

‘IT’S ALL IN YOUR HEAD’

Neurological conditions:
The journey to and impact of diagnosis

‘It’s all in your head’

Exploring the experiences of people with neurological conditions when seeking and receiving a diagnosis

Contents

Foreword	4
Executive summary	5
Section 1: An introduction to The Brain Charity	6
Section 2: The #BrainSurvey	8
Methodology.....	8
Who took the survey?	8
What conditions were represented?	9
Analysing the data	9
Section 3: Key findings and case studies	
Theme 1: A lack of information and support.....	10
Case study: Jeanie’s brain tumour story.....	11
Theme 2: Delayed diagnosis	
Sub-theme 2.1: Recognising symptoms.....	12
Case study: Rupak’s MS story	13
Case study: Sarah’s dystonia story.....	14
Case study: Avril’s brain aneurysm story	15
Case study: Lindsey’s MS story	16
Case study: Shirley’s syringomyelia story	17
Sub-theme 2.2: The wait for diagnosis	18
Sub-theme 2.3: Exploring the reasons for delayed diagnosis further	19
Case study: Jack’s Chiari malformation story	21
Case study: Helen’s subarachnoid haemorrhage story.....	22
Theme 3: Impact on mental health	23
Case study: Gareth’s brain tumour story	24
Case study: Erin’s ADHD and autism story	25
Case study: Karen’s fibromyalgia and FND story	26
Section 4: Wider context.....	27
Section 5: Recommendations.....	29
Accessibility	30

Foreword

Pippa Sargent, Chief Executive Officer, The Brain Charity



There are more than 600 different conditions affecting the brain, spine or nervous system. These are called neurological conditions.

Many are well-known, such as epilepsy, stroke, dementia, migraine and autism. There are also hundreds of rarer conditions, such as trigeminal neuralgia and Alice in Wonderland syndrome. Some neurological conditions can begin suddenly, such as brain haemorrhage. Some can affect a person from birth, such as cerebral palsy. Others, like multiple sclerosis, can develop over time.

The Brain Charity is here for every single one of them. Each year, we provide practical help, emotional support, and social activities to thousands of people from all over the UK.

The Brain Charity has a unique perspective. As we work with patients, family members, carers, clinicians and researchers, we can see the strains, stresses and problems in the systems from all angles.

For people with neurological conditions, the journey to receiving a diagnosis can be lengthy, stressful and lonely. Too often getting a diagnosis goes together with worsening mental health. We know this because our clients, and the specialist clinicians we work with, have told us so, and because we see it day in, day out in the services we provide. This report provides further evidence to support the need for change.

The Brain Charity's #BrainSurvey asked about people's experiences of being diagnosed with a neurological condition. From their first concerns, through to visiting their GP and on to the help and support they received following a diagnosis, this report explores all aspects of the journey to diagnosis and the life-changing impact it can have.

Some of the findings in this report are stark. They paint a picture of isolation, fear and a failure to be taken seriously. For too many people, delays and a lack of information and support exacerbates what is already a harrowing journey.

We hope this report and its recommendations can be a catalyst for change. 'It's all in your head' is designed to inform policy makers and clinicians and start a conversation. We see its publication as the first step, and we will seek to engage with organisations across sectors to make positive change a reality.

Thank you for reading.

Pippa Sargent

**Chief Executive Officer,
The Brain Charity**

Executive summary

'It's all in your head' highlights the experiences and challenges faced by people affected by neurological conditions when seeking and receiving a diagnosis, and the impact of that diagnosis in terms of their mental health.

The findings presented in this report are taken from analysis of feedback given through The Brain Charity's #BrainSurvey, carried out between September and November 2022, which asked people affected by a neurological condition, as well as their families, to tell us about their experiences. In total 827 people took part, 85% of whom had a diagnosed neurological condition.

The findings are summarised across three key themes:

1. A lack of information and support

2. Delayed diagnosis

3. Impact on mental health

Feedback from respondents paints a stark picture, revealing that many people with neurological conditions initially struggle to receive a diagnosis and feel their symptoms, which can often be debilitating, are not taken seriously by healthcare professionals.

After diagnosis, the majority feel that the information and support they are given is inadequate, which for many contributes to experiencing poor, or worsening, mental health.

The #BrainSurvey findings correlate strongly with anecdotal feedback from the people we support on a day-to-day basis at The Brain Charity.

Currently, mechanisms for more thorough nationwide consideration of the issues raised in this report are lacking. We propose the need for action to address this and to support a strategic policy approach which will make a positive and sustainable impact, delivering better support for the 1 in 6.

We believe a more streamlined system which improves standards of care and support for people with neurological conditions would not only save public money, it would save lives.

The recommendations at the end of this report are twofold:

1. The Brain Charity would like to see fuller consideration of the themes cited in this report through an independent review of the journey through, and impact of, diagnosis for people with neurological conditions. Initial areas to include in this are proposed.
2. Supporting The Neurological Alliance, of which The Brain Charity is a member, in their call for UK governments to set up a Neuro Taskforce to address the current issues facing people affected by neurological conditions.

The full #BrainSurvey findings are reported separately, in The Brain Charity's #BrainSurvey: Findings Report, accessed via our website.¹

Neurological conditions in numbers

- **1 in 6 people** in the UK have a neurological condition.
- There are **more than 600 different recognised neurological conditions**, including ADHD, MS, ME, dementia, stroke and chronic fatigue syndrome – plus many other rare conditions.
- There are **more than 1 million hospital admissions** per year due to neurological conditions, with individuals often arriving at A&E at the point of crisis.

¹ <http://www.thebraincharity.org.uk/its-all-in-your-head>

Section 1: An introduction to The Brain Charity

The Brain Charity helps people with all forms of neurological condition to lead longer, healthier, happier lives. For the last 30 years, we have helped many thousands of people affected by neurological conditions to rebuild their lives and achieve their potential. We also champion neurodiversity.

