



Insight

**Living with a neurological condition:
Experiences of health and social care
services**

June 2017

Contents

1. Introduction.....	5
1. Summary of Evidence	9
1.1. Introduction	9
1.2. Key findings.....	9
2. Conclusion and recommendations.....	11
2.1. Proposed recommendations.....	11
3. Introduction.....	15
3.1. Our approach.....	15
4. Services accessed and overall sentiment	19
5. Access to services.....	21
6. Experiences of care and support provided	25
6.1. Staff care and communication.....	25
6.2. Medication and complications with other illnesses	26
6.3. Diagnosis.....	27
6.4. Continuity and integration of care.....	29
7. Accessing enough care and support?	31
8. Conclusion and Recommendations.....	33

1. Introduction

The Joint Strategic Needs Assessment (JSNA) is a document which is compiled by the Public Health team of the local authority and looks at the current and future health and care needs of local populations to inform and guide the planning of delivery of health and care services.

Healthwatch Nottingham has been asked by Nottingham City Council to contribute to this document to ensure that the voices of local people are reflected within it. We were already aware of issues related to experiences of health and social care services for people living with a neurological condition and so we undertook some focussed work to support the development and refresh of this chapter.

Health and Social Care Services need to ensure they are delivering reasonable adjustments to prevent their service users who are living with a physical and/or sensory impairment from being disadvantaged in their access to, and their experience of, these services.

We therefore wanted to understand the experiences of health and social care services of people living with a neurological condition in Nottingham and from this analysis of experiences be able to identify the areas of greatest need for these groups

Summary Report

1. Summary of Evidence

1.1. Introduction

We wanted to understand the experiences of health and social care services of people living with a neurological condition in Nottingham. To do this we listened to the voices of 96 people through structured interviews, focus groups and by analysing experiences already held on our Healthwatch database.

This resulted in experiences gathered from the following people living with these neurological conditions or caring for people with these conditions:

Condition	Number	Percentage
Dementia, including Alzheimer's Disease	55	57%
Epilepsy	14	15%
Multiple Sclerosis	13	14%
Myasthenia Gravis	5	5%
Motor Neurone disease	5	5%
Parkinson's Disease	3	3%
Cerebral Palsy	1	1%
Total	96	100%

Data was collected via both primary and secondary sources

Primary data collection

Our main focus was talking to these individuals face to face so we approached community support groups in Nottingham and asked if we could speak to the people they support during May to October 2016. Through this approach we spoke to 21 people in total including people living with a neurological condition themselves and carers or people who support others living with these conditions. This included:

Condition	Number	Percentage
Epilepsy	7	33%
Multiple Sclerosis	6	29%
Motor Neurone Disease	5	24%
Myasthenia Gravis	3	14%
Total	21	100%

Secondary data analysis

This was derived from our database of service experiences for any shared by people living with a neurological condition, that specifically related to their neurological condition. Through this we included 79 experiences.

1.2. Key findings

Access to services can be a significant issue. Long waiting times acted as a barrier to people receiving the community-based care they need, when they need it most.

There were two references to how conditions worsen during this waiting time. Knowledge of services available to access and the physical features of service buildings and surroundings were also creating barriers to people's use of services particularly for those with mobility issues.

The times that we have to wait for equipment is diabolical. Seven months we waited for adaptations for his wheelchair. I don't mean to sound horrible when I say this but within that seven months he could've died because it could've come on that quick.

Experience of someone living with or caring for someone with Motor Neurone Disease

Almost half, (9) of the 21 people directly engaged by Healthwatch reported that they had definitely, or to some extent, received enough care and support for their condition.

Experiences of care and support were varied with the key themes emerging from our research being:



Staff care and communication was more likely to be praised than criticised. The majority of people talked about how staff showed understanding of their condition and demonstrated that they cared about them as a patient or carer. The opposite was true for those reporting negative experiences.



Medication issues and complications with other illnesses. People discussed errors in prescriptions, delayed access to medication when admitted to hospital as an inpatient, and medicines for their neurological condition causing complications for treating other illnesses.



Diagnosis was identified as an issue due to delayed referrals to specialist teams, waiting times for scans and their results and delays in diagnosing other conditions as a consequence of having a neurological condition.



Continuity and integration of care was referenced in terms of a lack of communication between and within services. Where services were more joined up this was a central factor in positive experiences.

2. Conclusion and recommendations

Our evidence suggests that the issues reported to us around delayed diagnosis and access to community support services have the potential to affect the health outcomes of patients and their carers. Whilst we heard stories of patients not being able to access the care and support they needed when they needed it the most, the positive stories of compassionate care provided by health and care professionals were encouraging and should be lauded. Efforts to improve understanding of neurological conditions amongst all staff would help to make these positive experiences for patients and carers even more frequent.

2.1. Proposed recommendations

(Identified by the people themselves who had neurological conditions).

We asked people to identify how they think their experiences of the services could be improved. There were three main trends which emerged:

1. Staff training to improve understanding of neurological conditions

There were 13 references to how improvements to experiences could be achieved if staff had additional training in neurological conditions to improve their understanding of the condition. This was suggested for neurology specialists and non-specialists such as GPs to support diagnosis and ongoing care, and community support services such as Occupational Therapists and Dietitians. The following quote identifies a perception of how improved understanding could impact on patients,

If we can have a way of giving them the specialist information, so they know when to refer but they also know they can use their specialisms to help people stay as healthy as they can. People like dieticians are hugely valuable. Psychologists, which are very thin on the ground usually, those kind of things that if they've got an understanding of the condition, they can then apply their specialist knowledge of their subject to help people live positively.

