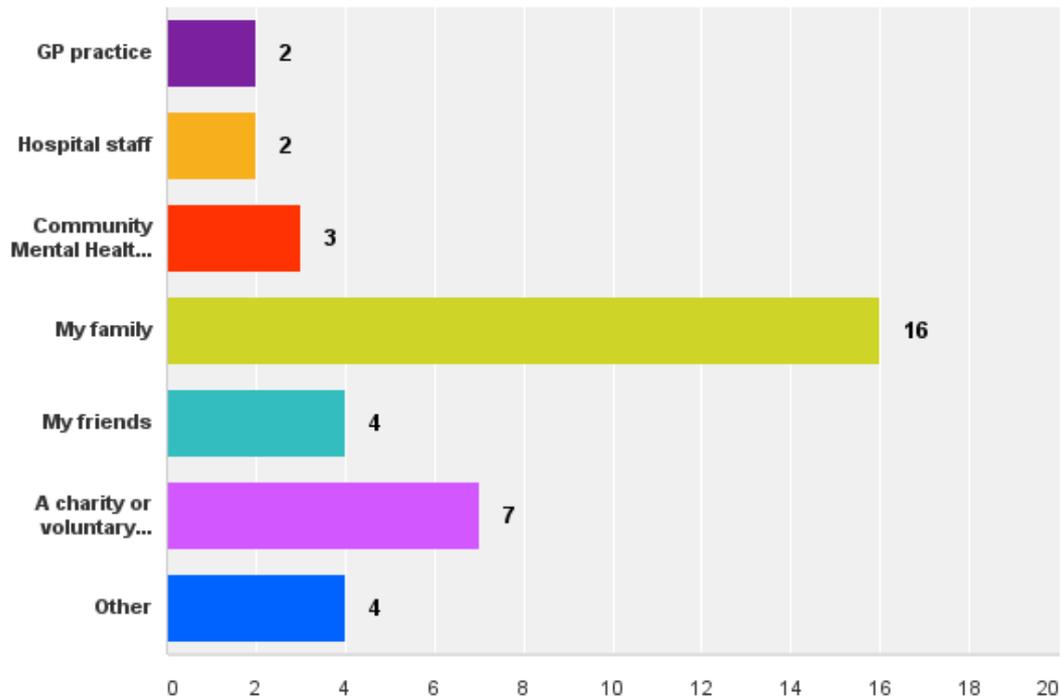
Answered: 18 Skipped: 6



13 respondents provided more detail: 7 respondents were told they had Alzheimer's, one being early onset, 4 had vascular dementia, 1 Parkinson's related, and 1 was told it was not vascular.

Q13 Who has provided you with the most support?

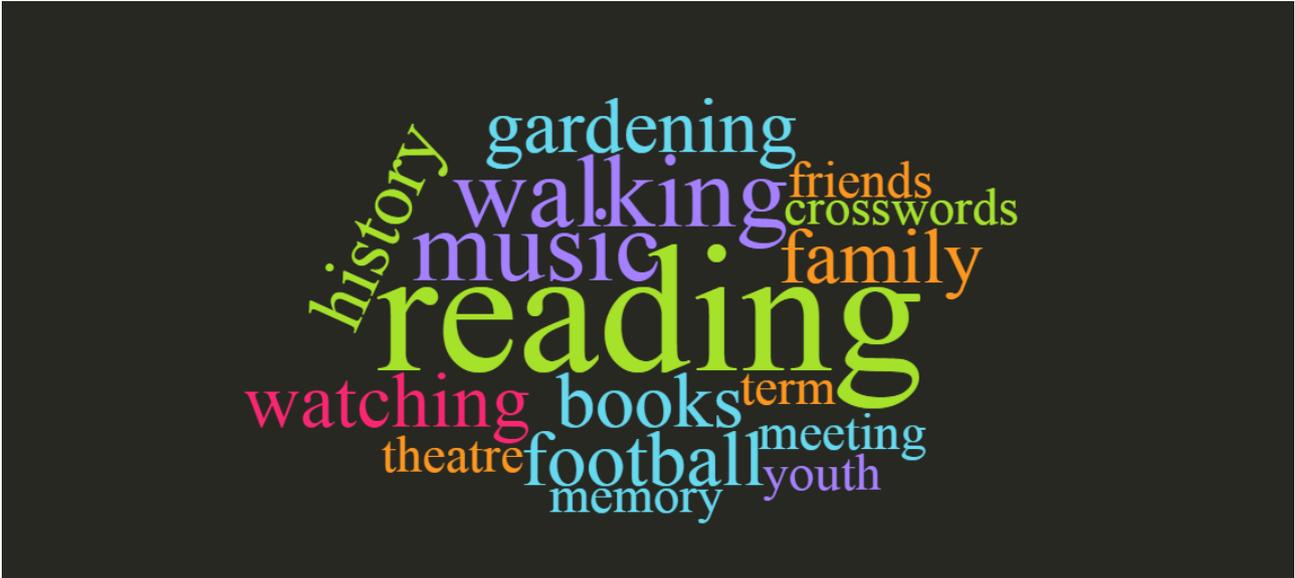
Answered: 20 Skipped: 4



Comments included:

- Aroma Café, Haxby
- Up until this year only GP. Now coming to this café that is providing support. Had 2 nurses from Selby to do a memory test. Still under York Hospital.
- Everyone – thank goodness
- Dementia café – Clements Hall. Visit from Dementia Forward initially.
- Nurse and family
- My husband and Dementia Forward
- My niece
- Nursing home

Q14 What hobbies did you have before your diagnosis?



Most popular answers: 12 mentioned sports (including walking, football, cricket, keep fit, and dancing) 7 mentioned reading, 7 games including chess, solitaire crosswords and bingo, 5 music , 4 meeting friends and family, 3 each for gardening, crafts and history, 2 holidays and days away, and 1 each for cooking, church, shopping and theatre.

Q15 Are you still able to enjoy these hobbies?

10 respondents said no, with 2 qualified answers

- Only normal every day walking. I wouldn't like a walk leader to have the responsibility of me getting lost when my dementia deteriorates
- not really. I am in a nursing home and wheelchair bound).