Neurological conditions shape the world around us. They affect people of all ages and backgrounds. Around 1 in 6 people in the UK have a neurological condition², so the vast majority of us will know someone affected. In schools, workplaces, and in health and care settings, supporting people with these conditions is part of everyday life.

For someone newly diagnosed with a neurological condition, life may become very lonely and frightening. People can lose control of their lives and many face unemployment, poverty and social isolation.

Neurological conditions are responsible for more than one million hospital admissions each year³, but their impact goes way beyond a patient's stay in hospital. The Brain Charity's role in supporting our clients practically, emotionally and socially gives us a unique insight into the challenges that people with neurological conditions face.

“People overlook you when you've had a stroke. I couldn't speak at all initially. I literally felt voiceless. Now I can talk but people think I don't understand, and they are scared to talk with me. Not having the ability to communicate has affected my social life as I was afraid of being misunderstood. Sometimes I hate aphasia, it makes me down. Invisible disabilities are misrepresented – people are shocked when they see me, and then realise I've had a stroke.”

Pamela, who experienced a stroke which caused aphasia, a difficulty with language and speech

The Brain Charity plays a crucial role in supporting people with neurological conditions. In the 2022-2023 financial year, we supported:

2,806 clients

85% of whom were new service users

301

people struggling with their mental health, running 2,408 counselling sessions

175

carers to help them manage their caring responsibilities

264

people to move into jobs or closer to employment, with another 133 clients given employment law advice

² <https://www.neural.org.uk/wp-content/uploads/2019/07/neuro-numbers-2019.pdf>

³ <https://www.neural.org.uk/wp-content/uploads/2021/04/neuro-numbers-2019-1.pdf>

212,352 people

also accessed our website pages, with our website content receiving 511,924 page views in total.

Our practical and emotional support services include support for housing issues (such as getting aids and adaptations), accessing the right welfare benefits, counselling, befriending and confidence coaching. We also have a strong track record of providing neurodiversity training, delivered by people with lived experience of being neurodivergent.

“Before the haemorrhage, I'd had a successful business and regular clients I didn't want to let down, but now I was struggling to get up the stairs. Being unable to work full time meant I started to get into a lot of money trouble. I had so much going round in my head – the debts were swirling and I was feeling the pressure to provide as a single dad.”

Paul, who experienced a subarachnoid brain haemorrhage which left him unable to return to his self-employed job in the same capacity as before

Why the #BrainSurvey?

As part of our day-to-day work, clients and their families share their experiences of seeking a diagnosis with us. They've already told us that the process can be distressing and lengthy, often taking years. Feelings of not being taken seriously are common and the experiences have had a very real and negative impact on their mental health.

Our role working with NHS providers, such as The Walton Centre NHS Foundation Trust, a specialist neurology hospital in Liverpool, helps build the picture, with specialists reporting that neurological patients often present late and visit A&E at the point of crisis⁴.

In spite of the best endeavours of primary care professionals, it seemed that too many people with neurological conditions were not being referred quickly enough for specialist assessment and not being given the right advice and support throughout their journey to diagnosis.

Our #BrainSurvey was carried out in response to this, to provide us with valuable lived experiences of the system, to understand why it didn't seem to be working as well as it could be.

'It's all in your head' is a summary of the key feedback from this #BrainSurvey and includes examples of people's experiences. It is designed to build a picture of the journey to diagnosis and its impact.

This report illustrates three key themes that emerged from the findings:

A lack of information and support

Delayed diagnosis

Impact on mental health

This report illustrates these key themes.

⁴ <https://www.gov.uk/government/publications/neurology-services-hospital-activity-data>

Section 2: The #BrainSurvey

The findings cited in this report are based on the findings of The Brain Charity's #BrainSurvey, which invited people affected by neurological conditions - whether someone with a condition themselves or a carer, family member or friend - to have their say on their

experiences of seeking and receiving a diagnosis, and its impact on their lives.

The survey's aim was to help The Brain Charity better understand the difficulties people were facing and how and where improvements could be made.

Methodology

The survey was live between September and November 2022. It was primarily completed through an online SurveyMonkey link, with a small minority of survey respondents completing paper copies of the questionnaire. Some people were assisted to complete the survey by carers, friends or family members if they required this due to a disability, neurological condition or other need for support.

The #BrainSurvey was distributed via a variety of means, including:

- Across The Brain Charity's own communications and social media channels.
- Via the communications channels of partner organisations and other key stakeholders.

Who took the survey?

The #BrainSurvey was completed by **827** people, **85%** of whom have a diagnosed neurological condition.

A further **8%** did not have a neurological condition but were the family member of someone who did, while **7%** were seeking a diagnosis.

The majority were female (**71%**, to **26%** male). Nearly all respondents were adults, with only **2%** under 18.

While respondents were spread widely over the UK, the greatest proportion were from the North West (**36%**).

As respondents were self-selecting, with views being given by those who wanted to give their opinion, the sample is therefore not fully representative. However, given the large sample size and diverse neurological conditions of contributors, the findings provide useful data and insight into the experiences of people on their journey through diagnosis and its impact.