Experience of someone living with or caring for someone with Multiple Sclerosis

When talking about the need for staff training four people also made reference to a lack of capacity, commenting on a need for more specialist staff. They felt that this would give patients more time with professionals to discuss their condition.

2. Improved information provision

There were 12 references for a need to improve the information provided to patients and the carers/families about their neurological condition and support services available to them, particularly at the point of diagnosis but also beyond. This was frequently talked about alongside negative experiences when they felt they were not given the information they needed, for example,

They need to offer something because I went away not knowing anything and I had to find out all by myself.

Experience of someone living with or caring for someone with Multiple Sclerosis

People felt that this would help them to identify the help and support which would be beneficial either in the present and/or future.

3. Better co-ordination and communication between services

There were seven comments about how services need to have better communication regarding the care and support patients receive. References were made to services within the NHS communicating with each other and communication between services in the health and social care sectors.

It just makes everything more complicated because, yes, just every time she asks anybody about anything it's, "Huh, Myasthenia, we don't know about Myasthenia, I'm not a Myasthenia expert, you need to see your Myasthenia Consultant for that" but the Myasthenia Consultant is not a knee expert, so he goes, "Well I don't know about knees" and round we go.

Experience of someone living with or caring for someone with Myasthenia Gravis

Our evidence suggests that the issues reported to us around delayed diagnosis and access to community support services have the potential to affect the health outcomes of patients and their carers. We heard stories of patients not being able to access the care and support they needed when they needed it the most.

However, the positive stories of compassionate care provided by health and care professionals were encouraging and should be lauded, efforts to improve understanding of neurological conditions amongst all staff would help to make these positive experiences for patients and carers even more frequent.

Main Report

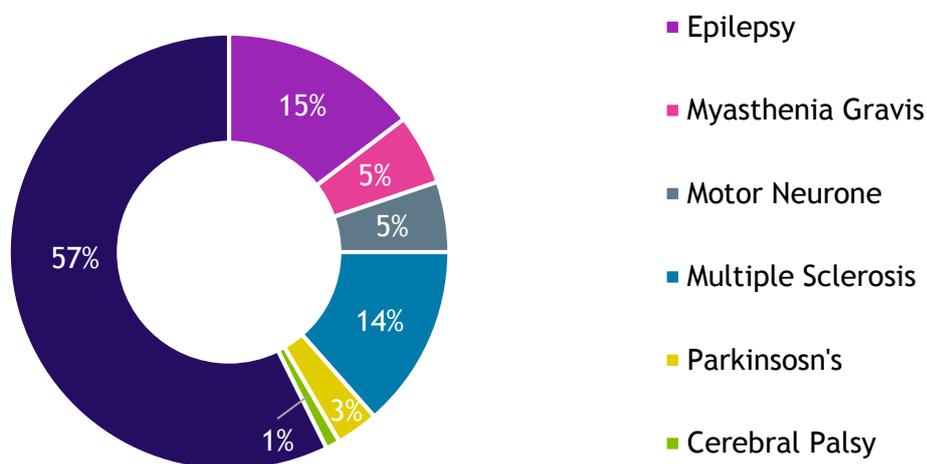
3. Introduction

The Joint Strategic Needs Assessment (JSNA) is a document which is compiled by the Public Health team of the local authority and looks at the current and future health and care needs of local populations to inform and guide the planning of delivery of health and care services. Healthwatch Nottingham has been asked by Nottingham City Council to contribute to this document to ensure that the voices of local people are reflected within it. We were already aware of issues related to experiences of health and social care services for people living with a neurological condition and so we undertook some focussed work to support the development and refresh of this chapter.

3.1. Our approach

We wanted to understand the experiences of health and social care services of people living with a neurological condition in Nottingham. To do this we listened to the voices of 96 living with neurological conditions or caring for people with neurological conditions. The number of people we spoke to, and the condition they live with or support, is as follows:

Condition	Number	Percentage
Dementia, including Alzheimer's Disease	55	57%
Epilepsy	14	15%
Multiple Sclerosis	13	14%
Myasthenia Gravis	5	5%
Motor Neurone disease	5	5%
Parkinson's Disease	3	3%
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Total	96	100%



We collected this data from people specifically for this project through structured interviews and focus groups (primary data collected) but also included analysis of relevant experiences already held on our Healthwatch database (secondary data analysis).

