



Listening to people with dementia

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healthwatch
York

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Acknowledgements

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Background Information

Dementia facts and figures

Dementia is a term used to describe a variety of symptoms including memory loss, problems with reasoning, perception and communication skills. Different types of dementia include:

- Alzheimer's disease;
- Vascular dementia;
- Dementia with Lewy bodies;
- Frontotemporal dementia.

A progressive condition with no cure at the current time, it is the leading cause of death in England.

In 2022 Public Health England (PHE) estimated that there were 850,000 people with dementia in the UK. This means that 1 in every 14 people aged 65 years and over has dementia. This figure is expected to increase to 1 million by 2025 and is forecast to increase to over 1.6 million by 2040. More than 40,000 people in the UK under the age of 65 are affected by dementia.

It is estimated that a quarter of people in acute hospitals and three quarters of the residents of care homes have dementia, yet 200,000 people with moderate and severe dementia do not get any kind of funded or professional support.

The local picture

There are an estimated 2,812 people over 65 living with dementia in York; one in twenty people over 60, and one in five people over 80 has a form of dementia. Of those 2,812, only 1,554 people have received a diagnosis. The dementia diagnosis rate for York is 55%; the average for England is 62%.

This suggests that some people living in York are not receiving a dementia diagnosis in a timely way;

“York has a larger than national average gap between the expected prevalence of dementia within our population, and the actual number of people diagnosed. Primary care has a challenge to proactively seek and assess people who may be at risk and identify the condition as early as possible to ensure the right people get the right support at the right time.”

<Extract from *Dementia Together; A 5-year Dementia Strategy for the City of York - September 2022*>

A 5-year Dementia Strategy for the City of York was launched in September 2022 by a partnership of local organisations. The strategy seeks to ‘transform the approach to dementia in York’ the key aims of aims are based on the National Dementia Well Pathway:

- Preventing well; the risk of people developing dementia is minimised;
- Diagnosing well; timely and accurate diagnosis;
- Supporting well; support plan and review within the first year;
- Living well; people with dementia can live normally in safe and accepting communities;
- Dying well; people with dementia die with dignity in the place of their choosing.

The strategy includes a programme of targeted support for GP practices to increase the rate of diagnosis, a dementia support worker based in every primary care network and the development of a new Dementia Hub.

Sources:

Office for Health Improvement and Disparities (OHID) Guidance Dementia: applying All Our Health - February 2022

Health and Social Care Committee’s 7th Report 2021-22

NHS Digital - Sept 2022 and November 2021

Alzheimer's Society York Profile - 2021

City of York Dementia Strategy 2022 - 2027

Project Background

Why are we looking at dementia?

At Healthwatch York we frequently hear from people with dementia and those who support them about the difficulties finding or getting the right support. In 2020, Healthwatch York received funding from the Joseph Rowntree Foundation (JRF) to develop a project for people living with dementia.

Previous work at Healthwatch York

Since Healthwatch York formed in 2015, we have had the opportunity to hear the views and experiences of people living with dementia by working directly with people affected by the condition and their carers. In 2017, Healthwatch York worked alongside Minds and Voices to run focus groups to understand how York City could be made more dementia friendly. In 2019, as part of the NHS Long term plan project, we ran a focus group for people with dementia and carers to listen to their views on priorities. Between 2018 and 2021, we had

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contact with 38 members of the public who raised concerns around support for people living with dementia and their carers. Many people told us about their difficulties of getting the right support when dementia needs had become more complex.

During the Covid lockdown in March 2020 we undertook welfare calls in collaboration with York CVS. We spoke to people living with dementia both via a hotline number and through lists provided to us by GPs.

This project aims to build upon what has been learned so far and to continue the conversation with York residents who have dementia, and their carers, friends and families.

Challenges and limitations

We were keen in this project to listen to residents with lived experience, carers and families of people with dementia and the many groups and organisations who support them.

The project took place during a period of uncertainty caused by the Covid-19 pandemic. Though we hoped that face-to-face engagement would become increasingly possible during the later months of the project, it continued to be problematic. Many groups for people living with dementia had not yet re-started. Keeping people safe and not exposing them to any unnecessary risk were paramount. As such, we had to work creatively and flexibly in order to spread the word and reach out to people living with dementia and their carers. However, we are acutely aware these challenges and constraints prevented us from reaching as many people living with dementia as we would have wanted. Thus we were unable to provide the face-to-face engagement so necessary for many individuals to be able to take part.

What did we do?

When the York Dementia Action Alliance spoke to people directly affected by dementia and professionals working to support them, they found five key areas needing improvement. These were:

- Improved accurate and early diagnosis
- To have a post diagnostic pathway of support
- For services to work together better
- The development of carers' support
- A positive campaign for living with dementia

The questions in this survey ask for people's experiences as well as what could be improved in these five areas.