827
Respondents

85%
have a
diagnosed
neurological
condition

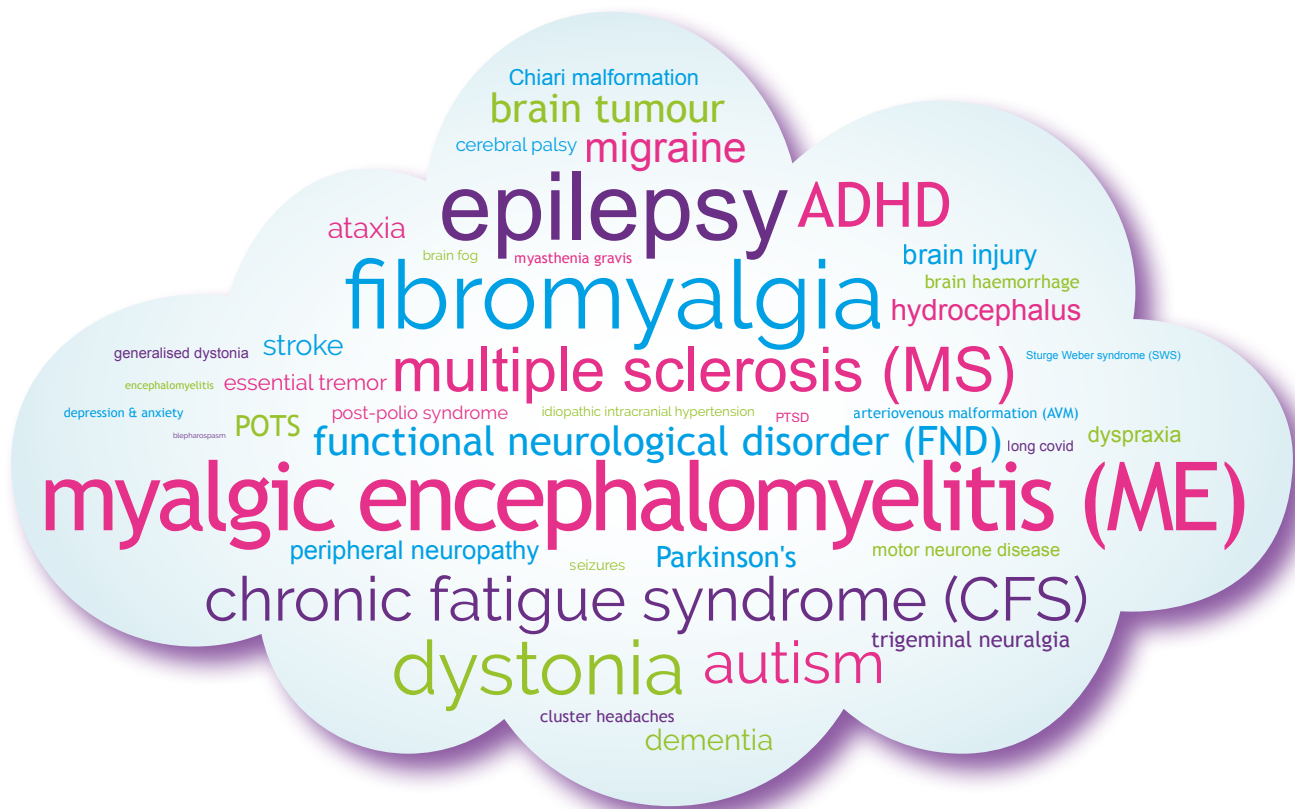
49%
aged between
45 and 64

88%
identified as
English, Welsh,
Scottish, Northern
Irish or British

What conditions were represented?

The survey was completed by respondents with a wide range of neurological conditions, including epilepsy, fibromyalgia, functional neurological disorder (FND), attention deficit hyperactivity disorder (ADHD), autism, multiple sclerosis (MS), brain tumour and ataxia,

amongst others. The largest proportion (25%) indicated having myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS). 18% indicated they had more than one diagnosis.



Analysing the data

The survey consisted mainly of closed questions with tick box answers, however there were also opportunities for respondents to elaborate further through free text boxes.

The free text responses were analysed using thematic review, whereby responses were assigned a code, and codes were then grouped into themes to allow a quantitative (numbers-based) representation of the feedback.

For all closed questions, responses are presented as a proportion of the total sample. For open questions, percentages are calculated as a proportion of those who provided a response.

Many questions were multiple choice, explaining why some of the figures listed in the report do not necessarily add up to totals of 100%, as respondents were able to pick more than one option.

The survey data was analysed⁵ by an independent research consultant whose further findings are fully detailed in our #BrainSurvey: Findings Report. The survey data in this report has also been supplemented with case studies to provide unique lived experience insights from people with neurological conditions and their families.

⁵ <http://www.thebraincharity.org.uk/its-all-in-your-head>

Section 3: Key findings and case studies

Theme 1: A lack of information and support

More than 4 in 10 people felt their symptoms were dismissed

The first clear theme to emerge from our data was a lack of information and support for people seeking a diagnosis. This seemed especially apparent following a first appointment with a GP or healthcare provider.

Our data shows that at this crucial stage when patients are beginning to have real concerns about their health, they can be left feeling unsupported, uninformed and scared.

Respondents were asked about the outcome of their first meeting with their GP or healthcare provider. While 43% were referred for tests at a hospital or other medical facility:

27%
did not get a referral after speaking to their GP

19%
say they were given an incorrect diagnosis

We also asked respondents how they felt following their first appointment with their GP or healthcare provider:

27%
felt their concerns were being taken seriously

44%
felt their symptoms had been dismissed

38%
felt depressed or anxious following their first appointment

49%
felt scared for their future

Most said they left their first appointment feeling poorly informed about the next steps towards diagnosis or treatment (48%) and unaware of where or who to go to if they had questions or concerns (39%). More than 4 in 10 (44%) had to do their own research to find charities and/or support groups.

Only 11% of respondents indicated that they felt they had enough support from friends

and family, and 17% felt optimistic they would get the right support for their condition. More than a third (37%) reported feeling lonely and/or isolated.

