



#SpeakUp: South East Sheffield Community Dementia Advice Service - Conversations with clients and carers

What is #SpeakUp?

#SpeakUp is Healthwatch Sheffield's micro grants programme, offering funding of between £500-£1000 to not-for-profit, voluntary, and community groups. The purpose is to run a project which will reach out to people across Sheffield, and hear what matters to them in relation to health and social care.

By working with groups which are already trusted partners in their communities, we can make sure we're hearing from even more people, including those whose voices aren't often heard by decision makers.



South East Sheffield Community Dementia Advice Service

Dementia Support Services were tendered for commission by Sheffield City Council as part of their People Keeping Well programme in 2019. During its first 20 months of operation, the South East model received in excess of 160 referrals to link people with dementia and their families into local activities and opportunities to extend their community engagement.



Healthwatch Sheffield

Healthwatch Sheffield helps adults, children and young people influence and improve how NHS and Social Care services are designed and run. We're completely independent and not part of the NHS or Sheffield City Council. We want to understand your experiences, and help your views to influence decision-makers in the city.



Background

During the Covid-19 pandemic, South East Sheffield Community Dementia Advice Service have been unable to meet clients face to face. Telephone contact has been the key feature during this time. From these phone calls it became clear that people were struggling as well as deteriorating in their health.

This #SpeakUp project explored the experiences of people living with dementia and carers during the pandemic and the challenges they have faced.

Who did we speak to?

The information in this report is based on the experiences of **38 clients living with dementia** (24 women and 14 men).

They were aged between 48 and 94.

To find out about their experiences, staff at South East Sheffield Community Dementia Advice Service had conversations with 10 clients (7 women and 3 men) and 28 carers (22 women and 6 men).



What did we ask about?

Conversations focused on the following topics:

- People's experiences with contacting health and social care services in the last year
- Obstacles to finding the help they needed
- People's ideas about how their experiences could be improved
- People's ideas about the easiest or best way to find support



“People our age, remember the war. When you can't have what you want you have to wait. COVID has altered our lifestyle but that is to be expected.”

Key findings

Separation and loss



A key challenge during the pandemic was that many people living with dementia were separated from their families. For people who lived in care homes, visiting restrictions could be difficult for residents and their relatives.

Being separated was challenging for many families, and some people worried that an extended time being unable to visit would have a negative impact above and beyond the emotional challenge:

I am not sleeping because I am worried about my wife whose dementia has got worse. She is in a home and probably won't recognise me. I am scared of going to see her.

People did have mixed experiences with visiting rules in care homes across the city. For example, we heard about short visiting times:

Covid has meant we cannot visit more than for 30 minutes. It isn't long enough. Hopefully it will improve.

However, we also heard about some good practice in relation to visiting:

It is our anniversary in June and I am allowed to stop overnight so we can have a little party.

One person spoke about the loss of their relative:

We were not told that my brother was end of life. We were unable to mourn his passing.

It made it easier when a family member was available to help:

Social Care is not needed. We have Attendance Allowance and make that work for us. The kids help us out a lot.

Carers struggling to cope



We heard about challenges experienced by carers:

I have to do everything myself. There must be a better way than this.

Another person found it difficult to cope on their own:

Felt like I am left on my own with [name]'s dementia.

Quality of support



People reported mixed experiences with the support they received from health and social care services.

Below are some examples of the things that worked well, and the things that could be improved:

Positive experiences	Poor experiences
GP doing home visits	Care agency staff coming very late at night to give medication
South East Sheffield Community Dementia Advice Service was seen as a "one stop place to go"	Not being able to see preferred GP
	Difficulty getting through to services (eg GP, pharmacy)
Being able to ring Parkinson's Clinic – one person was told "don't go buying anything. Parkinson's Clinic will help"	One person said "Mental Health Team were not very good. They should have been available to us more"

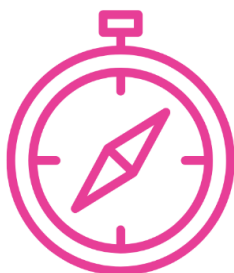
Experiences of some services were even more mixed. We heard both positive and negative comments about the Memory Clinic:

"Memory Clinic has been great, really helpful"



"Memory Service was useless. 'Nothing we can do to help', they said"

Difficulties navigating the system

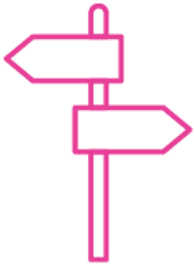


People told us about a range of challenges they faced while trying to get support for them or the person they cared for. Many people expressed disbelief that things could improve, and a lack of trust in the health and social care system:

Whatever I say isn't going to change the system. You can't look forward in the middle of this pandemic.

One person felt that it was their own persistence which helped them get what they needed, rather than the support of the system:

It's only because I can negotiate the system, it would have been difficult otherwise. I would have to rely on others and trust they have our best interests at heart.



Key issues raised in relation to navigating the system

It could be difficult to get any action from services:

We were back and forth with the social worker. We knew we needed a plan in place but it took a lot to get this.

One person told us about a lack of action after a person was assessed:

Social Care did an assessment then said they could not help.

Another person noted that there was a lack of ongoing support:

Physio was meant to come and get Mum walking properly again. They came once, never saw them again.

It could take a long time to make arrangements:

The Council were good initially but still waiting for outside rail.

People experienced a lack of information:

It is hard to explain what you don't know. Having information would be helpful.