We attended a group run for people living with dementia at Beetle Bank Farm to listen to the views of members. Some members talked to us about having a diagnosis; others preferred to talk about having memory problems. The group members are all involved in working at the farm, taking part in various tasks which support its running, including caring for the animals or various farming and gardening projects.

We worked closely with the group and the group's organiser prior to attending to make sure our approach was accessible and appropriate for members. The group organiser helped us to adapt our project, and their help and insight was vital to create an effective way for individuals in this group to share their thoughts or experiences with us in a relaxed and positive way.

We had a few conversation topics which were shared with members before we attended. On the day, we listened to members of the group talk to us about their work on the farm and the different ways they felt it supported their health and wellbeing. We also heard about some good and bad experiences of support from health and social care services.

Some people preferred to talk whilst they were busy doing an activity so we listened whilst helping out with some of the tasks of the day. Others liked to talk within a larger group and shared some thoughts and experiences with each other over tea and coffee during the breaks.

After the group, we gathered all the feedback under a few key headings and sent it back to the group to make sure we hadn't missed anything. The group told us that they had been pleased with the process and said:

"Thank you very much for offering the info. It's helpful that people are here listening to me and not laughing at me."

We are very thankful to the group and its organiser for the time and support they gave us for this project.

Our Findings

We have grouped people's feedback into five key areas:

The importance of being with other people

Participants told us that being part of a small group helped to build their confidence through talking and being with others. They told us about the importance of having a laugh and a joke and being around good people.

Meeting people dealing with similar situations allowed people to see how they coped and that in turn supported them to cope better. Participants said that they wanted to talk to people about their issues with others who could understand, not people who just ask a lot of questions.

People were able to share their knowledge and interests with each other and many members of the group had extensive knowledge about gardening and plants which they were able to draw on and share with others.

Being in the group also allowed some members that personal time which then helped with relationships and stresses at home or with family.

Some reflections on difficulties

Participants shared how they sometimes had difficulty getting sentences out. They described how their thoughts could be difficult to deal with. One person referred to it as though their “mind sometimes feels like it’s exploding.”

People shared the difficulties around this making you feel aggressive at times and how it can often end up being directed at loved ones. One person talked about how sometimes they just had to go into “survival mode” and had to find a strategy to deal with things.

The group felt that having someone to talk to about their issues would be helpful.

Some group members tend to tell people that they have dementia and others told us; *“I say memory problems, I don’t say the word”*.

Using activity to support wellbeing

Members of the group shared with us the positive effects that taking part in the group and its activities had on their wellbeing. People spoke about it providing the opportunity to have time away by yourself and time to be yourself. Some described it as being good to be able to take a break from others/family at times. One person described it as: *“somewhere to be me: I just want to be me.”*

The group provided opportunities for people to do things that interested them. Some spent time with animals which they found enjoyable and relaxing. *“Touching is a lovely side of being with animals.”*

Gardening was also an interest to many. *“Things that we can see growing and can give us pleasure.”*

Members of the group enjoyed being outside and told us they went out in any weather. They spoke about the feeling of achievement from the jobs done.

Having the right support/services at the right time

At some points members of the group reflected on support they had experienced in health and social care. They told us about the importance of having services that were able to respond quickly to any change and were able to provide the right support.

They spoke about support from their GP surgeries and felt that the ability to get in touch with them is impossible at times: *“It is no good when they call you back 2 days later or something. You need to talk to someone ‘in the moment’. Once they call you back so much*

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later you might have forgotten. You need a quick response.” Participants spoke about how it was a different GP all the time and so difficult to build any relationship.

Equipment services such as ‘Be Independent’ were said to have been very useful in some cases. People felt that equipment which could alert any dangers to local services or loved ones offered them some peace of mind and reduced their anxiety.

Some participants felt it was useful to have supportive services and other groups of interest nearby, especially if they were easy to reach and were easy to get to, also having other people to facilitate involvement was important.

For this group in particular, the members enjoyed the variety of activities they could be involved in, how they could take part and how much or little they could attend. Some people preferred to come for the whole day and others preferred half days. They stressed the importance of independence and how *“you need a bit of time on your own so you can get your brain thinking.”*

Impact of Covid

Many members had lost some connections to other groups and social activities they had been involved in before the pandemic. Many felt a loss of confidence which came from not being able to attend their regular groups and the disruption of not being able to get to the activities that they had usually attended.