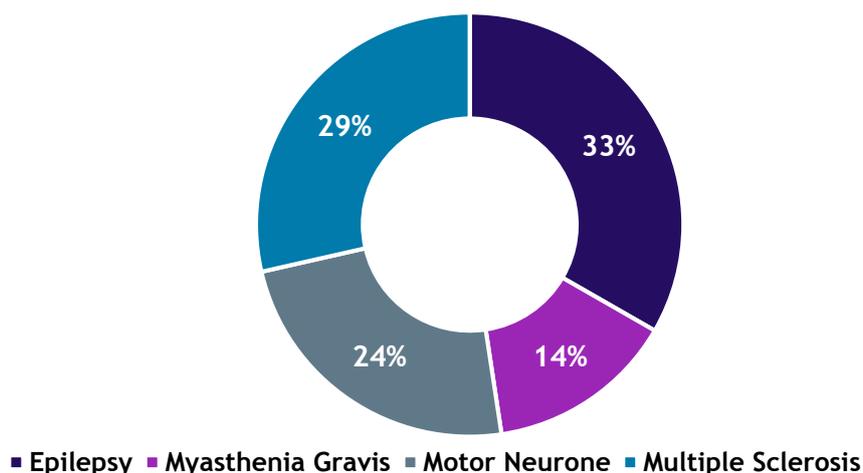
Primary data collection

We wanted to gain a deeper understanding of the health and social care service experiences of these service users and if and how these experiences affected them. Our main focus was talking to these individuals face to face so we approached community support groups in Nottingham and asked if we could speak to the people they support during May to October 2016.

Through this approach we spoke to 21 people in total including people living with a neurological condition themselves and carers or people who support others living with these conditions as follows:

Condition	Number	Percentage
Epilepsy	7	33%
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Total	21	100%

Breakdown of composition of people spoken to directly at Focus Groups etc. (Source 21 people).



All individuals were able to speak freely about what was important to them in their use of health and social care services, but we also had some key questions that we asked everyone. This included access to services, their experiences of the treatment and care provided and any improvements which could be made to these services. Taking part in the focus groups and interviews was on a voluntary basis and people were told that they could stop at any point. Everyone was given an information sheet about why we were talking to them and also given an opportunity to ask questions about the project. Focus groups and interviews were audio-recorded with all individuals giving informed consent.

Secondary data analysis

In addition to talking to people face to face, we searched our database of service experiences for any shared by people living with a neurological condition, that specifically

related to their neurological condition. Through this we included 79 experiences that were collected through:

- Healthwatch Nottingham website, telephone, email and face to face engagement work;
- Online monitoring which collects evidence from Twitter, blogs and local and national news sites;
- Patient Opinion, an independent service review website;
- Information sharing, primarily with other neighbouring local Healthwatch.

Combined data analysis

Not everyone that we spoke to generated a positive or negative experience.

The 96 people interviewed generated 44 experiences whilst 79 were taken from the HW database

This gave a total of 123 experiences.

4. Services accessed and overall sentiment

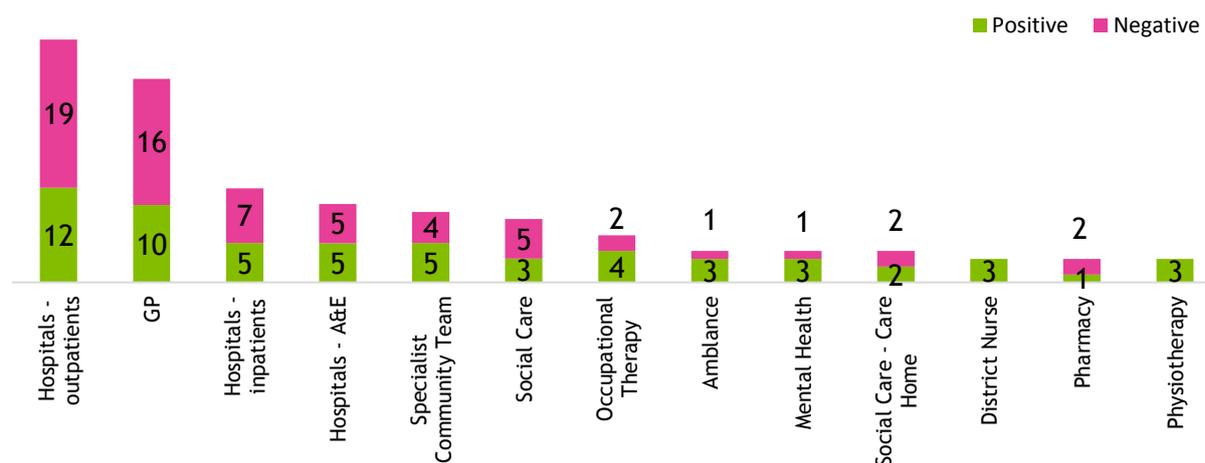
Primarily, people talked most about how they had accessed help and support with their neurological condition from specialist hospital services through an outpatient department and their GP.

Overall, there were slightly more negative comments about experiences (64 comments) than positive experiences (59 comments).

Almost a quarter (24%; 35) of all comments on the services used were about seeing specialist consultants through outpatient appointments and figure one shows that where people talked about their experience these were more likely to be negative than positive.

Service Accessed	Experiences Number	Positive Number	Negative Number	Positive %	Negative %
Hospitals - outpatients	31	12	19	39%	61%
GP	26	10	16	38%	62%
Hospitals - Inpatients	12	5	7	42%	58%
Hospitals - A&E	10	5	5	50%	50%
Specialist Community Team	9	5	4	56%	44%
Social Care	8	3	5	38%	63%
Occupational Therapy	6	4	2	67%	33%
Ambulance	4	3	1	75%	25%
Mental Health	4	3	1	75%	25%
Social Care - Care Home	4	2	2	50%	50%
District Nurse	3	3	0	100%	0%
Pharmacy	3	1	2	33%	67%
Physiotherapy	3	3	0	100%	0%
Total	123	59	64	48%	52%

Figure 1 Sentiment of services accessed



Source: 123 comments made about experiences of services where sentiment was provided. Comments which included no indication of sentiment were not included. For example, 35 comments were made about hospital outpatient services but only 31 had any sentiment attached and were included in this chart.