Of the 167 individuals who elaborated on their choices to the questions above, key themes included:



39% felt the GP was not interested, dismissed their symptoms and/or gave an incorrect diagnosis



10% commented on the length of time and difficulty they had in receiving a diagnosis, or were still waiting

Specific quotes from respondents included:

“I had blood tests and had to repeatedly go back. I heard comments about ME not existing.”

“I was not listened to and I was patronised.”

“GP was uncertain about the diagnosis. Uncertainty persisted for nearly two years.”

“Process was back and forth passed between different departments for years.”

For too many people with neurological conditions, a first appointment with their GP clearly leaves them feeling ignored, isolated and uninformed.

Case study:

Jeanie's brain tumour story



Jeanie had been experiencing dizziness, headaches, personality changes, mood swings and mental health difficulties for three years.

She visited her local GP 'repeatedly' but said she was told she was 'probably perimenopausal' and that this was likely to be causing the symptoms.

Jeanie said:

"I got on with it really, but it left me feeling almost like I was disbelieved – I felt humiliated.

"Blood tests were showing nothing, so I got the impression the doctors thought I was being over the top and that the symptoms weren't as bad as I was making out.

"It was like I'd been told 'it's all in your head'."

In May 2017, Jeanie collapsed and had a seizure at work and was rushed to hospital.

She received an MRI scan and was sent home, with doctors telling her it was likely to be a single seizure only.

Two days later, she received a phone call from a neurologist while she was at work, who told her she had two brain tumours in her brain's left frontal lobe.

Jeanie was told she was being urgently referred to The Walton Centre, a specialist neurology hospital in Liverpool.

Jeanie said it was 'torturous' waiting four weeks for an appointment with a neurologist.

She said: **"The horrible period of waiting was the hardest of everything – it was torturous."**

"Between diagnosis and getting my first appointment I didn't have any information and felt out of control."

Jeanie experienced more seizures, so 10 months later in September 2018 underwent surgery to remove both tumours.

Her operation was a full resection, which meant all of the tumours were removed and there was no need for radiotherapy or chemotherapy afterwards.

Jeanie said: **"I wish someone had prepared me for the recovery and told me 'actually, life won't be the same'."**

"It was never explained to me how my emotions might be different, and how I'd need to manage them differently."

"I think there should automatically be counselling and support after brain surgery, people shouldn't just be sent home."

"Your brain affects your entire life, your emotions and your personality."

Theme 2: Delayed diagnosis

Sub-theme 2.1: Recognising symptoms

3 in 10 people waited six months or more before seeking help for neurological symptoms

For many people with neurological conditions, the journey to diagnosis starts before coming into contact with healthcare providers.

We asked respondents to think back to when they first had concerns about their neurological health:

66%

said that they had noticed changes in their own health

33%

had been struggling at work

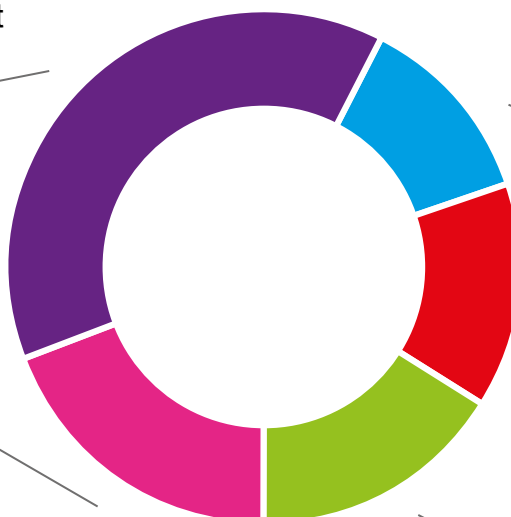
28%

said that family or friends were concerned about them

Respondents were asked what action they took when they first became concerned about their health:

76% made an appointment to see their GP

38% of respondents made an appointment within a month



32% discussed their health with family or friends

24% looked for information on the internet

28% waited six months or more before making an appointment

Concerningly, this action was not always immediate. There was a noticeable cohort who delayed seeking help, with fewer than 4 in 10 respondents (**38%**) making an appointment within a month of becoming concerned about

their health, and a sizeable minority of nearly 3 in 10 (**28%**) waiting six months or more. This suggests more public awareness of neurological symptoms and warning signs is needed.

“Kept falling over and eventually diagnosed. Not a quick or easy diagnosis and a lot of time wasted”

Comment from one survey participant

Case study: Rupak's MS story



Dad-of-three Rupak, from Surrey, had just set up his own business when he was diagnosed with primary progressive multiple sclerosis (MS) in 2018.

When the 43-year-old businessman began to fall over a lot, Rupak went to hospital in Surrey.

There, an MRI scan discovered lesions on his spine which seemed to point to MS.

He said:

“Not having a diagnosis taken seriously at the beginning had a really detrimental effect on my mental health.

“When I saw a neurologist, he said to me ‘I hadn’t proven to him I had MS’.

“This was heartbreaking to hear. I didn’t realise it was my responsibility to prove anything to him. It felt like I was being called a liar.

“I didn’t wake up one morning and say to myself ‘I want a life-changing neurological disease’.

Over the next few years Rupak’s condition got worse, and he was struggling to get up the stairs.

He became unable to work and lost the new business he had poured so much energy into.

Rupak’s partner and three children, aged five, seven and eleven, were forced to move in with family in Liverpool to ensure the children had a stable home environment.

Rupak was left homeless – living between Travelodge and Premier Inn hotels in Merseyside when the UK’s first COVID-19 lockdown hit.

He is now a full-time wheelchair user and only has one working eye due to his condition.

Rupak said: **“Before I got ill, I had a very successful career.**

“But when I got diagnosed, my business fell apart. I went from having a very comfortable life to being homeless, in a wheelchair and without anything – simply surviving.