Other Engagement Work in the City

Sheila Fletcher, NHS Vale of York Clinical Commissioning Group ran a series of workshops in December 2021/January 2022 at a variety of locations including Deans Garden Centre Carers Group, St Clements Hall Dementia Cafe, Minds and Voices and Beetle Bank Farm. Key themes included:

Timely diagnosis

A real mixture of experiences with some people having ‘very quick referral and assessment’ and others experiencing a long wait before their GP referred them. One person waited four years and was misdiagnosed several times until a brain scan confirmed early onset of Alzheimer’s. One patient had a family GP with understanding of the patient’s past history and immediately recognised dementia; this patient had a very quick referral and assessment. Another patient’s GP referred to the condition as ‘just old age’.

Access to good health care

Again there were mixed responses from people trying to access health care, but many reported a lack of routine annual physical health monitoring, and a lack of coordination between health care professionals:

- Complications when admitted and discharged from hospital;
- Delirium meant delay to diagnosis;
- Memory assessment suspended when patient admitted to hospital;
- Multiple long-term conditions managed OK, but dementia overlooked;
- Mobility issues prevented people participating;
- Health checks for Long Term Conditions don't always consider dementia diagnosis;
- Feedback generally indicated people were left to fend for themselves after their initial diagnosis.
- Overall feedback that there were gaps in coordination between social workers and care. People reported often going to their GP as first point of contact and often not getting information from a social worker on care assessments or home care/support
- Feedback about gaps in coordination on discharge from hospital and a long wait for practical support at home.

Feeling listened to

There was some positive feedback about individual GPs but overall people had to make multiple phone calls. Online access was not felt to be helpful or 'user friendly', and many preferred a telephone call when they were able to get through:

- Regular call from friendly GP staff would help';
- Dementia Forward 'a lifeline';
- Some people objected to word 'dementia';
- Some people found the diagnostic process confusing. Four people didn't even realise they were being given a diagnosis;
- One person gave positive feedback about the Police and Yorkshire Ambulance Service for understanding and care of people with dementia.

Able to plan for the future

Some people reported having 'no formal support: people generally had to source information themselves', 'just given leaflets and left to fend for themselves.'

Feeling connected to others

People wanted opportunities for banter, activities, trips, outings, physical and verbal contact, singing groups, musical connections and food.

Helpful links included: voluntary and community and not-for-profit sector, faith provision, word of mouth, courses, peer support and learning from others. Also, opportunities to participate in research bring hope.

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Participants emphasised the importance of local shops, libraries and bus drivers understanding the needs of people with dementia.

People felt more positive about dementia when they can participate and that personal care needs shouldn't be a barrier, for example, improving incontinence supplies.

Some people don't feel connected anymore to their local communities and the impact of covid has been profound;

- Carers' isolation: 'at the end of their tether';
- Impact on physical health: 'couldn't see GP';
- Fear of covid; 'what if carer succumbs?';
- 'Don't go out anyway so covid made no difference';
- A sense of feeling abandoned;
- No opportunities for stimulation resulting in cognitive decline.

Suggestions for improvements

- Better information about early onset, especially the middle to late stages (which are often the stages people don't want to talk about) including issues around behaviour and incontinence;
- A clear and simple pathway through end of life care;
- An annual review including carers;
- Improved coordination between GPs, social workers and hospital;
- Education and awareness all round to create dementia friendly communities;
- More opportunities for peer support;
- More opportunities for social connections and activities especially music and singing;
- Opportunities for age-appropriate activities;
- Respite for carers;
- Idea of a centre for care provision: a hub providing personal care, respite for carers and age appropriate.

Case Studies

Case studies: **Early onset dementia**

All names have been anonymised Period: May 2021 - April 2022



Paul was 58 years old and living with his wife Julie in their home in York when they referred Paul to Beetle Bank Social Farm in May 2021. Paul had been diagnosed with early onset vascular dementia in 2018 and was mildly impaired cognitively. He was physically able but was also living with multiple medical conditions including mental health difficulties.

Paul and Julie got in touch with our service to help find something for Paul to keep his mind active and to continue to do things he enjoys. Further outcomes they identified were to help support Paul's physical wellbeing and his mental health. Julie was also living with mental health difficulties so it was hoped that Julie would also benefit if Paul received support.

Paul has been a manual worker much of his life and held various jobs where lifting and labouring were part of his role. He also served in the army for many years. Since leaving the army Paul has spent a lot of his working and leisure time outside and is a keen gardener at home, growing his own fruit and vegetables there. With the social farm being a predominately outdoor-based service providing access to many of Paul's abilities and interests, it seemed an appropriate referral for Paul.