5. Access to services

Negative comments about access to services outnumbered positive comments by almost three to one, with 16 positive references and 45 negative references.

The most talked about negative issue related to waiting times. This was most frequently identified by those people we spoke to living with or caring for someone with Multiple Sclerosis but was also referenced by those living with or caring for someone with Dementia, Epilepsy, Motor Neurone Disease and Myasthenia Gravis. Waiting times for social care services and Occupational Therapy were most commonly and equally discussed, people talked about long waits and not receiving the services they felt they needed when they needed them. There were two references to how conditions worsen during this waiting time. For example,

The times that we have to wait for equipment is diabolical. Seven months we waited for adaptations for his wheelchair. I don't mean to sound horrible when I say this but within that seven months he could've died because it could've come on that quick. That is a big, big problem with some of the services, is waiting.

Experience of someone living with or caring for someone with Motor Neurone Disease

The discharge teams do all sorts of things, but when you get from the discharge team to social services they are sadly lacking...I'm not saying it's not there at all, I'm just saying when you need it...You need the care when you are discharged you don't need somebody coming up three months later to say we've just come to see what help we can give you, well it's all over then. In one particular case we had an OT (Occupational Therapist) turn up 14 weeks after [name] had broken her ribs.

Experience of someone living with or caring for someone with Multiple Sclerosis

If you've got problems, which a lot of people with other neurological conditions have, with continence for example, or spasticity or those kinds of things, sometimes there's a delay in getting referred, from their GP's particularly, to those community services which will then help people to live at home rather than get worse and then be admitted because they've got a urine infection or the spasticity's got so bad that they need hospital treatment for that. So access is difficult to those maintenance services.

Experience of someone living with or caring for someone with Multiple Sclerosis

There were single references to waiting times for appointments with hospital outpatients' services and GPs, which commented on the need to have appointments in a timely manner. There were five references to when this had happened, with people suffering from Multiple Sclerosis and Myasthenia Gravis describing that because of their condition they had a special understanding with their GP around the need for prompt appointments and call backs.

For example,

I've been told to say that I have got MS so I get GP doctor's appointment quicker, that generally works quite well, I mean as a whole you say that you have MS they will step back and help you straight away.

Experience of someone living with or caring for someone with Multiple Sclerosis

With my GP I have a special arrangement with him. I'm guaranteed at least a phone call back from the doctor on the day, or an actual appointment itself.

Experience of someone living with or caring for someone with Myasthenia Gravis

For people living with or caring for someone with Multiple Sclerosis accessing care and support through the specialist Multiple Sclerosis nurses was praised by three people. They commented on how being able to telephone them when needed was an 'outstanding' and 'brilliant' aspect of their care. For example,

I would say the MS nurses again because I have got their numbers in my phone and I can just literally give them call, leave them a message, and they will give me a call back, and if they feel that there is something that needs to be looked at they will get you in for an appointment as soon as they can.

Experience of someone living with or caring for someone with Multiple Sclerosis

Waiting times hadn't been an issue for everyone, three people we spoke to commented on how quickly they had been able to access care and support.

Another issue with accessing services was knowing what services were available, particularly social care services, for the person living with the neurological condition themselves and carer support services for their loved ones. For example,

Well for a start nobody actually tells you that you may be eligible to access social care services. I would think very few people here know that you could perhaps could get self-directive support, so nobody actually tells you that.

Experience of someone living with or caring for someone with Epilepsy

It's almost like I have to anticipate, nobody tells you what you need...

Experience of someone living with or caring for someone with Motor Neurone Disease

For those newly diagnosed there were a number of references to not knowing know what services they should be accessing and how this would benefit them.

They asked us what help we wanted, but at this early stage we found it difficult to express exactly what help would be useful to us. It would have been far more useful for the service to provide us with details of what the service could do for us, or examples of what they did for other families.

Experience of someone living with or caring for someone with Dementia

She asked me if there's anything I wanted which is like how long's a piece of string? We don't know really what would help.

Experience of someone living with or caring for someone with Motor Neurone Disease

For people living with or caring for people with Dementia there were numerous references to a lack of ongoing support services following discharge from the hospital outpatients' service that provided the diagnosis. For example,

My husband was diagnosed with dementia five years ago. He used to have follow up appointments at the St Francis Unit, but we can't do that anymore. All you are allowed to do is get your diagnosis, there is no follow up. They have cut down on the number of CPN's [Community Psychiatric Nurses]... People need this support desperately, but don't get it now due to all the changes.

Experience of someone living with or caring for someone with Dementia

My husband was diagnosed in 2009 and was discharged from the Sheila Gibson Unit over three years ago as he has vascular dementia and there is nothing they can do for him, therefore we are left out on a limb. It also means that I cannot have a Compass Worker to help me as I have my own health issues. I have no life whatsoever...