“During the COVID-19 lockdown I was put into sheltered accommodation by the local council, which was for people who had just got out of jail and had nowhere to go.

“It felt like my life was basically done at that stage. I had no support, and no one to turn to. Surviving is difficult enough, surviving with no support is impossible.”

Case study: Sarah's dystonia story



Sarah, 55, lived with an undiagnosed neurological condition from childhood until the age of 53.

Sarah has cervical dystonia, a neurological movement disorder which causes uncontrollable muscle spasms. Other symptoms Sarah experiences are migraines, a tremor, pain in her neck and shoulder and depression – which she first experienced aged eight.

Sarah repeatedly sought a diagnosis throughout her life and over the years was referred to five neurologists, but was still not diagnosed – despite having been hospitalised due to the severity of her headaches multiple times.

She went back to her doctor again after noticing her head was tilting in Zoom video calls during the pandemic. She was only diagnosed after making a request for referral to The Walton Centre NHS Foundation Trust, a specialist neuroscience hospital.

She said: **“Despite multiple appointments I’ve had to wait decades for a diagnosis. I joke that I’ve seen a doctor from every single department; actually not that far**

from the truth. I was aware of the impact of being unwell as a young person. I don’t think the impact of how I had to work around it has really come home to me until recently.”

Sarah said she struggled before having a diagnosis as she had to ‘formulate a way of dealing without one’.

She said: **“I couldn’t answer simple questions, like ‘Why does your head shake?’ or ‘Why do you drop things?’ You have to justify the way you are because you’re trying to make sense of it yourself. You do end up saying ‘It’s just the way I am.’”**

When she did eventually receive a diagnosis, Sarah said she felt a sense of relief.

She said:

“I was so happy as it put the missing piece in the puzzle that has been missing for so long. I do wonder how it went on for that long because 53 is very, very late for a diagnosis.

“I’ve never had any support. I wouldn’t say there’s been any holistic care. I think you [The Brain Charity’s staff member carrying out the interview] are the first person to ask me how I felt after my diagnosis apart from my mother.”

Case study:

Avril's brain aneurysm story



Avril passed away aged 59 on the 8th of September, 2022 due to a brain aneurysm – leaving a huge hole in her family.

The 'loud and feisty' mum-of-two had complained of a headache and began experiencing pins and needles in her arms along with neck pain.

Avril initially attributed the symptoms to the after effects of dental work she had a few years prior, and assumed she was experiencing pain from a tooth that hadn't been removed.

Avril called her GP and was given a phone appointment, where she was diagnosed with a tooth infection and given antibiotics.

The following week Avril collapsed at work with what her colleagues thought was a stroke. When she was taken to hospital she was diagnosed with a bleed on the brain. While in hospital Avril experienced a second bleed on the brain.

She was transferred to The Walton Centre but Avril's condition had deteriorated and her life support was withdrawn two days after she was admitted.

Avril's niece Emma said:

"I don't think once growing up I've ever seen a sign or advert for a brain aneurysm. It makes no sense when there are signs and symptoms.

"Unfortunately this isn't something one person can do. We need GPs to have more training.

"Earlier diagnosis can save a life."

Emma is now calling for greater awareness of brain aneurysms among the general public and the medical community in order to spot the signs at an early stage.

She added: **"In America, National Brain Aneurysm Awareness Month is September and it's a pretty big deal over there. Symptoms and signs are all over the place.**

"I didn't even know there were symptoms until after I lost a loved one."

Case study: Lindsey's MS story



Mum-of-three Lindsey was diagnosed with multiple sclerosis (MS) in October 2020.

The 60-year-old former deputy headteacher went from being a highly paid, hard-working professional to wondering how her family were going to survive.

Lindsey's MS, which is secondary progressive, particularly involves her cerebellum, the area of the brain which controls and coordinates movement.

For MS to be diagnosed, patients must have experienced two instances of damage to the central nervous system.

Lindsey had first seen 'possible MS' on her medical notes in the 1990s, but apart from one attack in 2011, had been well until she began struggling with her memory in January 2020.

Initially treated for an ear infection, she began experiencing a tremor, balance issues and dizziness. She was then rushed to hospital for ten days with a suspected stroke. Lindsey lost her eyesight and was told she could have a brain tumour and just days to live.

She challenged this, and asked doctors to consider MS – eventually being diagnosed in 2020.

Lindsey said: **“The worst thing about a brain condition is you don't know if you're feeling how you should be feeling.”**

Lindsey now lives with a facial droop, joint pain, confusion, memory loss, vertigo, dizziness and fatigue and said an earlier diagnosis could have made a huge difference to her life and saved the NHS money and bed space.

She stressed better communication between NHS departments is needed, and wants a clear initial flag of MS to be made on medical records so it is considered at an early stage.

She added:

“There is a huge lack of information around MS out there, and so much the doctors don't know.

“There should have been something in the system when I was back in hospital. I was seriously ill and it should have said on my notes I had experienced a first episode.”

Case study:

Shirley's syringomyelia story



Shirley, 63, was diagnosed with syringomyelia – a fluid-filled cyst that grows inside the spinal cord – in June 2021.

Less than one in 10,000 people worldwide have the extremely rare condition. Neurologists believe Shirley's cyst, which is located in her neck, was triggered by whiplash sustained in a car accident in 2004.

Over time the cyst, known as a syrinx, can get bigger and may in rare cases grow upwards towards the brain – damaging the nerves within the spinal cord.

Shirley first began experiencing unexplained neurological symptoms and regular falls in 2010, but syringomyelia was not diagnosed then, despite her going to her GP.

Shirley said: **“I couldn't pay my mortgage and bills and became a virtual recluse. I stopped talking to people and stopped going out.”**

She feels there should be better systems within the NHS to ensure patients do not fall between the cracks of different departments and so that the 'bigger picture' is assessed.