5 said yes, with 2 qualified answers:

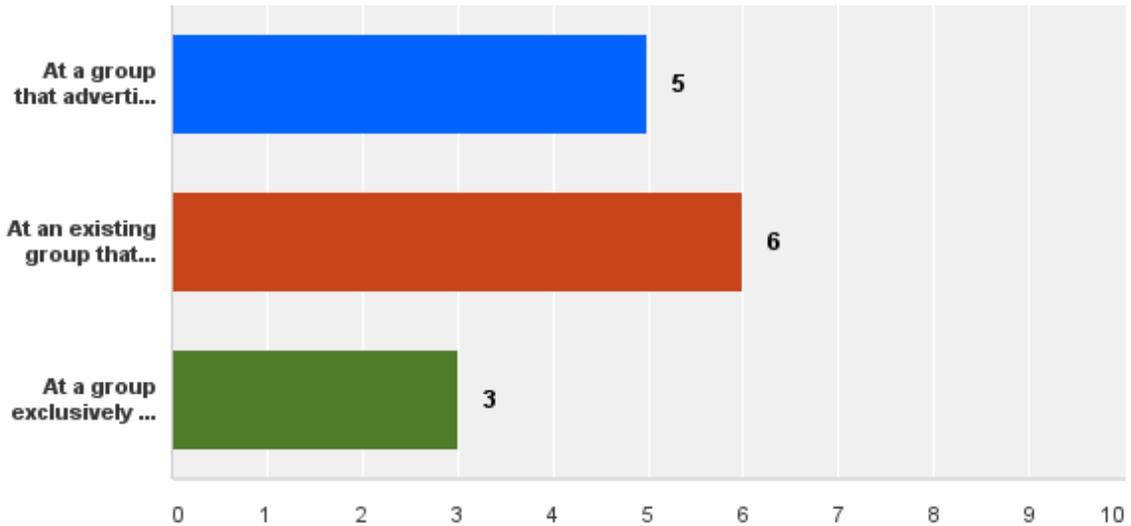
- at the moment
- except football

There were 4 other responses:

- Still enjoy music but don't bother about the garden any more
- Unable to continue with reading however now look at books with photos of certain areas in which we spent time walking, reads captions under photos
- Only solitaire
- To a small degree

Q16 Would you attend a group for this hobby if it was:

Answered: 14 Skipped: 11



Choices were:

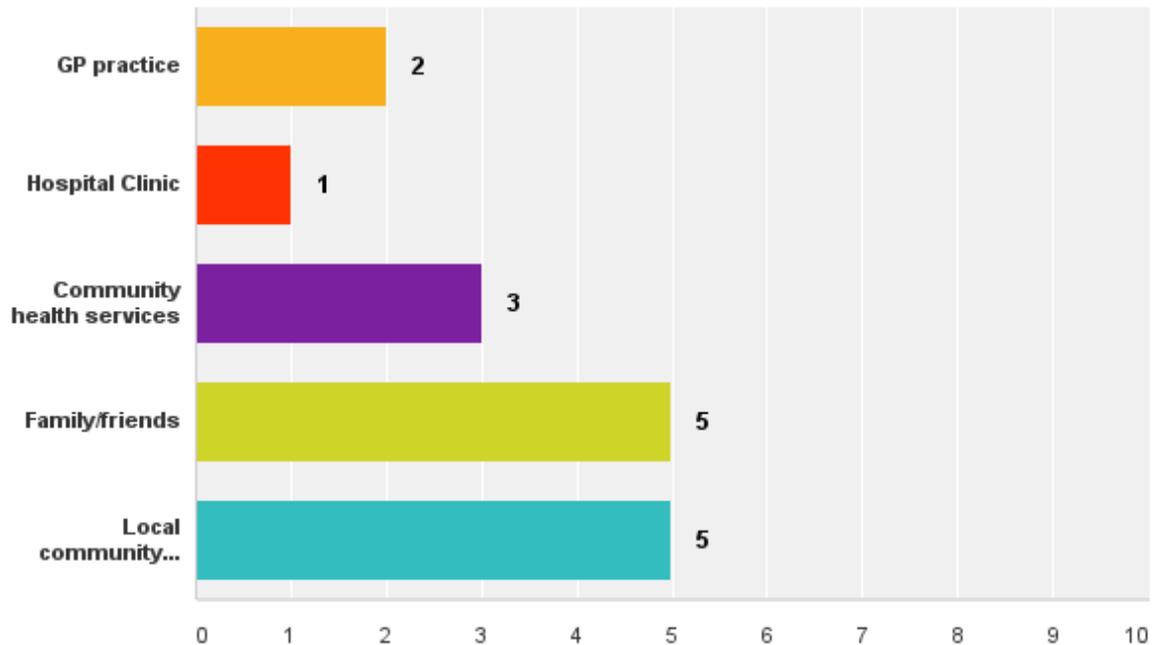
- At a group that advertised it was dementia friendly
- At an existing group that included people with dementia
- At a group exclusively for people with dementia

A number of people commented that they would attend all 3. Other comments received included:

- Lost confidence so would not attend a group
- Yes, still go to groups. And enjoy the café
- Possibly beyond this now
- Concentration difficulty

Q19 How did you find out about these clubs/activities?

Answered: 10 Skipped: 15



Other sources of information were:

- 4 - specifically named voluntary sector agencies
- 1 - internet searches
- 1 - found out by chance
- 1 - told at home visits
- 1 - information from a nursing home

Q20 How well do these clubs and activities meet your needs?

10 respondents made very positive answers, including “We are very happy with everything that is on offer. We never imagined there would be so much help out there” and “It helps to meet people experiencing the same problems as you. You don’t feel on your own and can talk things through and get advice”

3 respondents gave more qualified responses:

- We are at an early stage in the onset of dementia and are still trialling some of the different activities to see which currently suit us the best and also to identify activities for the future
- Only just been once as a new group so cannot say
- Good for social but little information retained