Experience of someone living with or caring for someone with Dementia

These findings support those in a report we produced in 2016 focusing on patient experiences of information provision and support at dementia diagnosis. This can be downloaded here:

<http://healthwatchnottinghamshire.co.uk/wp-content/uploads/2016/12/Insight-Report-Dementia-diagnosis.pdf>

Physical access to facilities was also identified by multiple people, particularly those suffering from neurological conditions affecting their mobility. Problematic features included:

-  The need to climb stairs to access buildings and treatment rooms
-  Long walking distances from parking facilities
-  Space within facilities to allow wheelchair access
-  Public transport links close to services

Two people who commented on how the physical features of facilities had not just made access difficult but had prevented them from accessing the care and support they needed. The following two quotes are illustrative of the facilities issues:

When I go to queens it's on the ground floor but it's quite a distance once you get off from your vehicle to walk along the corridor to area 2. I find that I can get really fatigued, even though I take medication before I go by the time I actually get there I get quite fatigued.

Experience of someone living with or caring for someone with Myasthenia Gravis

We're trying to find a dentist at the moment that will take him in i.e. because of his wheelchair and because of his mask and we just don't know where to turn at the moment to try and find one for him locally, so that is one problem from healthcare services

Experience of someone living with or caring for someone with Motor Neurone Disease

Communication issues were identified by one person suffering with Motor Neurone Disease who found it difficult to access appointments over the phone, but had got round this by using online systems and asking their carer to make appointments on their behalf.

6. Experiences of care and support provided

6.1. Staff care and communication

The most talked about aspect of treatment and care was the staff and how they provided compassionate care. There was over double the amount of positive comments (20 comments from 18 people) as there were negative comments (8 comments from 8 people). The majority of people talking about compassionate care talked about specialist doctors and nurses seen at hospital outpatient departments (33%; 6 people) and GPs (28%; 5 people). People most frequently talked about the staff showing understanding of the condition and demonstrating that they cared about them as a patient or carer. However, this wasn't always the case. The 8 people discussing a lack of compassionate care from staff were most likely to make these comments in relation to hospital staff in either inpatient or outpatient departments (64%; 5 people), and commented on how they felt there was a lack of understanding, empathy and a poor attitude was demonstrated, for example,

...the consultant said I'm running a bit late what do you want to talk to me about and I started talking and she said there's not much we can really do for you as you have primary progressive MS you will just have to go away and get on with it.

Experience of someone living with or caring for someone with Multiple Sclerosis

...consultant was very rude and not good at communicating and understanding.

Experience of someone living with or caring for someone with Dementia

The quality of care was frequently linked to poor communication, something referenced by 15 people (10 people referenced positive communication by staff) and was a central aspect of negative experiences. It was most likely to be discussed by people living with or caring for someone with Dementia (80%; 12 people) and experiencing their first diagnosis. This evidence supports our 2016 report on information provision at dementia diagnosis which can be downloaded here:

<http://healthwatchnottinghamshire.co.uk/wp-content/uploads/2016/12/Insight-Report-Dementia-diagnosis.pdf>

Four comments (27%) about poor communication were specifically linked to medication, people talked through experiences where explanations about medication had not been provided and how they felt their concerns were not being listened to. For example:

Sometimes it just seems like routines, "What medication are you on?" "Oh, that'll be alright" or "Can we put it up?" Sometimes they don't actually listen to what you're telling them.

Experience of someone living with or caring for someone with Epilepsy

...she is being taken off the medication four days before her operation and feels this is unsafe, she's previously been in hospital prior to an operation because of this.

She questioned this and was told "that's how it's done" with no reassurance.

Experience of someone living with or caring for someone with Dementia

6.2. Medication and complications with other illnesses

Negative comments about medication were not just related to communication, 14 people we spoke to made negative comments about the medication they received as part of their treatment and care. There were 5 comments about errors in medication which included patients being given prescriptions for the wrong medications, or the wrong doses of medications. The majority of these comments were made about GPs but also accounted for the negative experiences of pharmacies shown in figure 1. The following quotes are illustrative of this:

...when I got into difficulties he [the GP] did not know how to manipulate the medication to meet my needs and by the time I got to see the consultant I was being over medicated which then meant that I was worse than when I initially approached the GP.

Experience of someone living with or caring for someone with Myasthenia Gravis

...the GP prescribed an antipsychotic drug, to be taken regularly. This medicine is not recommended for dementia patients and should not be taken for more than 12 weeks...The patient has had 3 bad falls whilst taking this medicine and had to be taken to hospital with a head injury at one point. The dementia outreach team took the patient off the medication, saying that there were a range of other medicines that could be given, with less side effects.

Experience of someone living with or caring for someone with Dementia

4 people talked about being delayed access to medication, particularly when admitted to hospital as an inpatient. 2 people made reference to where possible taking their own medication with them into hospital to avoid such delays as they '*could not afford to be without their medication*'.

There were 3 comments about how their diagnosis and the medication they were required to take caused complications for other illnesses, including side effects from other medication. This meant that in some instances other health issues were left untreated and worsened. For example,

...either the medication that they might otherwise prescribe for other health conditions would interact with her Myasthenia medication or they would have an adverse effect on the Myasthenia itself. So she ends up with all these other conditions going more or less untreated to a greater or a lesser degree because they claim not to be able to do anything about it.

