ANNEX A

healthwatch
York

Dementia Support

Listening to carers of people living with dementia in York

Healthwatch York Report February 2022

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York

Acknowledgments

Thank you to everyone who took time out to respond to our survey and to all the organisations that have helped to develop this report, including Joseph Rowntree Foundation, Joseph Rowntree Housing Trust, NHS Vale of York CCG, Minds and Voices, York Dementia Action Alliance, City of York Council, Age UK and The Alzheimer's Society.

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Summary of Key Themes

1 in every 14 people aged 65 years and over has dementia. This number is set to increase as our population ages and lives longer. In 2020, it was estimated that there were 2,511 people with dementia aged 65 and over and 79 people with dementia aged under 65 years, living in York. Our survey of carers of people with dementia in the city has identified the following key themes:

Diagnosis

Some people had waited a very long time for a diagnosis without information or advice and some felt the diagnosis had been delivered poorly. Additionally, people reported little or no follow up support or contact after diagnosis leading to many feeling abandoned and alone. Carers talked about the challenges faced when the person they supported did not acknowledge a diagnosis. There appeared to be a lack of ability in services to offer support which responded to this either for the carer or person they supported. An inconsistency with GPs, both in their approach and ability to respond effectively to carers concerns was raised. The felt lack of knowledge from doctors around early onset dementia was also a concern.

Access to services/support after diagnosis

Access to support after diagnosis was a mixed picture and shows an inconsistent approach to support across dementia care in York. Follow up care had already been highlighted as limited in many instances. Some carers spoke about having a very good, accessible GP who had been supportive, able to access the right services and able to set in motion the right support. However, it was also reported by many that GP access was very difficult. Often carers felt unable to get through or that it took weeks to make contact. Many carers felt that their GPs were not able to offer the support needed for dementia related problems. They spoke about concerns when more specialist teams discharged them back to GP care due to the lack of support they then experienced. Carers also spoke about the difficulties caused by fragmented services, being passed between services and the difficulties grasping the number of services involved. Some carers had faced challenges trying to co-ordinate and ‘untangle’ all these services who often didn’t communicate well with each other. People talked about not knowing what to ask for or who to contact.

Longer term support

Kinds of support received varied across the public and voluntary sector either for themselves or for the person they support. However, some reported not receiving any support at all and others gave many examples where the support offered had not met their emotional or practical needs. People spoke about the ‘standard’ kinds of support they’d received such as phone calls or being given leaflets. Some people had benefited from these but there were many experiences where this support had not met the needs of individuals and families. This kind of support was often associated with feelings of being abandoned and ‘left to get on with it’. The inflexibility of services creates difficulties especially for carers currently in employment and increasing numbers of people are struggling to juggle work and caring commitments.

How services work together

Where services had worked well together carers felt better informed and had an improved understanding about the condition. In some cases, carers reported that the happiness of the person with dementia had increased. Carers had also been able to receive the needed practical support such as additional carers, or necessary equipment. Carers told us about experiences where services had not worked well together. These included poor communication between organisations and a lack of expertise in dementia.

Planning for the future

A large number of people felt they had not discussed planning for the future with professionals in health and social care but felt this would be useful. When asked about their concerns for the future carers spoke about wanting to understand dementia more including learning about what they could do to help. They wanted to know more about what help was out there and how/if they could access respite and day centres for support with care enabling them to return to work. People had concerns around housing and finances and understanding what to do and how to manage things as the disease progresses.

Activities and socialising

Many carers spoke about the difficulties of leaving the person they care for, which meant they were unable to do activities of interest to them. It made socialising particularly difficult. Some carers felt they didn't know much about what was available to them or felt there were no activities of interest to them. Carers told us about the effects of loneliness and the lack of support they experienced. This often caused them to feel as though they are on their own and unable to give the support they would want for their loved one. Carers also described the frustration and the lack of support and opportunity for stimulation/meaningful activity for the person they supported. Carers told us about the impact the pandemic had had on people they supported. They felt the consequences of the pandemic such as lock downs and closures of services had accelerated symptoms, decimated people’s routines and self-confidence, increased isolation, anxiety, and dependency on certain family members. Alongside coping with the impact on the person they support, carers told us about the immense challenges that came with not being able to get support from other family members or getting support from or being able to socialise with other carers. Some carers felt they were so familiar with isolation and a lack of any external input that they didn’t feel much of an impact from the pandemic.

Being listened to

Some carers were able to tell us positive experiences where they had felt listened to by health professionals. However, many told us about feeling ignored and having to fight to be heard. Some carers felt they had only been listened to when things had reached crisis point. Some carers told us their experiences of feeling as though they were listened to, but the outcome had been ineffective due to the lack of follow up or any real help.

Towards a New Service

Carers imagined:

- Reduced waiting times for diagnosis and improved communication and support following diagnosis
- A consistent approach to dementia care across the city with improved GP access and support from specialists, where care was integrated across a network of closely allied organisations
- A new service which included an allocated person to seek support from in the longer term
- A key physical place/centre to provide social and physical support for people
- Improved opportunities for activities and socialising for people with dementia and their carers across the city
- A network of respite and day centres for support
- Advice on housing and finances and understanding what to do and how to manage things as the disease progresses
- Being listened to by health and social care services, both as a person with dementia and as a carer.

Background Information

Dementia facts and figures

Research in 2019 showed that there were over 850,000 people with dementia in the UK (Alzheimer's Society 2019).

This means that 1 in every 14 people aged 65 years and over has dementia. This number is set to increase as our population ages and lives longer.

Dementia is not a single illness but a set of symptoms affecting areas such as memory or thinking caused by damage to the brain. Different types of dementia include:

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

Data from 2013, shows that there were 42,325 people in the UK with early-onset dementia (onset before the age of 65).