Former debt advisor Shirley said:

“When I was diagnosed I felt like I was left out on a limb on my own.

“I had always been a positive person, but the diagnosis combined with losing my job made me feel like a victim, wondering ‘why me?’.

“If my syringomyelia had been picked up sooner, I would have understood my symptoms more, taken the falls more seriously and potentially not done certain things.

“I think within the NHS it's no one's fault, but it's easy for things to slip between the cracks of different departments, so something can be diagnosed and not looked at again.

“Someone should be looking at the bigger picture and making those links.

“This would be a safeguard for when doctors move on and things aren't updated on systems.”

Sub-theme 2.2: The wait for diagnosis

1 in 3 people waited two or more years to receive a diagnosis

The second key theme is the wait for a diagnosis. A significant number of respondents expressed frustrations with the length of time it took for a referral to a specialist.

Respondents were asked how long it took from their first appointment with their GP for them to be referred to a specialist and what the length of time was between their first contact with a GP and diagnosis.

How long it took to get a diagnosis from first contact with a healthcare professional

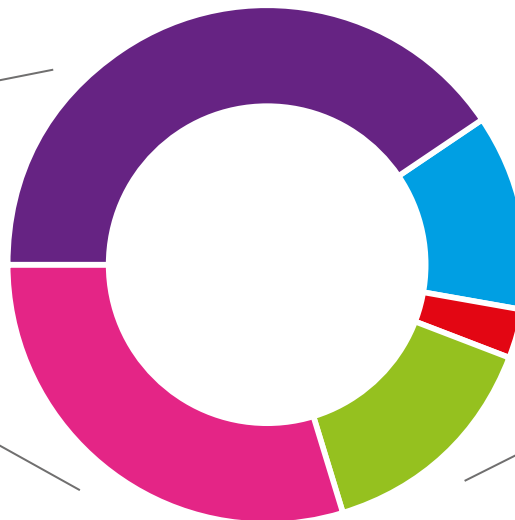
51% said it took less than a year

15% said it took more than five years

37% said it took two years or longer

4% said it took four to five years

18% said they waited two to three years



1 in 10 (12%) said they needed to see a different GP before getting the referral they needed

1 in 3 (34%) needed more than two appointments before being sent to a specialist



1 in 4 (27%) were referred after their first or second appointment

37%

felt they should have been diagnosed quicker

16%

felt they had 'far more appointments than should have been necessary'

53%

felt that they could have been diagnosed either more quickly or with fewer appointments

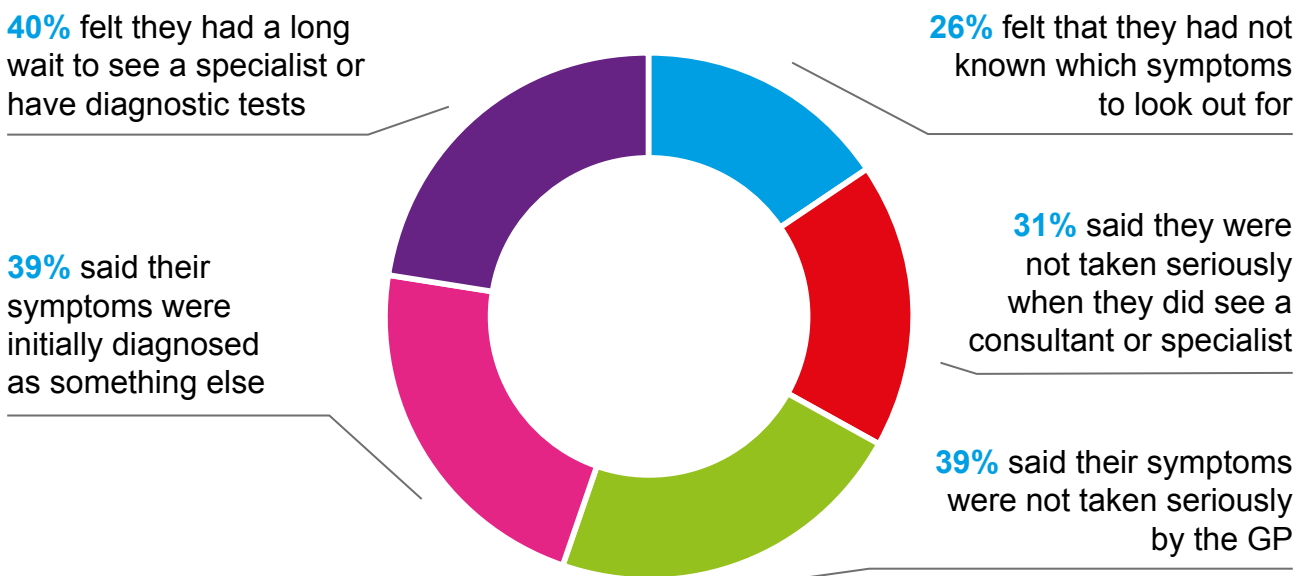
62%

felt they experienced unnecessary or unreasonable delays or problems in the process of getting a diagnosis

Sub-theme 2.3: Exploring the reasons for delayed diagnosis further

70% of people felt they weren't taken seriously

Our #BrainSurvey respondents were also asked what they felt were the key reasons for their delayed diagnosis.



Similarly to when they first sought medical advice about their concerns, respondents reported feeling poorly informed about the next steps towards their diagnosis (41%) and unaware of where or who to go to if they had questions or concerns (32%).

The above findings are backed up by the Neurological Alliance's 'Together for the 1 in 6: UK Findings from My Neuro Survey report'⁶. This analysed survey data from more than 8,500 people with neurological conditions.