Experience of someone living with or caring for someone with Myasthenia Gravis

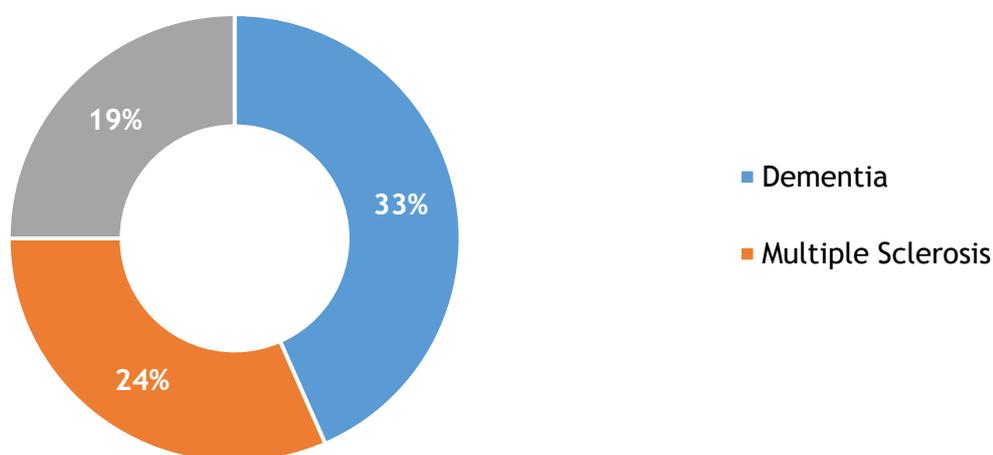
6.3. Diagnosis

Only 1 positive comment was made about the diagnosis process which referenced the speed with which diagnosis was achieved. There were 21 comments relating to negative experiences of diagnosis, the majority of which 16 (76%) of comments were from people living with or caring for someone with the following:

-  Dementia (7 comments)
-  Multiple Sclerosis (5 comments)
-  Myasthenia Gravis (4 comments)

Condition	Number	Percent
Dementia	7	33
Multiple Sclerosis	5	24
Myasthenia Gravis	4	19
	16	76%
Other	5	24%
Total	21	100%

Composition of 16 (76%) of negative responses split by specific named conditions



The most frequently identified issue was delays to diagnosis, there were multiple references to it taking 2 years or more to secure diagnosis but one person described a five year process of getting diagnosed with Myasthenia Gravis. GPs were perceived as lengthening the process through a lack of knowledge and awareness of symptoms and delaying referrals to specialist teams.

For example,

The feedback what we get from people is one of the key problems for people with all neurological conditions, MS being one of them, is actually getting diagnosed in the first place... it's the condition, a lot of neurological conditions are very difficult to identify exactly what is the cause. That period from somebody going to the GP regularly, trying to actually find out what's the matter, to then be referred to a neurologist, to then start tests, to then be diagnosed, all of that time is precious because there's real evidence that the quicker that people can be diagnosed and offered treatment, you can reduce the impact on the disability later.

Experience of someone living with or caring for someone with Multiple Sclerosis

GP's not having the awareness of what to look out for, for something like MS, so that delays them being referred into a neurologist.

Experience of someone living with or caring for someone with Multiple Sclerosis

When referrals were made there were numerous comments about the waiting times for scans and results from scans, which contributed to delays in diagnosis.

Delays in diagnosis weren't just confined to diagnosis of the neurological condition, we had reports of people being delayed in getting a diagnosis of another condition which they felt was a direct consequence of having a neurological condition. For example,

He had water on his legs and we told every single person, Physiotherapist, doctor, the people at the MND Centre, care centre, there was a few people and he had it for eighteen months and then he ended up in hospital with clots on his lung because it was due to the water. They just kept saying because he's in a wheelchair gravitation won't take it away but it wasn't that at all, it was a build-up that was getting to a clot.

Experience of someone living with or caring for someone with Motor Neurone Disease

It just makes everything more complicated because, yes, just every time she asks anybody about anything it's, "Huh, Myasthenia, we don't know about Myasthenia, I'm not a Myasthenia expert, you need to see your Myasthenia Consultant for that" but the Myasthenia Consultant is not a knee expert, so he goes, "Well I don't know about knees" and round we go.

Experience of someone living with or caring for someone with Myasthenia Gravis

A lady has been suffering for four years with pain in her back. The GP felt there was nothing wrong despite repeated attendances with the same problem. Because she suffers with Multiple Sclerosis the GP felt her pain was part of her condition, but would not give advice or refer her for specialist investigation. The lady's father has managed to get her an appointment at [name of specialist centre], where she has been told that she will need spinal correction and injections. She has adopted a poor stance because of the pain, which has led to deformity and spinal damage.

Experience of someone living with or caring for someone with Multiple Sclerosis

There were 2 experiences of people being misdiagnosed with other conditions before the correct diagnosis of a neurological condition was made.

6.4. Continuity and integration of care

There were 19 references to how people felt there was no continuity in their care, including those living with or supporting someone with Multiple Sclerosis, Epilepsy, Myasthenia Gravis, Dementia and Motor Neurone Disease. One of the main reasons for this was a lack of communication between services (8 references) and within services such as GPs, highlighted by a perceived lack of continuity in GP contact, (4 references).