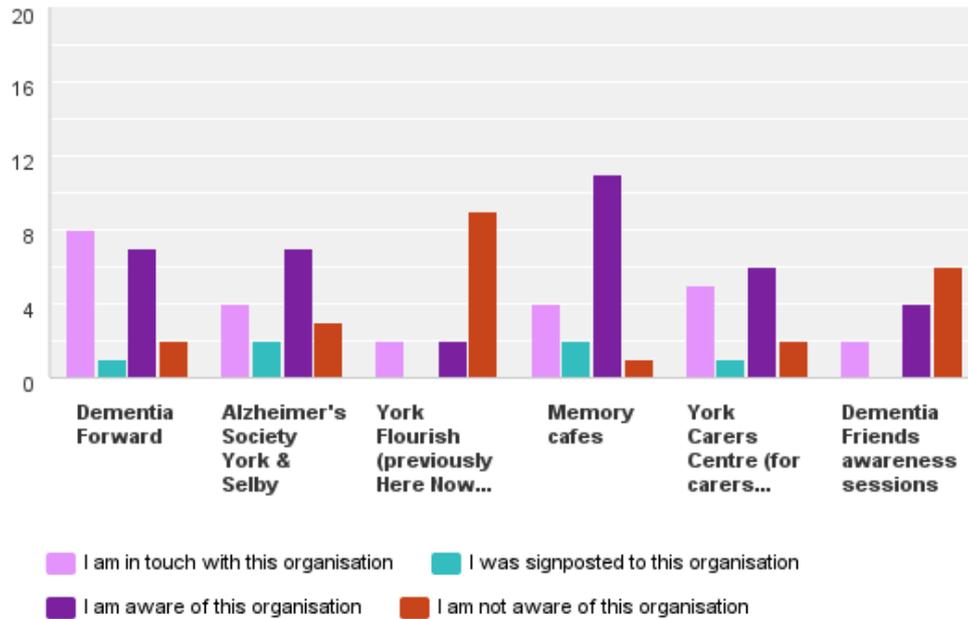
Q21 What would you like to see more of? Do you have any ideas for improvement of these services?

Suggestions included:

- Activities starting later – most start at 10.30am at a distance and I can't be dressed, washed etc before that
- Persuade more people to join in the fun!
- Perhaps coach trips leaving late morning, as they miss drives into the countryside
- Groups aimed at male carers of women with dementia. My dad like many men has never been the socialiser within their marriage and finds it very hard joining things as most are female dominated. He would really appreciate some male support
- Transport is the challenge, depending on voluntary cars

Q22 How aware of the following organisations are you?

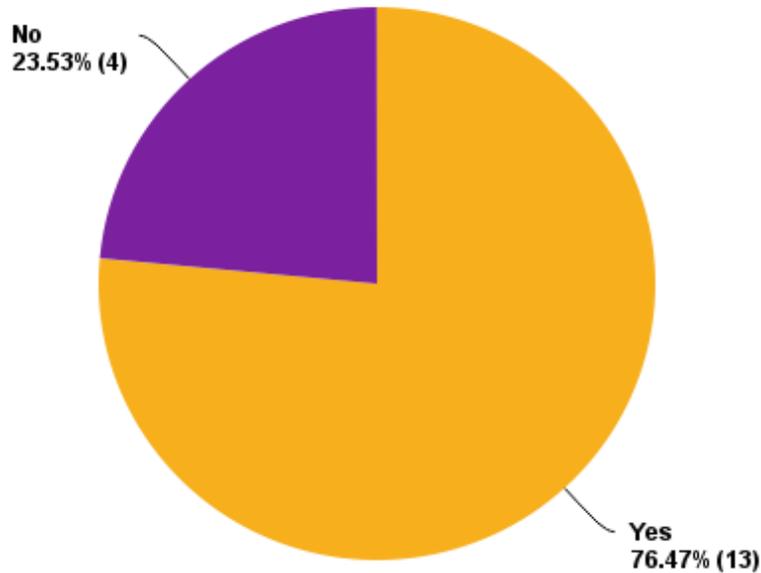
Answered: 19 Skipped: 5



Note: Within the survey we asked about York Flourish, which was previously Here Now dementia. We have since found that there is greater awareness of Minds and Voices, one of the activities this organisation provides.

Q23 Do you feel you have a good understanding about what dementia is?

Answered: 17 Skipped: 8

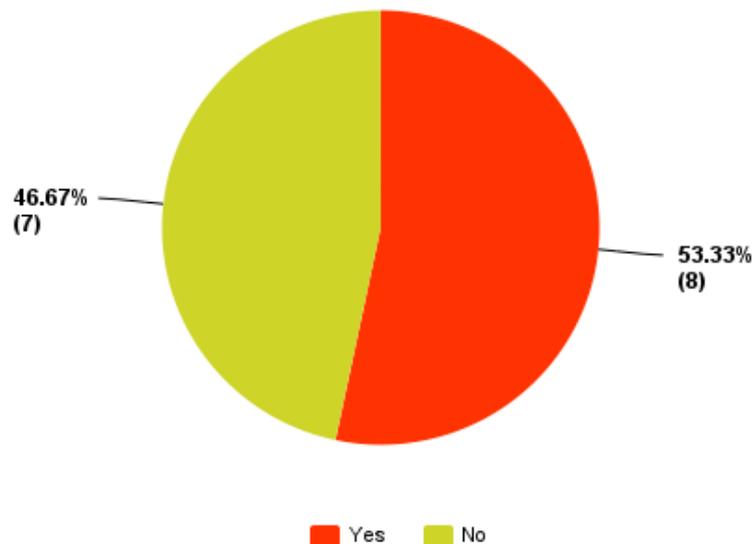


Comments included:

- Could be improved
- Is dementia a disease or something other?
- Don't know much about
- I do but my dad who is the main carer has never really from CMHT involvement had time taken to explain the diagnosis or the progression and impact on my mum and him over time
- A lot of research needed

Q24 Do you have unanswered questions about your dementia?

Answered: 15 Skipped: 9

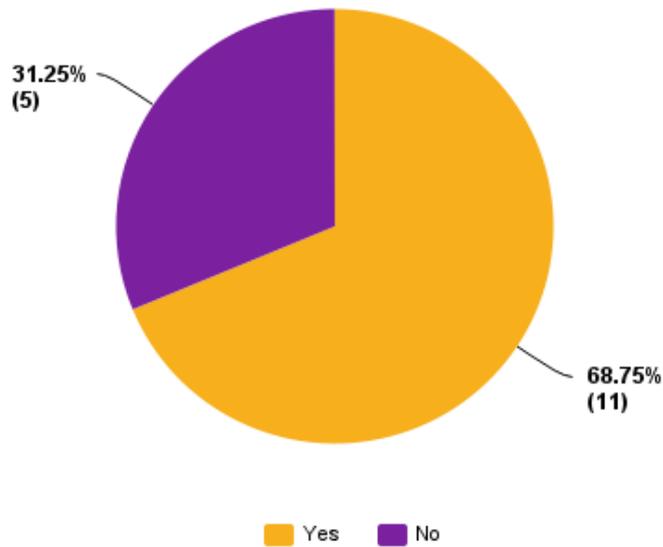


Comments included:

- Not at present, however as the dementia progresses I will need more advice
- Lots of unanswered questions. I think the tablets I have been on since 1980 have addled my brain a lot!!
- Nothing has really been explained since first diagnosis
- Why isn't more done to try and prevent symptoms worsening, i.e. brain / memory stimulation
- More info on how this will progress and affect over time. Only this way can people plan a bit and take control of their future.