The National Picture

As the number of people living with dementia steadily increases, the government and NHS England have pledged to make improvements to dementia care a key priority. Some key publications which outline current and future plans include:

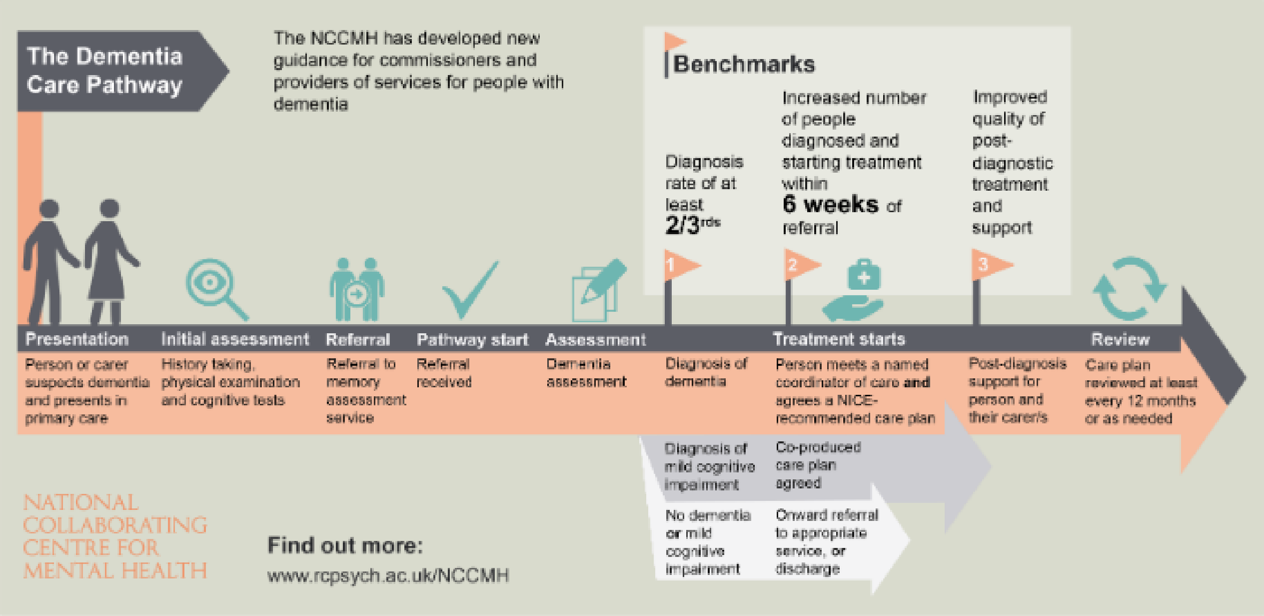
- The National Dementia Strategy for England 2009
- The Challenge on Dementia 2015-2020
- The NHS well pathway
- The Dementia Care Pathway: Full Implementation Guidance
- NICE pathways: Dementia overview

National policy discusses improving care for people with dementia through several initiatives. For example:

- Improving public awareness and understanding of factors which increase the risk of developing dementia
- Increasing and maintaining the rate of diagnosis of dementia.
- Improving the quality of treatment and support after diagnosis
- Reducing health inequality and ensuring equal access to quality care and support
- All NHS staff receiving training on dementia appropriate to their role
- Increasing investment in dementia research

Good dementia care is seen as needing to be delivered across the 'Well Pathway', from prevention through to supporting people at the end of life.

So what should good support look like?



Receiving a timely diagnosis is seen as giving people the best opportunity to get the right support from the beginning, plan for the future and prevent crises as well as receive any treatments which could slow progression of the disease. The aim is to increase the amount of people being diagnosed with dementia and starting treatment within 6 weeks of referral.

Following diagnosis each person with dementia alongside any family or carers should be offered consistent support in line with NICE-recommended care. It should involve having a named co-ordinator of care who would support with creating a flexible and up-to-date care plan which is reviewed at least every 12 months, but updated regularly to reflect the person's current needs and wishes.

The co-ordinator of care would be the point of contact for the person with dementia and their family and/or carer when they need information, advice or help. The co-ordinator should be suited to the individual needs of the person with dementia and could come from a variety of settings including primary care, the voluntary sector or memory assessment services.

"Good dementia care should be personalised and life-long, taking into account the individual needs and preferences of the person living with dementia and, where applicable, their family or carer."

The Local Picture

In 2020, it was estimated that there were 2,511 people with dementia aged 65 and over and 79 people with dementia aged under 65 years, living in York (PHE).

Public Health England publishes data which allows CCGs across England to compare performance across different local areas.

The data suggests that compared to England, York has a significantly lower dementia diagnosis rate for people aged 65 and over. The amount of people with a dementia diagnosis having their care plans reviewed every 12 months has also decreased between 2019 to 2020 and is also currently lower than the average in England.

This means that some people living in York are not receiving a dementia diagnosis in a timely way and that some people's care plans are not being reviewed regularly and kept up to date.

More positively, figures show that York has less emergency hospital admissions and a lower rate of mortality for people with dementia aged 65 and over, compared to the average in England.

Our Project

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 JRF to develop a project with people living with dementia.

Whilst planning this project it was announced that the City of York were developing a Dementia Strategy for the Autumn 2021. This has not existed in the city previously.

We felt it was vital that the voices of people living with dementia are at the very heart of this strategy and shape its development and creation.

We worked alongside people with dementia, carers and organisations across York who support people living with dementia to plan, develop and deliver this project.

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 through various engagement work.

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 contact with 38 members of the public who raised concerns around support for dementia. 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 loved ones.

Challenges and limitations

We were keen in this project to have the voice of people with dementia alongside the carers voice to achieve a balance of this.

This project was developed and delivered during a time of uncertainty during the Covid-19 pandemic. Though we had hoped that face-to-face engagement would become increasingly accessible during the later months of the project, it continued to be problematic. Many groups for people living with dementia had not yet re-started and keeping people safe and not exposing them to any unnecessary risk was 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 that due to these challenges and restraints we were unable to reach as many people living with dementia as we would have wanted and were unable to provide the face-to-face engagement so necessary for many individuals to be able to take part.

What did we do?

Planning and pilot phase

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.

Healthwatch York and these organisations have worked together to produce a draft survey. This survey is now going through a pilot phase whereby carers of people with dementia can test it and give their feedback. Healthwatch will produce the final draft. It has gone out to a sample of Dementia Forward's clients and the Minds and Voices. In collaboration with organisations across York, we developed a survey for carers of people living with dementia. We then asked carers to give us feedback about the survey and what they thought worked or didn't work. We used their feedback to make changes before releasing it more widely.

We were aware that online surveys were not going to be accessible to a large number of people we wanted to reach and so used the survey as just one tool to get feedback. We worked closely with different services and organisations to produce and disseminate multiple tools to get feedback. This included working with:

- Age UK and Alzheimer's Society who supported with dissemination of paper survey packs to their members and support workers
- Social prescribers to develop a "one sheet feedback" form to capture experiences or comments
- York Hospital to create a short survey so that staff could support people to answer questions
- New Earswick Folk Hall to provide surveys and support from staff plus a collection box
- Attendance at a local support group for people with dementia.