The following quotes are illustrative of this,

People get very frustrated because they're telling their story more than once and when you're living with a long term condition, you shouldn't need to go and say, "I've got MS and I need this, this, this and this." You should be able to seamlessly, whoever is dealing with you, should know the story so far so that then you can just take it on from there...if you've had a period of, for example, in a hospital where something happened then you go to see your GP or you see somebody else in the community, they're not aware of it.

Experience of someone living with or caring for someone with Multiple Sclerosis

Carer is registered as a carer at the surgery but doesn't feel this makes any difference. Ideally she wants to phone the surgery, and book an appointment for her husband with a doctor who he knows. Rather than seeing a different person each time.

Experience of someone living with or caring for someone with Dementia

We were given examples of where services were more joined up and did work together, this was a central factor in experiences which were positive overall. 3 comments related to GP practices where people noted that they were now allowed to see specific GPs who had a good understanding of their condition ensuring continuity in their care.

With regards to services working together the CityCare model in Nottingham City was highlighted with regards to Multiple Sclerosis and one person living with Myasthenia talked about a multi-disciplinary team meeting called to bring together services key to their care:

I think in the City they work fairly well. You've got the City Care which I keep quoting but it's such a good model that is health and social care and actually is contracted by the Commissioning Group, so they work, seem to, seamlessly and certainly the feedback we get from people who live within the boundary of the city, that works as well as it can do. It's never brilliant living with a condition but if you're going to live with it, Nottingham City is not a bad place.

Experience of someone living with or caring for someone with Multiple Sclerosis

[Doctors name] said right let's get everybody together, and they got everybody together and lets sort you out...they all got together and they were all in the room.

Experience of someone living with or caring for someone with Myasthenia Gravis

7. Accessing enough care and support?

We asked people directly involved in our engagement whether they felt that in the last six months, they had had enough support from local services to help them manage their long-term neurological condition. 14 people provided a response and the findings are illustrated in figure 2 and show that only a minority of people (2 people) involved felt that in the last six months they had not had enough care and support from local services to manage their long term condition.

Response	Number	Percent
Yes	5	36%
No	2	14%
Yes, to some extent	4	29%
No, I have not needed such support	3	21%
Total responses	14	100%

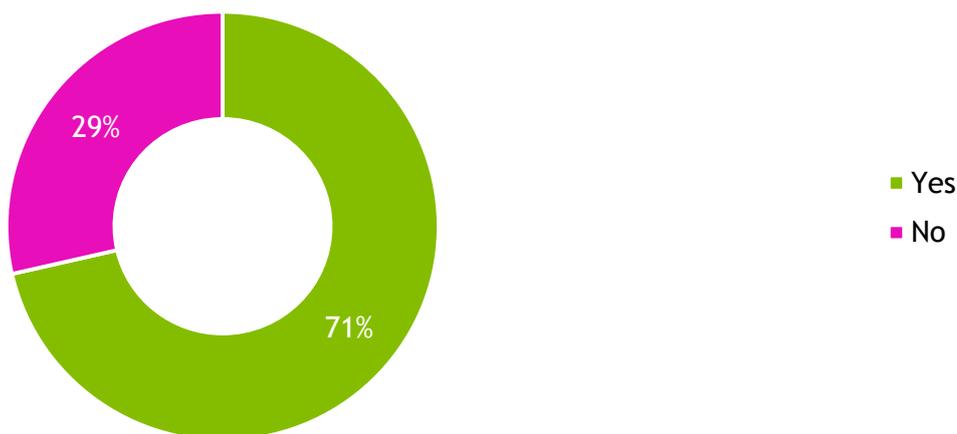
Out of the 9 responses for 'Yes'

Response	Number	Percent
Yes	5	56%
Yes. To some extent	4	44%
Total	9	100%

Out of the 5 responses for 'No'

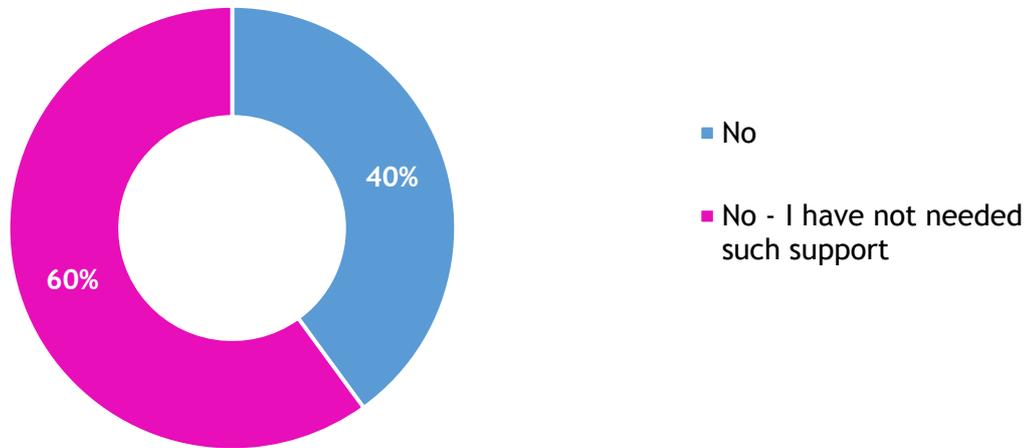
Response	Number	Percent
No	2	40%
No, I have not needed such support	3	60%
Total	5	100%