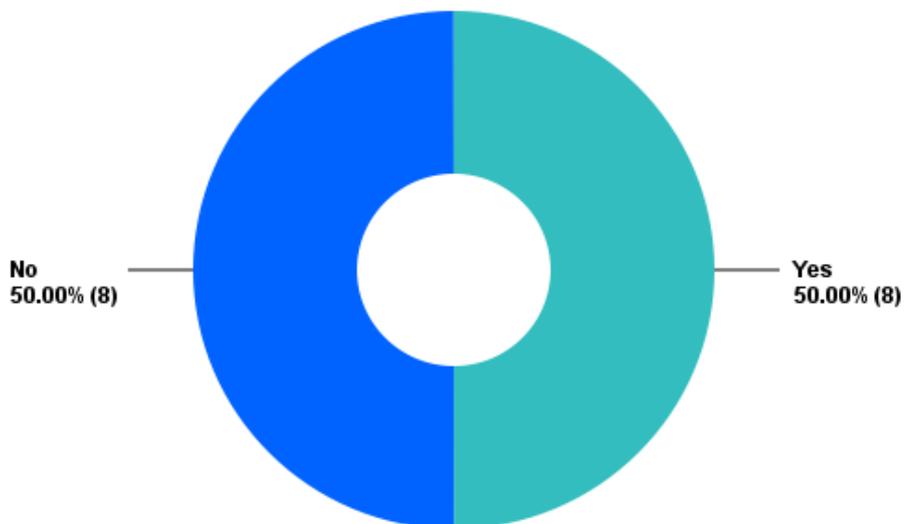
Q25 Do you know where to get further information / answers to your questions if needed?

Answered: 16 Skipped: 8



Q26 Have you been given information about how to stay as well as possible?

Answered: 16 Skipped: 8

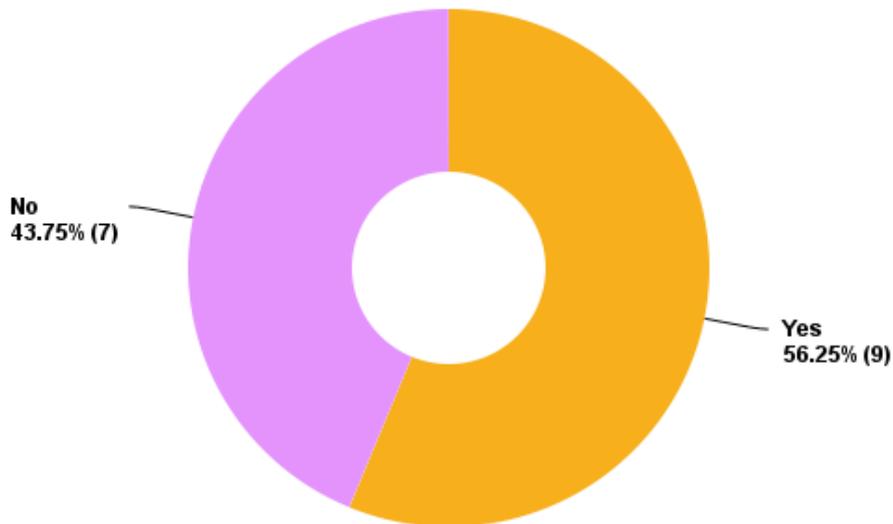


Comments included:

- Not really
- Some, at first
- Only what I have seen on TV. But so many contradictions foodwise.

Q27 Have you had conversations about planning for the future? If yes, with who? If no, would you like to?

Answered: 16 Skipped: 8

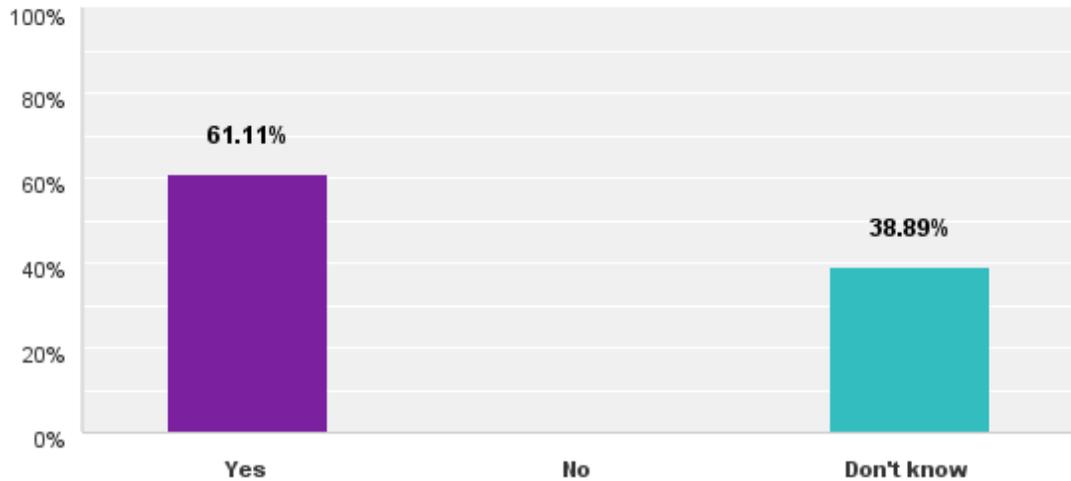


Comments included:

- Information on planning for the future would be helpful.
- Yes would like info
- Would like to discuss the future with someone
- Help is always appreciated
- This is very poor. At no time do GPs discuss this and neither did the CPN she simply turned up for a chat for a short period of time.
- With family online

Q28 Are you receiving all the benefits you are entitled to?