Findings

Responses

We heard from 84 people in total.

There were 74 responses to the carers survey, 67 of these were from carers and 6 stated they were writing it together with the person they support. 1 person did not answer the question. One carer emailed us their experience.

We visited a group run for people living with dementia and received feedback from 5 people. We also heard from 4 people living with dementia who completed the online survey. This will be covered in a separate report.

Diagnosis: Summary

Some carers talked positively about diagnosis. For them it had been timely and delivered in a kind and professional way. Carers spoke positively when they felt they had been well informed during the process and staff had been approachable and understanding towards all the people involved.

However, many carers talked about their experiences of diagnosis negatively. Some had waited a very long time for a diagnosis without information or advice. The inconsistency with GPs, both in their approach and ability to respond effectively to carers concerns was raised. Some felt the diagnosis had been delivered poorly. Additionally, people reported little or no follow up support or contact after diagnosis leading to many feeling abandoned and alone.

Carers talked about the challenges faced when the person they supported did not acknowledge a diagnosis. There appeared to be a lack of ability in services to offer support which responded to this either to the carer or person they supported. The felt lack of knowledge from doctors around early onset dementia was also raised.

Diagnosis: Themes

Waiting times

"My mum went to the GP due to memory problems and got a diagnosis a year later."

"Process reasonably quick."

"I feel three years was too long to wait and perhaps taking medication three years earlier may have held it at bay for a while longer, who knows?"

"From the initial appointment to diagnosis was far too long"

"It took several years to diagnose"

"It took a long time to get a diagnosis and there was no/limited support until we did receive the diagnosis. We were lucky in that the Memory Clinic was just being phased out so we were able to get a diagnosis with relative speed but I cannot imagine how difficult it must be without a central service and being reliant on overstretched GPs to make a diagnosis, etc."

Poor recognition of early onset

“My husband stopped work because he was no longer able to do his job but was not diagnosed with dementia until 6/7 years later thus losing many opportunities for treatment. His dementia was quite advanced at this time. I feel that GP’s could be better trained to spot possible symptoms especially in younger patients.”

“My wife, aged 62, was showing signs of dementia. We booked to see the GP and he said there is nothing wrong. I passed him a note saying that she has a short-term memory problem. He asked questions mainly about politicians which she answered mostly correctly. She was unable to recall the postal address he gave her two minutes previously. The GP said there is no memory problem. We had to go back again 4 years later. A different GP referred her to the memory clinic.”

Follow up care

“We were quite shocked and went away not understanding the normal procedure. I expected annual reviews and assessments …but there are none.”

“We were handed a pile of leaflets and a booklet and told to read it and call dementia forward who would help with any questions. It was brutal to say the least.”

“The diagnosis did not come as a surprise, but what I did expect and didn’t get was some sort of follow up…I felt rather abandoned.”

“I felt we were dealt with sympathetically but needed much more information as to what the future could or would be like.”

“Support for helping people to understand challenges of accepting diagnosis I would like to know how we could get my mum to understand and accept her condition in order that she would allow help from outside to step in.”

“My main social contact is with a person (s) who has limited understanding of the current world and is isolated . The person I care for is not the person I have known from the past . The person does not comprehend the situation and support I give them and is resistant to my help . I find myself doing things behind their back which puts a strain on my mental situation as I am constantly hiding my actions and their consequences . I would like someone experienced in Dementia care to actually visit my parent and chat with them about the need to accept help and understand their position and how they can agree to prepare for possible future challenges . I don't think most GP's could do this.”

“As a registered carer the carers assessment team have been helpful in trying to give me a break i.e. respite care for mum while i take a break. But mum won’t agree to any of this so it is left to me to carry on with no break for 6 years in total. They have signposted us to Alzheimer's society and dementia forward etc but as my Dad has not accepted my Mum's condition and she is unaware it is difficult.”

Poor delivery

“Was given in an uncaring and quite blunt way”

“Diagnosis was very blunt and to the point”

“The diagnosis was given after a memory test…whilst she was in bed!”

Challenges for carers around diagnosis

"We felt very awkward. Felt unable to ask questions."

"As the accompanying relative/carer I would have appreciated an additional face to face session with the consultant after diagnosis, I did have power of attorney for health at the time."

"It's very difficult taking a family member to the doctors or dementia clinic and having to talk to them about their problems in front of them. Also, the clinic would ring the patient to make appointments and the patient would refuse the appointment making it very difficult all round."

"It is a challenging situation when someone with dementia living on their own refuses to acknowledge any problem, I think through fear of diagnosis"

"His diagnosis was only achieved when it was needed to advance care packages. Should we or the professionals have pushed for earlier diagnosis? I don't know."

Access to services/support after diagnosis: Summary

Access to support after diagnosis was a mixed picture and shows an inconsistent approach to support across dementia care in York. Follow up care had already been highlighted as limited in many instances. Some carers spoke about having a very good, accessible GP who had been supportive, able to access the right services and able to set in motion the right support.

However, it was also reported by many that GP access was very difficult. Often carers felt unable to get through or that it took weeks to make contact. A large number of carers felt that their GPs were not able to offer the support needed for dementia related problems. They spoke about concerns when more specialist teams discharged them back to GP care due to the lack of support they then experienced.

Carers spoke about the difficulties caused by fragmented services, being passed between services and the difficulties grasping the amount of services involved. Some carers had faced challenges trying to co-ordinate and "untangle" all these services who often didn't communicate well with each other. People talked about not knowing what to ask for or who to contact.

Access to services/support after diagnosis: Themes

The "GP Lottery" – Access to primary care

When access was poor

"It took us some weeks before we could get an appointment to discuss our concerns with a GP. It is very much a lottery getting access to a GP who shares our concerns."

"The GP surgery have not even recognized the diagnosis or referred to it or made it have any impact on care provided."

"Ringing the GP surgery isn't successful as it takes weeks to get an appointment."

"The GP was reluctant to prescribe medication to enable us both to get a good night's sleep. Fortunately, I received help from the York crisis team."

"I discussed my husband's memory problem with a GP. A blood test was done but nothing else until some considerable time later when I told a different GP."

When access was good

“When I have been to our GP they have been very good to talk to and advise me what to do.”

“Nothing happened for some years but during the covid pandemic I was desperate. At that time I saw the GP and she was excellent and set in motion the mental health assessment.”

“The GP was very supportive but I struggled to know who to contact. As the illness progressed my husband became incontinent we managed to get an assessment but never heard of any information or contact.”