Figure 1: Accessing enough care and support (Base 7 responses)



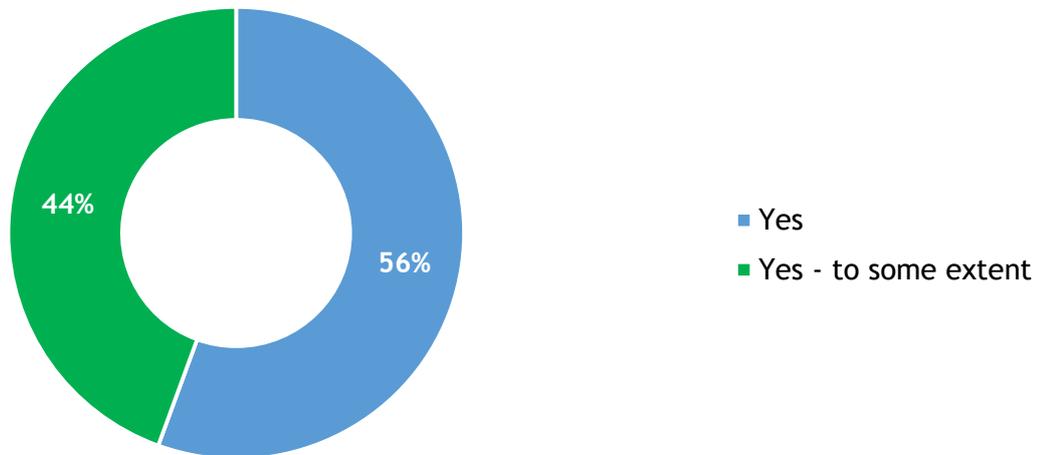
Note: the above graph represents 5 responses and 2 responses respectively)

Figure 2: Accessing enough care and support (Base 5 responses for 'No' options and 7 responses for 'Yes' options)



(Note: the above graph represents 2 responses and 3 responses respectively)

Figure 3: Accessing enough care and support (Base 9 responses)



(Note: the above graph represents 5 responses and 4 responses respectively)

Base: Total of 14 people involved in direct Healthwatch Nottingham engagement activity

8. Conclusion and Recommendations

Our evidence suggests that the issues reported to us around delayed diagnosis and access to community support services have the potential to affect the health outcomes of patients and their carers. Whilst we heard stories of patients not being able to access the care and support they needed when they needed it the most, the positive stories of compassionate care provided by health and care professionals were encouraging and should be praised. Efforts to improve understanding of neurological conditions amongst all staff would help to make these positive experiences for patients and carers even more frequent.

We asked people to identify how they think their experiences of the services could be improved. There were three main trends which emerged:

1. Staff training to improve understanding of neurological conditions

There were 13 references to how improvements to experiences could be achieved if staff had additional training in neurological conditions to improve their understanding of the condition. This was suggested for neurology specialists and non-specialists such as GPs to support diagnosis and ongoing care, and community support services such as Occupational Therapists and Dieticians. The following quote identifies a perception of how improved understanding could impact on patients,

If we can have a way of giving them the specialist information, so they know when to refer but they also know they can use their specialisms to help people stay as healthy as they can. People like dieticians are hugely valuable. Psychologists, which are very thin on the ground usually, those kind of things that if they've got an understanding of the condition, they can then apply their specialist knowledge of their subject to help people live positively.

Experience of someone living with or caring for someone with Multiple Sclerosis

When talking about the need for staff training four people also made reference to a lack of capacity, commenting on a need for more specialist staff. They felt that this would give patients more time with professionals to discuss their condition.

2. Improved information provision

There were 12 references for a need to improve the information provided to patients and the carers/families about their neurological condition and support services available to them, particularly at the point of diagnosis but also beyond. This was frequently talked about alongside negative experiences when they felt they were not given the information they needed, for example,

They need to offer something because I went away not knowing anything and I had to find out all by myself.

Experience of someone living with or caring for someone with Multiple Sclerosis

People felt that this would help them to identify the help and support which would be beneficial either in the present and/or future.

3. Better co-ordination and communication between services

There were 7 comments about how services need to have better communication regarding the care and support patients receive. References were made to services within the NHS communicating with each other and communication between services in the health and social care sectors.

It just makes everything more complicated because, yes, just every time she asks anybody about anything it's, "Huh, Myasthenia, we don't know about Myasthenia, I'm not a Myasthenia expert, you need to see your Myasthenia Consultant for that" but the Myasthenia Consultant is not a knee expert, so he goes, "Well I don't know about knees" and round we go.

Experience of someone living with or caring for someone with Myasthenia Gravis

Our evidence suggests that the issues reported to us around delayed diagnosis and access to community support services have the potential to affect the health outcomes of patients and their carers. We heard stories of patients not being able to access the care and support they needed when they needed it the most.

However, the positive stories of compassionate care provided by health and care professional were encouraging and should be lauded, efforts to improve understanding of neurological conditions amongst all staff would help to make these positive experiences for patients and carers even more frequent.

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We would like to thank all of the residents and visitors who spent time talking to our project team.

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