Answered: 18 Skipped: 7

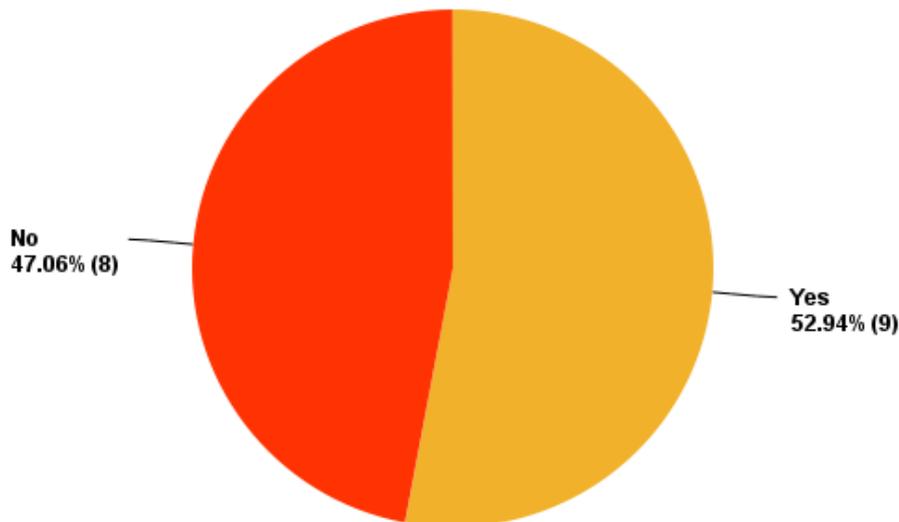


Comments included:

- My husband had a pension
- I've got one benefit and don't think we are entitled to any more
- I have made sure through my professional knowledge that this is in place

Q29 Do you know where to go for financial and legal advice?

Answered: 17 Skipped: 7



Comments included:

- City of York Council advised us on the benefits, but I don't know where we would go for legal advice. We've learned what we know from relatives of others with dementia

Q30 What forms of transport do you currently use?

Most popular were cars (3 people specifying a carer who drove them) and buses with 8 each, 4 people also used the train, 3 taxis, 1 coaches, 2 mentioned community transport. 1 person also indicated they used public transport if accompanied.

Q31. Do you have any comments about your experiences of transport since being diagnosed?

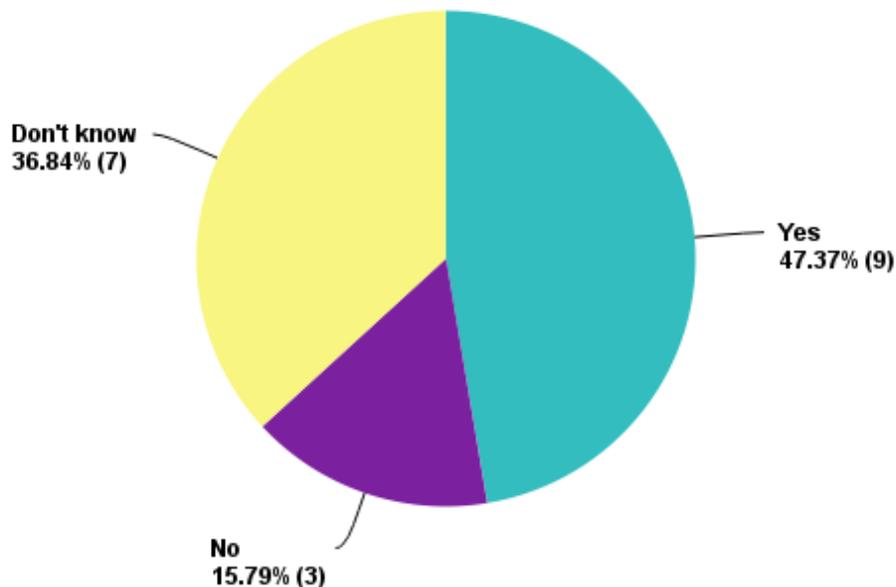
11 comments received. These included:

- Usually nice friendly people drivers and passengers. I use buses mostly.
- I need a blue badge. I become very tired returning to a car park.
- I use a walker to get to the bus stop. I have had this pushed away in a bus to make room for pushchairs.

- Yes! Difficulty parking at the hospital for appointments.
- Disabled car blue badge very helpful for my driver door's open widely in disabled spaces. Supermarkets are so narrow they are a nightmare

Q32 Do you think York is a Dementia Friendly City?

Answered: 19 Skipped: 6



If yes, why and if no why not?

Comments included:

- More and more people and organisations have become aware of dementia and this helps
- I have lived in York for 70+ years and a very high percentage are really friendly and kind
- Plenty of activities
- 1. Plenty of info. 2. Public awareness. 3. Significant elderly population
- Lots of training but no good to my relative who does not leave her home, mobility and confidence issues
- Support from voluntary organisation good
- I'm sure it's okay if you are able to be out and about. However, for those who are quite limited in their social outlets I think York with dementia is very isolating. If it were not for me then I believe that no-one would have had contact with my parents since the CPN last visited

(probably 3 years ago). They are in contact with their GP for medication and as matters arise but still there is little appreciation of the dementia impact here. For example letters simply get sent to mum from health, e.g. for routine checks. We have already asked that post is not addressed to her as she cannot process the info and will read the letter and simply do nothing with it, yet my dad still feels obliged to give her her post. This may seem simple but it is very impersonal and doesn't acknowledge the dementia at all. Even then to arrange and get her a routine appointment is difficult. If you have to wait too long at the surgery even for the planned appointment it can be really problematic as her mood can change in an instant, causing upset to her, embarrassment socially for us, and her desire to leave. Also busy noisy waiting rooms are not helpful for this reason, she is very noise sensitive due to the dementia and this can add to her mood quickly turning and her need to get out. On the last occasion we went I did explain this to the receptionist and they were excellent getting her straight into the GP. However it does feel like files really need red flagging a little more and a bit more personal service. This is also where having a regular GP would help. Being dementia friendly needs to be more about reaching out into communities to identify (via GPs) those who may be in need and are isolated with this problem alongside educating the population as a whole. Too often we wait for crisis point instead of some good outreach work via GPs who remain the key point of access for older people.

Q34. If you could ask for one thing to make York more dementia friendly, what would it be?

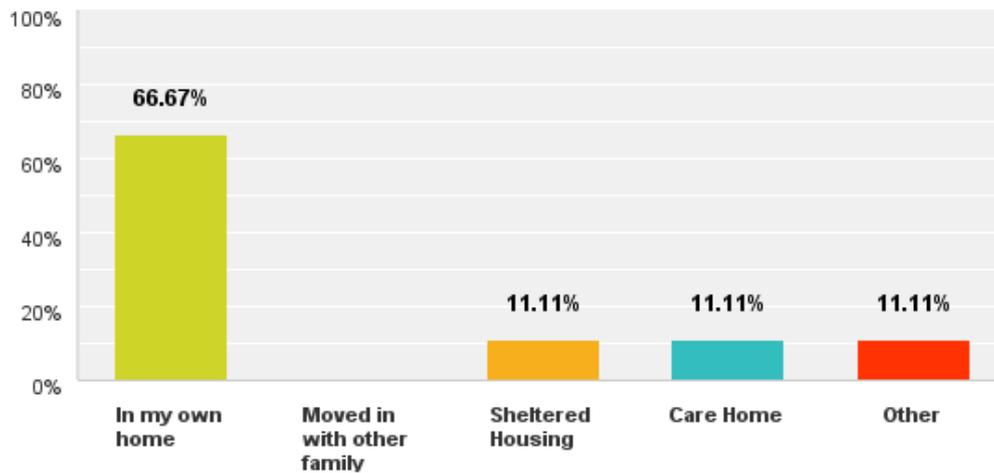
Comments included:

- Theatre performances as the Playhouse do in Leeds
- More groups to study our health
- More understanding from people of York.
- More awareness
- A better system
- An organisation that got in touch with me instead of me trying to find out who and where they are!