“My husband had an appointment a year after diagnosis. Then that ceased to exist and we were referred back to our GP. The only contact we have had with the surgery is a once or twice yearly check of his blood pressure. The only good thing is when we had to see our GP about another issue and I mentioned how much worse the dementia was, and his balance was now poor so I was looking for a wheelchair. She sent an application to the wheelchair Service who acted quickly and delivered one within a week.”

Fragmentation of services

“It’s difficult to grasp why so many agencies get involved, hospital care workers, dementia forward, integrated care team, Alzheimer’s Society, Age Concern, York Council…”

“I found the experience of being given support initially from secondary services good but the experience…but then was told to revert to access only by GP. Very disturbing and unfair as his illness was acute and ongoing but all support was withdrawn.”

"It has been difficult as he has moved Authorities, so York had to hand-over to them."

Kinds of support: Summary

Kinds of support received varied across the public and voluntary sector either for themselves or for the person they support. However, some reported not receiving any support at all and others gave many examples where the support offered had not met their emotional or practical needs.

People spoke about the "standard" kinds of support they'd received such as phone calls or being given leaflets. Some people had benefited from these but there were many experiences where this support had not met the needs of individuals and families. This kind of support was often associated with feelings of being abandoned and left to get on with it. The inflexibility of services creates difficulties especially for carers currently in employment and increasing numbers of people are struggling to juggle work and caring commitments.

Ideas about what should be available and what would help included:

Having a support worker who is someone to talk to about feelings and also someone to turn to ask for advice over time.

More support with the challenges of being a carer whilst trying to work and services being able to understand and be flexible for this, and the importance of needing a break.

The support that works for some didn't work for others; there needs to be a more questioning attitude from services; 'are we meeting your needs?' or 'do we need to be thinking about something else?' Most people had suggestions for improved support.

There was evidence of a need for more appropriate and engaging activities to meet the needs of people living with dementia.

Experiences of kinds of support: Themes

Telephone calls

"I get a telephone call from a lady (carers support I think) every 3 or 4 months but that is of no help when you are with him 24/7 and so he is in the room and is not unaware that he is the subject of the conversation. I just want to cry and say how bad I feel but I can't as it would upset him so the stock answer of 'I'm ok' trots out. I was upset to see that these phone calls are logged on my medical notes as social prescribing. The only concession I feel we have is that I am allowed to come into consultations with him now."

"When help was requested, it was always forthcoming as long as you were patient but the feeling that you had been abandoned was very strong. A spontaneous phone call even at infrequent intervals would have made a huge difference."

"I haven't had any support, I've had the occasional phone call from Dementia Forward, nothing from the GP."

Signposting and leaflets

"There has not been any support really. Beyond being supplied with leaflets we have been left to our own devices. I do not know what could have been better. Perhaps a support worker to talk through feelings and where to turn for support if needed."

Respite and care services

"To be able to rely on carers service would have been so beneficial, everyone else has been great, especially the Be Independent Service."

“I have been able to discuss problems but unpaid carers need some breaks and respite. It's very unfair that having a much needed break should be so expensive.”

“When my husband was in hospital I spoke with someone from Social Services regarding some respite for a couple of weeks. Nowhere suitable was available and I couldn’t leave my husband in hospital until there was a suitable place for him to go to. As a family we decided to bring my husband home as he was deteriorating, he stopped trying to feed himself and the incontinence was getting worse.”

Flexibility in services for carers

“I travel over 60 miles to care for my relative in York. Health professionals make it a battle all the time to get access. They want all sorts of paperwork including LPA (Lasting Power of Attorney) documentation sending. Appointments are made without taking into account the distance I have to travel. They do not always appreciate that it takes a long time to get people dressed, etc to get to the appointment. Parking is also a major issue when you have a person with dementia whose mobility is very weak. Obtaining a blue badge is impossible in York.”

“In the early stages the health, social care system seemed to conspire to make life more difficult. [You have to act as a] go between for different services when you don’t understand the system or speak their language. Always having to take parents to appointments and take time off work when the district nurse could easily have taken blood, or doctors and pharmacies arranged to send each other prescriptions or information directly. Picking up incontinence pads when they could have been delivered. There was a difficult period in the community when there were so many appointments with various services that my sister and I had to take them to when many could have been done more easily in home visits. The impact was severe on

me. I couldn't juggle work and all the needs of my parents. One example is when flu jabs were required but carers for a whole block of elderly people were expected to take people taking time off work, when a couple of district nurses could have done it in an hour in the block."

"The most help we got was from Dementia Forward which I'm so glad we attended….Any problems I had they could help me solve, and it was so helpful as a carer to talk to other carers. At the end my husband was sectioned under mental health but twice I called the crisis team out and they were very good. Nothing but praise for them. They acted very quick."

"We don't feel we have received much support from health professionals. They do not seem to have any understanding of what it is like trying to look after 2 people with dementia and trying to work."

How services worked together: Summary

Carers told us about their experiences where services **had** worked together. These included:

- When discharges from hospital had been coordinated well
- When hospital wards liaising well with specialists e.g. neurologists
- Good communication between different professionals e.g. mental health nurse and care home, occupational therapists and consultants.

Where services had worked well together carers felt better informed and had an improved understanding about the condition. In some cases carers reported that the happiness of the person with dementia had increased. Carers had also been able to receive the needed practical support such as additional carers, or necessary equipment.

Carers told us about experiences where services **had not** worked well together. These included:

- When numerous agencies were involved but not communicating with each other

- When there was a lack of expertise of dementia and dementia specialists within certain services
- When there was no correspondence between different GPs
- When different services blamed each other
- GPs not having appropriate knowledge to access appropriate pathways of support
- Having to repeat history and issues to multiple professionals
- Problems claiming benefits as health professionals had not responded to forms
- Pharmacies and GPs not talking
- Not aware of agencies working together

> *“The result of a blood test was given by a receptionist, followed up by a disinterested nurse. It left my wife in bits, with me having to pick up the mess.”*

Concerns for the future: Summary

A large number of people felt they had not discussed planning for the future with professionals in health and social care, but felt this would be useful.

When asked about their concerns for the future carers spoke about wanting to understand dementia more including learning about what they could do to help. They wanted to know more about what help was out there and how/if they could access respite and day centres for support with care enabling them to return to work. People had concerns around housing and finances and understanding what to do and how to manage things as the disease progresses.

Concerns for the future: Theme

To have more understanding

“Not really sure what will happen as the disease progresses.”

"Needed to understand what the route cause was and tests haven't been done to understand this."