In adults, more than a third (36%) reported waiting more than a year between first experiencing symptoms and getting a

diagnosis. There were 1 in 5 (20%) who waited more than 12 months between first seeing a GP and seeing a neurologist. A total of 6% of adults said that they had never seen a neurological specialist, and over a quarter (26%) said they last had an appointment more than a year ago. For 19%, this was more than 18 months ago.

When given the opportunity to elaborate on their answers, many respondents to our #BrainSurvey (41%) commented on the lack of medical knowledge, treatment and support they received from healthcare providers and/or NHS services.

⁶ <https://www.neural.org.uk/wp-content/uploads/2022/05/Together-for-the-1-in-6-UK-Findings-from-My-Neuro-Survey-v6.pdf>

This was particularly the case for:

- Neurological conditions that are particularly rare, and where the research is felt to 'not be available'.
- Chronic fatigue syndrome / myalgic encephalomyelitis, where respondents highlighted the lack of knowledge that healthcare professionals have about the condition, the lack of specialist / support services, as well as the stigma that exists.

- Those that were diagnosed many years ago when medical knowledge / testing wasn't as advanced e.g., those diagnosed with post-polio syndrome.

For many, there was a feeling that once their diagnosis was received, they were 'left to get on with it'.

Specific comments included:

"GPs I saw were not well informed about ME. They did not recognise my post exertional malaise, which is a defining symptom of ME. I had never heard of PEM so did not spot it either."

"My original GP left and the next one I saw completely dismissed my symptoms and treated me with contempt. I had to wait eight months and a major relapse that left me with permanent problems before I was referred to a specialist."

"For two years I was told my son would grow out of his tics, that it was just a phase. I had to go private for a diagnosis because no one within the NHS [was] interested."

Elements of their diagnosis journey that respondents were most likely to rate as very good or good included:

- Knowledge of the specialist / consultant (35%)
- Getting a GP appointment / appointment with a private healthcare provider (23%)

In contrast, aspects that respondents felt were poor or very poor included:

- Knowledge of GP / private healthcare provider (52%)
- The support received following their diagnosis (51%)
- The waiting time to see a specialist (49%)
- The information / advice received after seeing a GP (48%).

52%

rated the knowledge of their GP or healthcare provider as very poor or poor

The reasons most frequently given for respondents' delayed diagnosis were:

- Delays or waiting times to see a specialist / have diagnostic tests (40%)
- Misdiagnosis (39%)
- Symptoms not being taken seriously by the GP (39%)
- Symptoms not being taken seriously by the consultant / specialist (31%)

Along with 44% of people not feeling that their concerns and symptoms were being taken seriously, this paints a picture of a lack of understanding of the breadth and complexity of neurological conditions within primary care.

Case study:

Jack's* Chiari malformation story



Jack, 25, experienced severe headaches from the age of 16 as a result of a Chiari malformation. It is a condition where part of the brain pushes down through the base of the skull into the spine.

In 2015, when Jack was 16, he began having headaches which he described as “at the very high end of the pain scale”. He also experienced other symptoms including issues with his balance and coordination and fatigue. He “put up with it for a bit” but as the pain continued he knew he needed medical support.

Jack says he was initially told his headaches were due to exam stress.

He said: **“I knew there was something more to it because none of my peers in college were having what I was having and didn’t seem to be struggling as much as me.”**

After his exams Jack persisted in seeking a diagnosis over two years thanks to encouragement from his mother.

GPs worked to rule out a tumour and other conditions. He was referred for an MRI and only then was diagnosed with a Chiari malformation.

Jack said:

“Eventually it got to the point where I just needed an answer.

“I knew there was something there. I wouldn’t just keep going back and keep putting myself through that for no reason.

“It’s very dispiriting to be disbelieved. I feel there’s people out there who are really, really suffering and will have given up trying to get treatment.

“There needs to be greater awareness of the painful implications of a condition like mine, otherwise people will continue to suffer without a quick resolution.”

After diagnosis Jack received surgery within six months of being approved.

He said: **“After the first surgery I felt loads better. The pain was still there but it was much, much, much reduced.**

“The headaches would go away with paracetamol whereas before no amount of drug would touch it. I’m so much better, and I could have been better earlier.”

Jack also had a second surgery in 2019 and is now studying for a health course.

He said: **“I’m using my own experience as I feel I can empathise a lot better than the average person. I’ve turned a bad thing into a good thing.”**

* Jack is a pseudonym to preserve anonymity

Case study:

Helen's subarachnoid haemorrhage story



Helen died from a subarachnoid haemorrhage in November 2016, aged just 56.

In the months leading up to her death, Helen experienced numbness down one side of her face, which came and went.

Her widower Steve does not know whether this was related to the brain aneurysm, as the majority of subarachnoid haemorrhages occur without symptoms beforehand.

The day she died, fitness fanatic Helen woke up with a numb headache. It didn't stop her from going to the gym, but she didn't feel up to doing her usual exercises.

As she was leaving the gym, a brain aneurysm ruptured, causing a subarachnoid haemorrhage. Helen collapsed and died instantly.

Steve said: **“To lose the person you love at just 56, completely out of the blue, is very shocking. It was just absolutely terrible.”**

“Helen was an absolute powerhouse, you couldn't find a photo where she wasn't smiling. She was a much loved and extremely popular person – 400 people attended her funeral.”

“She truly lived up to the saying that the best get taken first. She left a lot of people completely upset and puzzled as to how someone so fit and active could pass away.”

Helen was incredibly fit, having completed the London Marathon in 2012, and had no other health complaints.

After Helen died, her sisters hoped to get themselves checked for possible brain aneurysms in case there was a genetic or hereditary element, but said they were unable to do so.

Steve said:

“Helen's symptoms weren't painful or debilitating, but she definitely knew something was wrong, no question, and was worried.”