- More updates on trials and someone who would give me HOPE that I do have a future and not to resign myself that I have dementia and nothing can be done
- Increased mental health services / support that could operate more of an outreach service
- Better understanding that people with dementia may be disabled in other ways too

Q38 Where do you live?

Answered: 18 Skipped: 6



Q35 Do you have any further comments you wish to make?

Comments included:

- I haven't found any groups yet. I am hoping to
- I would like the cafes to be longer than 1 ½ or 2 hours
- More help for carers as behaviour can get bad quickly, slow referrals
- They all seem to act independently of one another
- The only help we get is from Dementia Forward to refer me to other organisations
- Following discharge from hospital and despite the obvious signs of memory loss we were given no support from the hospital social worker other than returning home with the same care package – which we have as carers been left to sort out

Other feedback

We spoke to a number of individuals throughout the production of this report. These include:

October 2016

A woman got in touch looking for information about organisations and activities available for people with dementia. We sent a range of leaflets, the dates for future Minds & Voices meetings, and details of books about dementia available from the library.

November 2015

A woman with dementia and learning difficulties was taken into York Hospital. She has a really detailed passport which explains her communication challenges in detail. The nurses pushed back the bed to use the hoist and the passport ended up on the floor. None of the information in it was used throughout her stay. Staff were trying to communicate with her, saying things like "can you move up the bed a bit?" but did not seem to understand why she was not responding to them as they expected.

October 2015

A man contacted us. He has been waiting for a referral to the memory service. He got a telephone message from someone inviting him to a short notice appointment due to a cancellation. He couldn't make it so he tried to call back to find out where and when he should be coming in. He felt this was not very helpful if you are already struggling with your short term memory. He asked for an email to confirm his appointment. They seemed reluctant to do this but eventually agreed.

June 2015

A woman contacted us about her experiences of caring for her mother. She was pleased to hear the remit of the report was being defined by people with dementia. She confirmed "My mum had insight into her condition until a late stage, and she was so tired of people telling her what she ought to be thinking / doing when actually she could have expressed quite clearly what she felt about many things."

She was interested in how former carers could become volunteers working alongside people with dementia, or with organisations that people were involved with. She felt that she had learnt a lot about dementia through her mother's experiences, and wanted to keep using her skills and experiences to contribute to improving the lives of people with dementia.

She highlighted one particular thing which had caused real difficulties for her mother, from quite an early stage. She has noticed this is also a problem for an older friend she goes shopping with who has mixed dementia. Many entrances to large shops and banks are not easy to use for people with visual or spatial difficulties. She found where there were banks of glass doors next to shop windows, this seemed to be intimidating and caused a loss of confidence. Dark floor mats in entrances also caused problems for her mother, as she perceived them as a step down although they were flat.

June 2015

A woman called about her husband. He has dementia and Parkinson's and has been in York Hospital for 3 months. He is desperate to go home and she feels his condition is deteriorating as a result of being in hospital. They have been told he needs a full package of care but there are not the carers available to do this. He has been on the waiting list for carers for 9 weeks.

May 2015

A woman in her 70's whose husband was diagnosed with dementia. They coped at home until 13 months before he died, when he became unable to walk.

She stressed how important it is to her that others have an awareness of dementia. She is a dementia friend, and is now training to become a champion. She wants to encourage more places to become dementia friendly.

She valued the coffee mornings available, and used to go to one in Acomb with her husband. But many came without the person they were caring for. She felt it was very difficult to talk openly about your personal circumstances as a carer in front of others who are living with dementia. She did not want to embarrass or upset anybody. For example, she felt carers would not say "we had a dreadful night last night, when he soiled the bed and then was awake

for hours”. So she felt it was really important, whilst maintaining life as a couple, to provide separate spaces for carers and people living with dementia to share their experiences.

She and her husband used to go out for lunches. This was something they enjoyed and was important for them. She feels that a big issue is accessible toilets. Often in shops they are in one or other gender specific toilet space. E.g. at the Range this was inside the ladies. This meant she had to take her husband into the ladies toilet. She felt it wasn't right for men to have to do this. She said something this simple – knowing there was a toilet they could use together or worrying one wouldn't be available - made such a difference to the quality of their day.

May 2015

A woman contacted us. Their relative has dementia and is moving to York. They wanted advice on how to choose a suitable care home.

May 2015

A woman whose relative has dementia contacted us. Their relative is in a care home, but they want her to leave. The family have been told “she has been exhibiting difficult behaviour and trying to leave”. She is struggling to find the right information to help her understand her options. We sent details of possible care homes in York, plus information on choosing a care home.

March 2015

A man whose wife has Alzheimer's contacted us about his concerns that there is a lack of day care provision in York. He told us that his wife is able to go to excellent day care in York 2 days per week. However, this involves 4 car journeys from home each day. He feels there should be more provision available throughout York.

February 2015

A woman contacted us for advice regarding care homes in York for her brother. He does not need care at the moment but is becoming a bit forgetful & worried. He has decided it is best to go into care. He will have to fund this himself. She had phoned a local charity who suggested she contact City of York Council. She felt she spent "3 hours going round in circles", being

passed around a number of people at the council without her query being resolved. We provided a number of leaflets and booklets about choosing care.

February 2015

A woman contacted us about problems with accessible parking at Bootham Park Hospital. She could not find the accessible parking bays, and wheelchair access to the building not obvious. Her mother is a wheelchair user and has mixed dementia. The problems with parking increased the stress and anxiety for both mother and daughter. She appreciates the issue is probably not wholly in the power of Bootham Park Hospital to address, but feels it must be. She also had difficulties finding the hospital as although her mother lives in York she does not. She believes that improved signage would help.

Changes to the benefits system

We became aware, towards the end of our information gathering phase, that a number of individuals living with dementia had been invited for a PIP assessment. One of these people saw their benefits cut, and their appeal was turned down. Another was in the process of being reassessed, and had found the first interview challenging. She felt that the whole focus of the interview was to identify ways of removing or reducing support, rather than understanding her circumstances and what could help her keep independent for as long as possible. This reassessment process now seems to be picking up momentum and it would be useful to revisit this when more people have experienced it.