"Just understanding [the] illness."

"As the dementia progresses. What to expect and what to do to help?"

To know what help there is

"I may need more help and I would like to know what there is."

"Lack of contact. When I feel I need support I am not always in the best situation to ask for it."

"At the moment I know how to access help if necessary but if/when my situation deteriorates this will likely change."

"I'm trying to find some day care so I can have some respite myself. I have managed to get my husband on a waiting list but due to the Covid situation there is no telling how long it may take to get a place. I also think a step-by-step guide to care homes and how to access them would be helpful."

"What we currently need is a day care centre to drop Dad off at so we can go to work."

"Next stage of care as the illness worsens and how we can proactively put in place Plan Bs for when Plan A no longer works. Finding out about different options, what are the best possible options/solutions, what level of support

is available/funding and how much we might need to self-fund."

"I'm concerned for my own health and would appreciate being able to talk about my situation."

"We just have no idea how to proceed and are just keeping our fingers crossed, hopeful for the best. It's outrageous."

What will happen when I'm not around?

"Nobody has discussed anything with us. My main worry is if I become ill and he has no one here to look after him. I also worry if he should have to go into care if I became ill or predeceased him."

"I am concerned about care should I not be available for any reason."

"We have no idea what options will be available to us when our mother can no longer be cared for by family."

Finances

"We struggled to get financial help. Citizens Advice helped us, no-one else mentioned the fact we are 60 so how do we pay bills, get benefits, which benefits etc. I was always worried how and when/if he went into care, how much it would cost, and all the things involved with that we only had a small amount of savings."

"Lack of financial support."

"Finances regarding my Mum's care on a permanent basis in her current residential setting."

"My partner has young onset. I have to work. He needs a large package of care to enable me to do this, and to keep him active. This I feel needs to be taken into consideration for younger people."

Loneliness

"When are dementia sufferers going to be allowed to meet together, as people can in cafes and pubs, etc."

"My main concern currently is how lonely mum is, especially with Covid, people have got out of the habit of visiting."

Housing, Care Homes

"I am concerned about housing and support at a later date."

"Information about finding a care home for respite care for my husband to give me a break. It has been inferred that if you have savings there is no point in contacting social care and that I have to contact care homes and make arrangements."

Activities: Summary

Some carers told us about activities they were involved in. These included: walking, cycling, gardening, swimming, live sport and outdoor bowls. Carers also mentioned meeting with friends and family as well as going to groups such as Musical Connections, York Carers, Alzheimer's Society, Singing for all, Age Concern and Healthwatch.

However, many carers faced barriers to participating in activities. The majority of carers spoke about the difficulties of leaving the person they care for, which meant they were unable to do activities of interest to them. It made socialising particularly difficult. Some carers felt they didn't know much about what was available to them or felt there were no activities of interest to them.

Activities: Themes

Difficulties engaging in activities due to leaving person behind

"…. he goes for his sleep and I can join the class while he sleeps."

"Unfortunately, I can't take part in any activities as this would mean leaving mum for long periods of time and she would become agitated and confused because I wasn't with her."

"My walking group and art group are important but I need help otherwise I can't leave my husband alone."

"Age UK offer me a few hours respite but I would very much like more to see friends, go to the cinema, socialise, walk, etc. I cannot be away from home long enough to pursue these interests."

"I have engaged a private carer for 4 hours a week…so I can have a walk, meet a friend, or do some shopping. It's expensive but something I've had to

do for my sanity. I would still love to hop on a bus and go to the coast for a day though!"

"As a carer I no longer feel as if I have a life of my own. If I need to go to the hospital for myself I have to get my son to come and look after his father and work from our home. I'm lucky in that but as for a social life, forget it."

"The only way to continue with activities that are important to me would be to have more care for my husband but that costs money. Financial support is the real key to helping carers maintain some independent life."

"I am unable to do anything as I can't leave my husband."

"…we also used to go out for coffee or lunch a couple of times a week but that is becoming difficult as toilet access is difficult. I can wait outside the toilet for him but if I want to go he forgets where I am and on one occasion he was walking out of the garden centre looking for me."

No knowledge of what's there

"Didn't know much about any activities open to us. We already belonged to a walking group so we carried on with these…"

"We have no access to services for Dementia activities for my relatives. However, York Carers Trust regularly keeps me updated with their activities but they are the only professionals that send me details of activities."

"No activities which the state or voluntary sector deliver were appropriate to my interests."

Feeling listened to: Summary

Some carers were able to tell us positive experiences where they had felt listened to by health professionals. However many told us about feeling ignored and having to fight to be heard. Some carers felt they had only been listened to when things had reached crisis point. Some carers told us their experiences of feeling as though they were listened to but the outcome had been ineffective due to the lack of follow up or any real help.

Feeling listened to:

"After seeing the GP in November 2020 everyone was very supportive."

"The genuine interest which is shown when they contact me."

"They have always listened to us and given us advice."

"The quality of the staff and their listening skills was always excellent but it was always at my request and never from them."

"Always take time to listen and offer sympathetic support, a listening/caring ear not just a cold/clinical response."

"Now we feel listened to. At first when we got social services involved it took them a while to see the situation how we saw it."

Not feeling listened to:

"Feel it is unrealistic to expect to be listened to and so only ask for factual information which I obtain. No one has time to consider the stresses of caring or listen to my particular situation, so I try to sort difficulties out myself."

"There has been no advice given as when you seek information you are sidelined or can't even get through on a phone."

"The initial diagnosis by the mental health doctor could have been handled a lot better I felt as if I was talking to myself. The impression I had was he wanted us out of his office. When we were re-referred back to the mental health team it was a new doctor and it was all change. I was listened to and given time to explain what was going on without the person I care for in the room. It's very difficult to tell a doctor how a person is behaving when they are in the room with you even if they don't understand what you are saying or will forget it straight away."

"The hospital nursing staff seemed to think my mum was capable of living alone despite my informing them about my mum's deteriorating condition. I felt I was battling against them whenever my mum was admitted to Hospital. Very stressful to say the least."

"GPs ignored me, largely. Hospital did not explain the nature of the medications used, or their impact. Nobody ever discussed alternatives with me."

“Some health professionals are better than others at listening to my concerns. Some GPs are very good and supportive, whilst others… are appalling at listening to my concerns. The Memory Clinic could be better at providing support and listening to concerns.”

“I have had to go through complaints procedures to get anything remotely useful considered by care providers.”

Listened to but ineffective:

“They have listened but with resources as they are there is very little they can do.”