Services didn't always work well together:

Memory Clinic put up Mum's medication. GP said the dosage wasn't on the letter from the Memory Clinic. Dealing with the GP practice has been a nightmare. Trying to get action sometimes feels impossible.

It was difficult finding the right person to contact:

I feel fairly confident on the phone contacting people. It is finding the right person to ask which is most tricky.

It's unclear what to do when things change:

It's hard when circumstances deteriorate or change. Not sure who to ask for what.

It's unclear who is responsible in the system:

Health departments are all blaming each other. I am not happy with how we have been treated.

Some people sought private care due to the challenges they experienced navigating the statutory system:

The physio we pay for has been fantastic. Mum can now walk. She is eating better and even her dementia seems less of a problem.

Some people reported a lack of support for complex needs:

Social Services cannot deal with complex needs. They haven't got the skills to deal with chronic health problems. The carers are underpaid and undervalued and there are excellent carers. There are also some not fit to be called carers.

Non-medical/non-social care support: People also spoke about wider support they needed. For example, in one case, Fire Services provided a smoke alarm. Sometimes this broader support was challenging to arrange:

It is not just about health and social care services. Home environment which needs decluttering. Old people cannot afford the sort of costs tradesmen charge.

Communication



Communication was a challenge for many of the people we spoke to during the pandemic. We heard about a range of issues relating to communication - including communication from services to families, from staff to families, and between different organisations and professionals.

Below are the key issues people raised.

Being unsure who to contact:

I had more than enough numbers to call - probably too many. It gets confusing.

Difficulty getting through to someone:

We should not have to spend so much time ringing telephone numbers that are never answered.

Not hearing back from services:

People haven't got back to me when they said they would.

Phone calls were not suitable for some people:

- One person explained their preference for a face-to-face conversation:
I am quite able to express what I need. Phone calls are not the same.
- One person expressed doubt about the effectiveness of remote appointments:
We are unable to see the doctor face to face. How can they diagnose over the phone?

- Not being able to have face-to-face contact was particularly challenging for one person living with a hearing impairment:

I have to walk to the surgery but now you can't get in. Got told to go home and ring them. I have hearing problems and using the phone really difficult especially for important calls.

Too many letters could also be an issue:

Something should be done. I get that many letters I feel bombarded.

Issues in communication between staff and family members:

- In one case a family member found it difficult to get involved in their relative's care:

We had a battle with the GP calling my mum instead of me. Took a while to sort out.

- We also heard about broken trust between care home staff and family:

One of the receptionists at the Home told us lies. Said he was sat up in the lounge. He was actually unable to get out of bed.

Poor communication between professionals:

Communication was an issue it seemed like nobody was talking to anybody else.

Accessing GP services



Some of the issues falling under the categories above were specifically mentioned in relation to accessing GP surgeries.

Support from GPs was seen by many participants as a key route to getting support. While we heard about some good practice (e.g. a GP doing home visits, referring to a mental health team), people experienced a range of challenges with their GP.

These include:

- **Difficulty getting through** to GPs on the phone *“it's a right job”*
- **Poor quality of service from GP reception staff:** *“The receptionists are rude and unhelpful”*
- **Not being able to speak to the preferred doctor** *“Because of COVID when you ring you get the receptionist and I get referred to any doctor not the one I have known for 30 years”*
- **Lack of action** from GP in relation to patient concerns: *“GP hasn't really done anything for me. My memory is getting worse but I am getting by”*

Suggestions for improvement:

The people we spoke to had a number of suggestions about how their experiences could be improved, most of which focused on support navigating the system, and improved communication. Here is what they told us:

Navigating the system:



- A one-stop shop where providers have been “vetted so you feel comfortable with the choices on offer”
- Offering more support for families
- Involving the family at an early stage

Communication and information:



- Being able to see professionals face-to-face
- Being given information at an early stage.
- Having “someone to explain ‘this is what you do if...’ would be better than reading loads of booklets”.
- Having information about a post 6- week care plan and what to do
- Improving communication with families

Other suggestions:



- Provide more dementia training to staff
- Having a befriending service and dementia friendly groups where people with dementia can be taken to visit places.

Recommendations:

The recommendations below are based on the findings in this report, as well as the suggestions for improvement made by participants. These recommendations are aimed at commissioners and providers of health and social care services working with people living with dementia and their families/carers.

The following improvements should be made in service delivery:

- Establish clearer procedures around offering support to families early on when a dementia diagnosis has been received
- Create clearer communication channels for families so calls are not left unanswered
- Increase staff capacity for Dementia Specialists throughout the Health and Social Care system. Where they exist currently in the system, what they do and how they can help should be more widely communicated

The following services should be commissioned to address gaps in support:

- A clearing house system/one stop shop/centralised dementia centre to offer practical support to families living with a person who has dementia
- A Sheffield Dementia Information Hub to fit with existing dementia support services (for a good example of this model, see the Dementia Services Development Centre at Stirling University)
- A volunteer led befriending service to enable people living with dementia to have a better quality of life

The following commitments should be made to ensure system-wide change:

- Ensure clear standards that all support workers employed with Adult Social Care should be able to meet if they are employed to deliver personal care
- Health and social care leadership teams should commit to making Sheffield a dementia-friendly city
- Create a multi-agency discussion group with the aim of seeking solutions that are Specific, Measurable, Achievable, Realistic and time-bound (S.M.A.R.T.)