Recommendations

Key theme	Recommendation	Recommended to
2. 5	As part of the renewal of the Health and Wellbeing Strategy for the city, clarify the structures relating to strategic responsibility for making York a great place to live for people with dementia, and how this fits with the Dementia Action Alliance in York. This should include clearly identifying the route for people with dementia to be heard.	Health and Wellbeing Board
3.	Bring together people with dementia and GPs to explore the importance of diagnosis and consider effective signposting. Co-produce a consistent dementia pathway to make sure individuals have access to the support, information and advice they need (and improve our dementia diagnosis rate).	NHS Vale of York and the Council of Representatives, Minds & Voices, Healthwatch York
2	Consider ways of making sure engagement with people with dementia continues in York, making sure their voices are at the heart of all dementia initiatives	Health and Wellbeing Board
2. 4	Consider ways to support and refer onto a co-produced post-diagnostic course, involving people with dementia as tutors and course designers.	Health and Wellbeing Board
2. 4. 5	In embedding co-production as a way of working in York, consider how we make sure involvement of people with dementia moves beyond token representation and directly involves them in decision making and shaping services	Health and Wellbeing Board
4. 5.	Consider the needs of people with dementia when reviewing York's volunteering strategy, to include how we enable more people with dementia to take up volunteering opportunities, and how volunteer involving organisations can provide good volunteering experiences	York CVS
2. 5.	Consider ways of embedding dementia awareness	YorOK

	within secondary schools PHSE, making sure people with dementia are involved	
2. 5.	Consider ways of embedding dementia awareness into contracting arrangements for the city, making sure people with dementia are involved	Health and Wellbeing Board / Joint Commissioning Group
4.	Consider additional ways in which small opportunities to do things separately can be developed and supported for people with dementia and their carers	Commissioners and providers of dementia support services
4. 5.	Tap into the passion and willingness of people with dementia to get positive messages out there in all awareness raising activity	Dementia Action Alliance, Health and Wellbeing Board
1.	Consider ways of increasing advocacy, mediation and support for couples and families to work through changing relationship dynamics	Health and Wellbeing Board
1. 3. 5.	Consider how we make sure those who need face to face information, advice, and customer service are not left behind by increasing reliance on modern technology and “digital by default” approaches to information.	Health and Wellbeing Board
4. 5.	Consider producing a map of accessible toilet facilities in York and making this available through tourist information, as well as through existing information channels within the city.	Make It York
4. 5.	Consider whether there are sufficient accessible toilet facilities in York to enable people to stay independent.	City of York Council / Make it York
1. 2.	Undertake further work with key partners (e.g. Citizens Advice York, York Carers Centre) to understand the impact of the PIP assessment process on people with dementia	Healthwatch York / Dementia Service Providers and the Dementia Action Alliance

Appendix One - Reflections on the carers sessions from Damian Murphy^x

Dementia Friendly Communities:

An interesting session where we posed what does dementia friendly mean to you. With Barnitts being a local favourite, we had our answer – it's not about stickers in windows, it's about good customer service. **If it's dementia friendly then it's friendly.**

Support and Information

There was a common theme emerging that many people found out about various forms of support and information via chance meetings. Some had a 'switched on' doctor. Others did not get any support for a long time.

Based on what people were saying about inconsistent post diagnostic support, the question was posed, 'how much medical involvement is needed after diagnosis?' If it is very little (apart from six monthly check-ups) **then should we really be surprised that the support we seek is not forthcoming from professionals with an understandable medicalised focus?**

The group all mentioned the many questions they and their partner were left with following a diagnosis and the need for something simple to understand and something that also focusses on addressing the fear. The positive message – 'you CAN live well with this.' **Appropriate face to face contact rather than overwhelming with leaflets** was the favoured option at this crucial post-diagnostic period. Good examples out there are that Tang Hall Surgery has a link worker.

One carer mentioned the powerful phrase:

'you want to feel as if you are still part of the world' – this is certainly a message that I imagined was also being sent by the group of people living with dementia.

The carers were asked what would be the one essential in their eyes. **More knowledge at the GP surgery** – at least being able to point people in the right direction for the REAL information. One carer mentioned the idea of our input here being used for surgeries and groups to adopt a common, consistent local standard across all surgeries in York.

Peer Support - a safe place to express thoughts, feelings, emotions etc. (We all agreed this was vital for both carer AND the person with dementia.)

Not to feel embarrassed – why should we worry if our partner does things or says things that others see as different or strange – this is clearly their problem not ours. ‘Why should we ask permission to join in, remain part of a group etc?’ – a powerful point made by one of the participants that highlights the need that dementia is seen as a disability and that remaining part of communities is a disability rights issue and probably something at the heart of what a dementia friendly community is.

This is all the more relevant now since the publication of the powerful ‘Our Dementia, Our Rights’ booklet from DEEP.^{xi}

Transitions – all agreed that it is difficult to keep readjusting as people’s needs change and this is not helped by the many periods of transition involved along the way – in/out of respite, day care, hospital. So a smoothing out of these sensitive periods of transition is essential.

Still remaining as husband, wife, lover – the importance of keeping one’s independence, voice, control, identity.

We asked, ‘how much time had passed at home, wondering what was happening, before going to the GP for the first time?’ The insidious nature of the onset of dementia made it hard to pinpoint exactly, but answers were around the 18 month – 2 years mark. It’s important to get access to practical support services (usually psycho-social support at early stages) whilst the diagnostic process is underway. **This is why diagnostic involvement should begin long before diagnostic process is complete.**

In summary the overall feel was that we want a more upbeat positive message – information on how we can all live well with the presence of dementia and just information that is consistent and easily understandable.

Thoughts about a pathway from Healthwatch York meetings

The first point of call is always the GP. It is important that the patient requests ‘referral to the specialist consultant in Old Age Psychiatry for further investigation of an obvious impairment’ - always a good phrase to use rather than hoping that the GP refers or not.

Various people/services seem to be saying how there is a ‘pathway’ yet no-one seems to have taken the same route! But how might one expect people with a cognitive impairment and a whole range of unique experiences, feelings, symptoms and life histories, to follow a linear pathway?

Notes on: The experience of living with dementia and what you think people should know about the experience of living with dementia.