“GP’s may have listened but not taken effective action.”

“There has been a lot of sympathy but no real help.”

“Beyond the diagnosis appointment there have been no contacts with health professionals. At the diagnosis appointment mum was asked if she had considered suicide. Mum said she had but that she would not act on this as she did not want to upset her grandchildren. To have this question asked and answered and then no action taken or support suggested felt brutal. I understand the need to collect data but there was no positive outcome for mum as a consequence of having answered this question. It felt like a tick box exercise for the collation of information not to assess Mum's needs. This has understandably made me feel cynical about the service provided.”

Feeling positive

What made people feel positive?

Carers spoke about their self-determination and trust in themselves. Carers felt positive when the person was receiving good and “the right” support for them and when they knew where to go if they needed more help.

“I am a determined person who is comfortable researching information; chasing down the right professionals/services to use etc. I am not afraid to pick up the phone and badger. I am a very positive/proactive person who believes in solutions not that there are only problems. It is my inner strength that helps me feel positive, not necessarily what is available out there. I fear there are many who are not like this and probably fall through the net/do not get the support they need i.e. fly under the radar.”

“I am happy he is being cared for and that I am able to visit him.”

“I feel I can support my husband well at the moment.”

“I feel I do something that is demanding regardless of it’s poor recognition. I have kept one diagnosed (and one probable) dementia sufferer safe and out of hospital during the pandemic.”

“Just trust in myself and what I do.”

“My wife looked after me for almost 50 years through my working life.”

“Aware of help if/when needed.”

Why did people not feel positive?

Carers told us about the effects of loneliness and the lack of support they experienced. This often caused them to feel as though they are on their own and unable to give the support they would want for their loved one.

Carers also described the frustration and the lack of support and opportunity for stimulation/meaningful activity for the person they supported.

Loneliness and no support

“More help at the first instance on how to cope with such a devastating diagnosis. No one asked me how I was ok. How I was coping I just had to be strong or I would have collapsed. Had to have anti-depressants at first to help me sleep.”

“Very lonely. No support.”

“Shouldn’t have to get to a crisis point before help is offered. Assessments should be carried out if promised.”

“Looking after someone with dementia 24/7 is really hard. Carers need a break.”

“More support for my mental health.”

“My husband requires full time support because of his wandering; therefore it has been difficult to make sure he is looked after if I go out at all.”

“I need help with understanding benefits.”

"There have been no offers of help from health care professionals other than the GP advising that she is available to speak to with concerns, which is so difficult in the present climate."

"Once you get the dementia diagnosis, we are very on our own."

"Meeting with someone to tell me where we are with my wife's illness. More communication."

"Condemn both the patient and carer to humiliations that are never understood. So feeling positive about the situation is not one that springs to mind"

Lack of stimulating opportunities for a person being supported

"We have no family nearby so reliable, experienced companions to stimulate my husband would enhance his life and give me time to myself."

"My husband is no longer the man I married. I obviously still care for him and do my utmost to give him some sort of meaningful life, but I get nothing from him. Much of the time he doesn't know who I am. I feel cut off from life and constantly frustrated that I can't do things. Even going on holiday is not possible now. The only support I have had over the last 18 months is from Age UK. They have phoned regularly and run a zoom session once a week instead of the day club my husband used to go to."

"I am the support for Mum and Dad and I do not feel that there has been any support beyond the diagnosis of dementia and the initial session at Selby Hospital that Mum attended and was not positive."

"Better diagnosis and correct drugs at the correct time. Part of dementia is feeling like urinating frequently but short term memory stops individuals remembering they have just urinated. Given right royal run around trying to sort either bladder sensitivity or enlarged prostate. In the end no firm diagnosis still so no real treatment so still has problems. This makes it impossible for trips out and has a massive impact on day to day living."

The effect of the pandemic: Summary

Carers told us about the impact the pandemic had had on people they supported. They felt the consequences of the pandemic such as lock downs and closures of services had accelerated symptoms, decimated people's routines and self-confidence, increased isolation, anxiety and dependency on certain family members.

Alongside coping with the impact on the person they support, carers told us about the immense challenges that came with not being able to get support from other family members or getting support from or being able to socialise with other carers.

Some carers felt they were so familiar with isolation and a lack of any external input that they didn't feel much of an impact from the pandemic.

"As mum is not recognising or refusing to access help we are left waiting until she is very ill. Not sure what can be done apart from lifting stigmas from ageing."

"I love my husband and loved aspects of caring for him, but all the institutional systems have been appalling to non-existent."

The effect of the pandemic: Themes

Impact on person with dementia

“He is very sociable and loves to be with others but because he is classed as extremely vulnerable he has not been out much.”

“At the start of the Pandemic my husband was told to shield (no reason given and it did not happen in the second lockdown). We were given a reference number on the letter and went on the government site but the health reasons on there did not apply to him and we were told we could not get help. It took me 6 weeks to find a supermarket slot to get a food delivery and many many tears...6 months later I got the first phone call from the carer support worker and she said if she had known she could have got me help. However, as I did not know of her existence at the time, how could I have asked for help? The main impact I can see is I think his Alzheimer’s has progressed much faster and he has become like a lap dog frightened if I leave him alone (which I have never done). All our little trips out each day to keep him engaged we stopped and as he was shielded we could not even go out for a daily walk and our children could not come and visit."

“Routine is everything and day club stoppages really had an effect that would be too difficult to restart.”

“The pandemic isolating has coincided with my parents' (sufferers) ageing. They have had little or no opportunity to interact with others outside their home. I have become literally their only face to face contact with the world. This has not helped them to be stimulated mentally or even physically. They are now fully housebound and cut off from neighbours and few friends /relatives. Support could be some face to face visits from a skilled /experienced dementia professional to talk through the support they really need and should accept. When dealing with medical services it has been hard for me to be fully involved with consultations due to restrictions on access.”

“Lack of personal contact with family friends and social contacts has increased the decline in my wife's mental health.”

“The Age UK day club my husband attended for 5 hours once a week obviously closed - and still has not opened. I was with him all the time with no break as no-one was able to come in. He became a lot less fit and his dementia got worse. There was nowhere to go to mentally stimulate him. I had support from my family over video calls which kept me in touch with other people. Nobody had any idea of the strain I was under looking after him though. The Age UK calls and zoom meetings were a lifesaver though, and I had a useful call from Dementia Forward.”

“It’s been a nightmare and my husband has gone downhill rapidly. It’s extremely difficult to explain to someone with dementia why they can’t go out as they just don’t understand that you go over the same discussion all the time.”