Paul and Julie could not afford the full fees and transport costs to attend Beetle Bank Social Farm and would not have been able to join us without a subsidy. Paul did not meet the criteria for social care funding or for a health budget. Fortunately a grant from Social Prescribing was available and a trial period was agreed with the potential to access the service with a 50% subsidy and full transport costs for six months. Social prescribing is a way for local agencies to refer people to a link worker. Link workers give people time, focusing on 'what matters to me' and taking a holistic approach to people's health and wellbeing. Social Prescribers connect people to community groups and statutory services for practical and emotional support. They could afford to pay the remainder of the fees.

Because the symptoms of his dementia were mild, he was able to take on a planning role in his involvement at the farm. He has decided what he'd like to do and has helped to develop his experiences at the service from the outset. For example, Paul took ownership of an area of land next to our cabin at the farm which he organised and maintained. We purchased him a lawn mower with some available funds after he requested this and Paul now mows the lawn regularly. Paul has also brought various

plants and tools of his own which he wants to share with the service and other service users. For example, he brought in rhubarb and pepper plants to plant and look after. Paul engages socially with others in the service and each week helps in farm maintenance roles of which he is knowledgeable and able. This placement enables Paul to maintain a valued and useful role and in turn helps the farmer maintain her farm at no extra cost to her. Paul was able to access another grant to keep his subsidy going for 6 further months.

Paul has expressed how much he likes the service and how well suited it is to him: “It's brilliant, I feel alive when I'm here”. Paul has been enabled to stimulate and maintain his cognitive functioning by planning what he does at Beetle Bank Social Farm. He has also managed his emotional wellbeing and spoken about the impact dementia has had on him on numerous occasions. Paul also spoke about another unexpected outcome and commented how it enables him to handle his dementia: “It gets me out of the house and gives me a chance to meet people. Also gives me a chance to learn how to cope with my illness by observing other people”. Julie has also been able to access regular respite for nearly a year.

Paul is planning to apply for a Personal Independence Payment (PIP) and if successful could use this to pay towards his place at Beetle Bank Social Farm after the subsidy period ends. Beetle Bank Social Farm are also applying for grants to enable continued subsidies but there is no guarantee we will access this funding. Therefore Paul's place is at risk of not being funded.

Written by Justin Mazzotta Dementia Practitioner at Beetle Bank Social Farm April 2022



Case studies: **Retired farmer**

All names have been anonymised. Period: March 2018 - May 2019



Derick, a retired livestock farmer aged 78, was referred to Beetle Bank Social Farm by the Community Mental Health Team in March 2018. Derick and his wife Linda lived together in their private house in a rural setting on the outskirts of York. Derick and Linda had been in conflict much of the time at home and the Community Mental Health Team were aiming to help alleviate tensions by enabling meaningful activity for Derick and regular respite for Linda. Derick was mildly impaired by his dementia.

Derick had been a livestock farmer his whole working life. Farming was a way of life for him and he had not had much time for other occupations or hobbies outside of this. Derick was very knowledgeable and interested in farm animals so a referral to Beetle

Bank Social Farm was particularly suited to him because of the traditional farm animals on site where the service operates.

Derick was able to use his own financial savings to fund his placement. Attending the service Derick quickly settled and bonded with staff and other service users there. He expressed a desire to be involved in the care of the animals at the farm and activities around animal care became a regular feature of the service. For example, he would feed the sheep and cows and other animals as well as muck them out. We would also frequently support the farm owner by helping her with maintenance jobs, also something familiar and meaningful to Derick. Derick was able to utilise his knowledge of animals when at the service and put this skill of his to good use; for example, he would observe the animals carefully and let staff know if there were any health issues which needed looking into. The service facilitator would then pass this information onto the farm owner to follow up on.

Derick would also gain social and emotional support at the service by being enabled to reminisce about his past with staff, volunteers and other service users. There were positive experiences in his life which staff and volunteers were able to reinforce and help Derick to maintain a positive self image. Reminiscing was therefore a preserved ability and interest of Derick's which was tapped into during the service sessions.

Derick was able to engage in meaningful activity whilst attending a social farm. Many of the animals there were traditional farm animals and familiar to him, enabling meaningful activity and purpose. Derick was also able to hold onto a status of someone knowledgeable and important whilst attending the social farm. It's worth noting it would have been difficult to find other suitable placements for him since farming was such a large part of his life. Linda was able to access regular respite each week for over a year until Derick became seriously unwell and left the service.

Written by Justin Mazzotta Dementia Practitioner at Beetle Bank Social Farm September 2019





healthwatch York

Healthwatch York
Priory Street Centre
15 Priory Street
York
YO1 6ET

www.healthwatchyork.co.uk

t: 01904 621133

e: healthwatch@yorkevs.org.uk

 [@healthwatchyork](https://twitter.com/healthwatchyork)

 [Facebook.com/HealthwatchYork](https://www.facebook.com/HealthwatchYork)