It was striking the extent to which the years of a prevailing ‘care for carer stress and burden’ model can really inhibit seeing the other side of the story. It was not the case with everyone, and a few became extremely thoughtful in thinking back and really putting themselves as far as possible into the shoes of their partner.

The passage below highlights what dementia-friendly means within a relationship. **Carers spoke a lot about the ‘difficulties’ and ‘aggression... when they’re angry.’** We looked at possible reasons behind such anger. The group offered a whole range of valid reasons:

- **frustration at not being able to express oneself as well**
- **feeling bossed about and told off**
- **frustration at being tested and questioned when seeking quiet time**
- **a whole range of other physical illnesses (cancer / heart disease / arthritis)**

One carer astutely pointed out that when looking back, he could nearly always pinpoint a logical trigger to any ‘outbursts’. The powerful message was that such ‘aggression’ is not down to dementia. Rather it is down to

situations that we can all find ourselves in. One carer mentioned his wife who has dementia saying, ‘Sometimes I have a bad day’ – don’t we all?’

‘It’s like looking after a 2-year old’ was another comment. I asked how it made people feel if they were treated like a child. I pointed out that no-one in the other group would be describing themselves as like infants.

There were however lots of insight into the experience of their partner:

- Everyone mentioned the tears and devastation at point of diagnosis
- Everyone acknowledged how their partner frequently wants their own space and independence
- They acknowledged how their partners complain about being ‘bossed about’ – (a difficult but necessary balance to strike when thinking about support and safety and one’s own concerns)
- The importance of a safe space to switch off (and also ‘let rip’ sometimes!) after a day that may have included the difficult task of putting on a social veneer – in a way a real compliment to the carer (however painful it might be!)
- Wanting to keep your independence with just about the right support
- Wanting the reassuring presence of familiar faces
- All acknowledged the frequent ‘You know I love you, don’t you’ – very much a recognition and insight into the condition – and perhaps also a plea implying no little sense of insecurity, ‘don’t leave me’ or ‘don’t hold this against me’

We finished with one statement from each of the seven carers present. I asked them to say one thing that they feel their partner would want to say about their experiences:

1. ‘You can live with this, I just need to adapt’
2. ‘You just have to get on with life’
3. ‘Bugger off, Dementia, you’re not going to stop me living my life’
4. ‘I’m glad I enjoy my ‘club’ and the love of my family
5. ‘It doesn’t bother me but I do worry if I’ll get like that’ (when seeing negative stereotypes in TV and media)

6. 'I love routine and regular things'
7. 'I do love you, you know'

In summary.

The opportunity to share and acknowledge each other's feelings and perspectives is so limited for families where one partner is living with dementia.

The comment 'I'm not bothered' (reported words of a partner with dementia in response to a complaining spouse) really poses a question 'Then who is it a problem for?' Clearly the early statements associating dementia with aggression indicate that the problem may lie with the lack of understanding and knowledge, acknowledgement of care partners about feelings and experiences, and about the nature of dementia too. This is no criticism. Dementia does not come with a handbook.

This session revealed clearly the type of practical support needed around the time of diagnosis. It repeats a message that has been a real theme through these sessions. Groups complain about lack of follow up 'from the doctor' yet what we seem to be looking for is very much the emotional support, the relationship-centred approaches that can equip families in just living the day to day. I understand the other group made up of individuals with dementia spent a lot of time mentioning some of the antagonisms they experience in their close relationships with family and friends. This does not surprise me.

References

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- ii <http://www.healthwatchyork.org/the-population-of-york/specific-population-profiles/frail-elderly/dementia.aspx>
- iii <http://www.valeofyorkccg.nhs.uk/data/uploads/governing-body-papers/5-january-2017/item-10-quality-report.pdf>, page 19
- iv <https://www.jrf.org.uk/report/evaluation-york-dementia-friendly-communities-programme>
- v <https://www.jrf.org.uk/report/developing-national-user-movement-people-dementia>
- vi <https://www.jrf.org.uk/report/how-can-we-make-our-cities-dementia-friendly>
- vii <https://www.jrf.org.uk/blog/dementiaville-failed-give-people-dementia-voice>
downloaded 10th November 2016
- viii <http://www.nhs.uk/LiveWell/volunteering/Pages/Whyvolunteer.aspx>
- ix <https://www.helpguide.org/articles/work-career/volunteering-and-its-surprising-benefits.htm>
- x York-based Director of Innovations in Dementia, and one of the facilitators of the Minds and Voices Forum and the meetings with Healthwatch York
- xi <http://dementiavoices.org.uk/deep-groups-news/our-dementia-our-rights/>

Other useful information:

Reasons why people with dementia are admitted to general hospitals in an emergency <http://www.yhpho.org.uk/resource/view.aspx?RID=207311>

Barriers to finding a cure for dementia

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/447529/Dementia-Report.pdf

Portrayals of dementia and debate

<http://theconversation.com/films-like-still-alice-are-crucial-to-keeping-debate-about-dementia-alive-38675>

<http://livingwelldementia.org/2015/07/14/living-better-can-become-a-reality-for-people-with-dementia-if-they-lead-policy/>

Acknowledgements

When we informed people that as part of our work we were going to be spending time each month with people with dementia, the usual reaction was an expression of sympathy. It seemed inevitable to friends, family and colleagues that this was going to be a difficult time. In reality, this was nonsense. We've had the privilege of spending time with a great bunch of people who all happen to have a dementia diagnosis. We talked about so much, for example:

- fighting for a diagnosis
- trying to find help and advice
- ideas to change the world
- the way that chance meetings could open up opportunities to be part of new activities
- getting involved nationally and internationally in the fight to involve people with dementia in improving their futures

In discussing their experiences of dementia, whilst there were poignant and sad moments, our overriding memories are uproarious laughter.

Thanks to everyone who spent time with us during this project, especially the members of York Minds & Voices Forum. It has been an honour and a privilege, and it's not over. We look forward to working with you on making the recommendations in this report a reality.

Grateful thanks too to the amazing Emily (Abbott, York Flourish) and Damian (Murphy, a Director of Innovations in Dementia), both of whom support the York Mind & Voices Forum. Their unstinting support in doing this work made this project possible. When you work with great people, it doesn't feel like work at all. Your passion and commitment to making sure people with dementia are heard and making their worlds better is infectious.

Thanks also to the Joseph Rowntree Foundation, for their funding, their ideas, and their commitment to making the world a better place for all.

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York CVS

Healthwatch York is a project at York CVS. York CVS works with voluntary, community and social enterprise organisations in York.

York CVS aims to help these groups do their best for their communities, and people who take part in their activities or use their services.

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