“Lockdown placed entire dependence upon me which has continued to an extent and that causes distress to sufferer if left with a third party.”

“Our parents with dementia have only had us to support them throughout. They must have felt abandoned and so alone.”

“The pandemic has really affected someone with dementia, their whole situation/daily schedule has been turned on its head, not being able to get out etc., having to tell the patient on a daily basis why things were difficult/different just adds to the stress of trying to live with some kind of normality during this stressful time. I consider myself lucky that my husband is relatively calm, otherwise things would have been harder. Maybe a weekly phone call would have helped, at least we wouldn’t feel so alone.”

“It had been challenging being restricted as my husband cannot amuse himself and had become more anxious.”

“Isolation has worsened short-term memory.”

“I think for mum having had a recent diagnosis of dementia and the pandemic then occurring mum has lost a lot of the skills that she previously had. Mum had worked for many years with Age UK and we had planned on trying to keep this going as it would have benefited both mum and Age UK however this interruption that the pandemic caused means that I fear mum may never get these skills back. Apart from a walk around her village (with dad checking on her whereabouts by phone) mum does not do anything on her own now. I feel that this has been accelerated because of the pandemic.”

No support and isolation of carer (loss of family members, other carers/knowledge

“Having no support apart from my son has been difficult as when I go up town to the bank and shopping my husband gets very agitated.”

“The patient has not really understood what is happening but has not wanted to go out anyway. When other family members have appointments it can be a struggle as the patient cannot be left on their own. Also being the only other female in the house I have to deal with the personal bits.”

“Totally left to caring throughout the pandemic. If we had been able to access day clubs maybe we would be better informed (by talking to others, sharing experiences) Did not know that a rapid decline was a possibility so when we got to crisis point we were in shock and felt we were failing in caring for our loved one.”

“Getting in touch with the GP/Local Authority. Hours waiting on the phone, impossible whilst working.”

“No access to any day clubs. No meeting face to face with other carers who may be able to pass on advice /share experiences.”

“It was really hard. My husband was getting worse and I could do nothing for my own wellbeing. Only later did I get a 2 hours a week break thanks to Age UK.”

“Being unable to socialise and having my husband totally reliant on me for company has been very draining. Government information leaflets have been of help in sourcing food deliveries and providing emergency phone numbers although they haven't been needed. Last winter was very hard because of not being able to take him out for short walks and not being able to talk face to face to friends”

“Hugely isolating and lack of support as no home visits from GPs or community nurses. Only time any support was forthcoming was too late and when my family was in crisis. Further assessment was needed and nothing happened; now he is in a home and this has been requested but they are still waiting!”

“There has been little or no response or access to virtually any support either physical or moral.”

“My dad as main carer has been isolated with my mum so much of the time he is beyond stressed. My mum is not really comfortable going anywhere anymore other than with me and as I am their only child it is a huge burden.”

“Everything normal shut down so we couldn't access dementia clubs/activities. I phoned charities to talk over any pointers to help in dealing with issues rather than GP, as a family we felt left to deal with the situation. My own life was on hold and my well being suffered as a result; feeling down and exhausted.”

“We were a couple quite happy in our own company and I went to the gym 3 times a week which I now cannot do as he won’t stay on his own and I can't leave him in the car as he would forget where I was and go looking for me. We are Christians and the lockdown decimated our routines as the Church was closed. We used to go to the cinema every week, if nothing else it gave me two hours peace. Still not feeling safe enough to return.”

No visits and experience of care home

“My husband was in the care home when the pandemic came along. I used to visit him but suddenly I wasn’t allowed to. It's agony knowing no visits are allowed but I understood why of course. Even now it’s difficult to visit because of rules for entering the care home.”

“I have been able to be tested and visit my sister on a regular basis either in a pod or later in the building. They have done as much as possible to keep them entertained and active, giving them a ride out in their minibus, musical entertainment, cheese and wine tasting and art activities etc.”

“I was unable to see my husband for many months and he no longer recognises me.”

“It has just been horrific. Knowing my dad was in hospital on his own with no way we could contact him or see him was heartbreaking. I was terrified he would die on his own in hospital.”

What helped?

“Certainly our local coordinator has been a huge help.”

“Initially I had to cope. It was difficult to ask for help when everyone was so stretched. It felt necessary to manage. This continued until my husband’s behaviour became too difficult for me to manage. Once this was acknowledged everyone helped but particularly [the] social worker who was excellent.”

“For the first time ever we did a few shops online. Although not as good as being in person we were able to do most of our pre-pandemic activities on Zoom.”

“I feel the support I have received during the pandemic has stepped up to be as good as it could be under the circumstances. In general it has been good and I am hugely grateful.”

“During the pandemic and subsequent lockdowns my relative with Dementia received no support at all apart from myself. I received regular support from York Carers Trust throughout the lockdowns for which I am very grateful because without their support, I would not have been able to manage and cope during this very difficult time. If there were any support services available, they all seemed to disappear overnight. We were truly forgotten in York. Social Care are still not doing face to face visits. We have had an assessment and two reviews of care needs without one professional meeting us. None from City of York Council have ever contacted us to ask if we needed any help/support during this pandemic or subsequent lockdowns. Neither has any other professional apart from York Carers Trust.”

“My mum lived in independent living (extra care) so had care without the restrictions of a care home. We are very thankful for the staff and the approach they took.”

Inventing something new: Themes

A New Service

Carers described different elements of a service which they felt would be able to provide the support needed to themselves and those they support.

The key elements of this services include there being an allocated person to seek support from and a key physical place/centre to provide social and physical support.

The key person:

- Would have knowledge of the whole person (physical health/social situation) and would be able to monitor change
- Would have knowledge of the care sector and the ability to monitor it and make change or highlight problems with care services
- Would provide face to face contact and a one stop shop for any help and support
- Would have close connections to the GP surgery
- Would have knowledge about local organisations, equipment services and benefit advice to provide the needed support

The physical space (dementia hub):

- Would provide an accessible social space for carers and people living with dementia
- Would provide a space for multi-agency working and joined up services
- Would offer activities and interest groups and opportunities for people to spend the day
- Would provide a communication hub where all relevant services would be available and accessible
- A place where people can listen to you
- Regular face to face contact with the same people

“An allocated ‘goto’ person who has all medical record access and can see the whole picture who can co-ordinate specialist services when needed and monitor the decline of someone with a diagnosis of dementia. Someone who knows the current state of care available.”

“A specialist team based at the local surgery to visit / support dementia patients cared for by that surgery. This person or people could have an understanding of the whole situation of each sufferer including physical conditions and their social situation. They could help with connecting with support organisations. If such providers are there, they could start to monitor or evaluate local private providers as I have not been impressed with the private provision options.”

“A dementia village as other countries have done.”

“A local hub or one stop shop for multi-agency working and support for family members.”

“A support service that genuinely offers support and clear advice and information about options (of any kind).”

“A single point of contact like an umbrella across all service providers, support groups/charities, health care and social care professionals to access services/professionals/support/equipment/what we are entitled to etc.”

“Something that joined the services together and funding for services.”

“A centre that provided not only a social space but had activities that could be accessed from the beginning of the diagnosis and where clients could

spend the whole day."

"It would help to have regular face to face contact with a professional so that the person with dementia could get to know them as a friend."

"Communication hub where we could access all relevant services available to us. To have an active listening device. We know our relatives and their care needs better than anyone else and we need our concerns to be taken seriously. Contact Hub where we could access all the professionals both statutory and voluntary services. To see professionals face to face."

"Once people are diagnosed it would be nice for the agencies to work under an umbrella and provide support which continues. Support should be offered and once in the system should be reviewed. People should not have to feel unsure about asking for help, or where to go. Wouldn't it be more sensible if you continued with the same social worker as well as they would have more insight into needs and circumstances and any changes."

Improved emotional and practical support for carers

"More support for carers mental health."

"Someone to visit regularly and listen to our problems would be good."

"Obtaining the Blue Badge needs to be more accessible without the need to take our relatives with dementia for an assessment. If we fail to meet the criteria for the Blue Badge, the £40 needs to be refundable. GPs need to form better relationships with their patients and carers in order to understand their situation and get to know their needs. GPs will then be able to complete the questionnaire correctly based on the needs of the patient that

they have to come to know. Professionals need to build up relationships with both carers and the patient with care needs. We need to access Admiral Nurses for specific medical support, especially as Older People's Mental Health Services discharge upon diagnosis. Getting a GP appointment is almost impossible. We do not have access to a named GP anymore who knows their patient and carers well."

"Group support locally would be good for more help for people with early onset."

"We eventually got disability allowance. A lot of forms to fill in which the women at Citizens Advice filled in for us. I can see why others don't bother to apply even then when he had to be interviewed to see if he could follow simple instructions to see if he could do things. He couldn't, of course, so getting disability allowance helped us. No-one but a friend told us we could get a bus pass for him which we did as we were only 60 when diagnosed. The bus pass helped a lot. No-one but another friend told us. We could get our rates cheaper from the council. When we applied for the first time to York City Council we were turned down and told we couldn't have a reduction in our rates. Eventually through Dementia Forward telling me they were wrong I applied a second time and was told 'yes' we could have a reduction in our rates so the Council gave us the wrong information the first time."

"[We need]…more places locally like Dementia Forward, more helpline information. Anything along those lines to help people like carers to get help with practical and financial and future plans as things progress. By more information I mean printed leaflets as a lot of older people don't go online so they are useless to people who don't own computers."

"Monthly telephone calls to provide the feeling that you had not been abandoned."

“Unpaid carers are saving the country a fortune. They should be appreciated much more.”

“Not an invention, but a plea for information about support a carer should have available to them, instead of getting a diagnosis and being shown the door. Virtually no information given, everything I've learned I've had to research myself. I've just remembered that I attended a course on caring for people with dementia run by the Alzheimer's Association and that was very useful, informative and good for a small group of carers to get together and share experiences.”

Financial Support

“Why don't ‘the powers that be’ accept that when a diagnosis of dementia is made there should be no obstacle applied that stops you getting help in any form. Automatic attendance allowance for example.”

“More financial help for services to carers. Nothing new and this would solve many problems.”

“Easier access to monies/allowances.”

Improved medical and social care for people with dementia

“Regular health/mental checks with patient, regular reviews/updates with family. And more dementia care. How to help the patient day to day?”

“More help. I was left to look after mam for 3 and a half years until the crisis team was called. No-one phoned to see how she was, the surgery was not

interested and we were just left to get on with it. However, when I phoned 999 (police) they were fantastic but it was very sad as that night my mam was sectioned and is now in [hospital] where the care is fantastic and they let me know everything that goes on."

"Dementia is a disease that is not recognized as a terminal illness. The government keeps putting off their 'oven ready social care plan' and families are left to fend for themselves, leaving the vulnerable to their unlucky 'lottery' fate."

"I understand about hidden disabilities and have purchased a sunflower lanyard for my husband so if we were to be separated while out my contact details are on it. However I do feel it has been abused by folk using it to not wear masks when it was a requirement. In fact a relative who is an occupational therapist actually said it was for exemption from wearing a mask and did not know it was available long before the pandemic. We first heard of it at an airport. Maybe a new symbol such as the 'forget me not' would be an idea for the lanyard so people do not just think it's about masks. My husband wore his when we were out but also wore the mask as we just need it in case he loses me."

"A reliable service of affordable carers who employed ladies / men of a certain age! And paid them a good enough wage that the older generation of workers would be happy to work for. This said I mean all ages/ sexes paid well. People with dementia do not always want a young person helping them."

Improving expertise and knowledge of staff

“If someone could pop in now and again who I could ask questions on how to do things in the best way, [he] cannot talk now and I have to help with feeding and with the toilet, he can hardly do anything himself. But he smiles all the time to me and others so that is good.”

“When the young social worker came to assess mum she had no experience of dementia patients. I was shocked when she told me to just leave mum. Mum is not capable of doing anything for herself, when I asked what if mum starts to wander off outside the girl had to ring her boss for the answer. Each time I asked her a question she had to ring her boss for the answer. The questions I asked were as follows. What if mum leaves the hot water on and scolds herself? - after asking her boss - we will turn the hot water off (would that not confuse mum even more?) - what if mum starts wandering outside? put a lock on the garden gate - what if mum fell downstairs put a gate on the stairs there were many more shocking replies to my questions coming from her boss. At the end of the assessment the girl mentioned that it was all to do with finding. That was my first encounter with social workers and my last. I now understand why social workers get such a bad press. They are the most unhelpful people I have come across so far. It beggars belief that they tell people to just leave a person with dementia to look after themselves. I have spoken to another person in the same position as me, who also asked social workers for help and they were told they were being abusive?? (for asking for help). I did write a letter of complaint to the social services and unsurprisingly never received a reply.”

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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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