“It seems there are fairly straightforward things which could be done if a brain aneurysm is found, or treatments which could have a positive impact.”

Helen saved three lives when she died by donating her organs.

Theme 3: Impact on mental health

Half those surveyed felt scared for the future - 1 in 3 developed depression or anxiety after their neurological diagnosis

The process of receiving a diagnosis for what could potentially be a life-changing condition is understandably a stressful and emotional time. The clear evidence from our survey respondents was that, for many, the journey to receiving a diagnosis has negatively impacted their mental health.

The impact of a lack of information and support and delays in receiving a diagnosis made an

already difficult and emotional process far harder for people.

The support received following a diagnosis was the second most poorly rated overall aspect of the journey to diagnosis, with **51%** of respondents rating this as poor or very poor.

Respondents reported most commonly leaving their first appointment with a GP or healthcare provider feeling:

48%

not well-informed about the next steps

39%

unaware of where to go to if they had questions or concerns

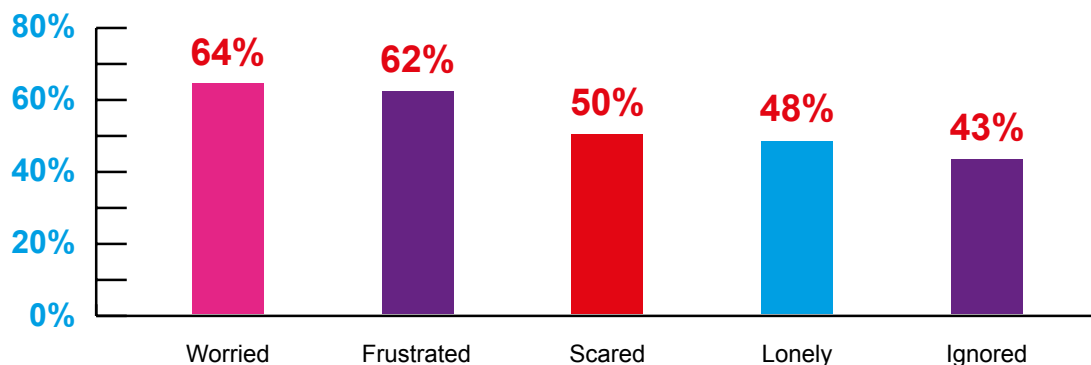
49%

fear for the future

37%

loneliness

During the overall journey to diagnosis, respondents felt:



35%

were diagnosed with depression or anxiety since diagnosis of a neurological condition

16%

already had a diagnosis of depression or anxiety

11%

felt that the length of time it took for them to be diagnosed made their depression or anxiety worse

This is significantly higher than national statistics, which suggest 1 in 6 people in England have a mental health condition.⁷

Our #BrainSurvey respondents were also asked how that felt when they received their diagnosis.

66%

felt scared for the future

44%

felt depressed or anxious

43%

felt loneliness or isolation

⁷ <https://commonslibrary.parliament.uk/research-briefings/sn06988/>

Case study: Gareth's brain tumour story



Gareth was 38 when he died due to a glioblastoma brain tumour in January 2019.

He was diagnosed with the stage four tumour on his left frontal lobe in November 2017, having spent much of his life in psychiatric hospitals.

Gareth had received mental health treatment since the age of 17, following a diagnosis of schizophrenia and psychosis.

Barbara, Gareth's mum, and her heartbroken family believe he may have survived if any possible symptoms of his brain tumour had been picked up earlier.

They are calling for more awareness of how brain tumours can cause problems like personality changes, communication difficulties and psychiatric symptoms such as depression and anxiety.

Barbara said: **"It is absolutely agonising for me to think he could have been around for at least another five years, and his quality of life could have been much higher."**

The symptoms of his apparent mental illness began in 2014 and included verbal outbursts,

trembling, dribbling, numbness, pins and needles and difficulties communicating.

Gareth was discharged from hospital in October 2017 but experienced a seizure and collapsed the following month. He was taken to A&E, where he was given an MRI scan and the glioblastoma was discovered.

He underwent a three-hour operation in November 2017 to remove part of the tumour but was readmitted to hospital in December 2018 and died five weeks later.

Barbara said:

"Although Gareth's health improved for a while after the operation, I find it difficult that his original diagnosis was never reviewed or the possibility of anything other than a mental health issue considered.

"I want to raise awareness of the potentially overlapping symptoms between mental health issues and brain tumours."

Gareth's hospital apologised to Barbara and told her Gareth's case will influence the training their staff receive.

Case study:

Erin's ADHD and autism story



Erin, 40, was diagnosed with attention deficit hyperactivity disorder (ADHD) and autism aged 39.

Like many undiagnosed women, Erin felt she didn't fit in and couldn't understand societal rules.

In school, she regularly received the same criticism; 'Erin is bright; she just needs to apply herself.'

During the COVID-19 pandemic, Erin completed an online questionnaire which concluded she had a sensory processing disorder and marked her 'high likelihood' for autism and ADHD.

She said:

"I started looking into it and it became very, very clear that things I'd considered character flaws and failings in my life, were symptoms of neurodivergence."

"From there I contacted my doctor and said I would like to fill out the adult self-report scale questionnaire for ADHD."

"They refused and told me, 'It's not a grown women's thing, it's a naughty boy thing'."

Erin was eventually diagnosed with ADHD. Once diagnosed she received an assessment after six months, with the whole process taking three and a half years.

Erin said: **"Doctors said it was depression and tried to give me medication for that, but I knew I didn't have anxiety or depression."**

"I came away feeling that I'd not been heard or helped to understand the root cause of my symptoms."

Post-diagnosis, Erin said she felt relief and clarity on a lot of the unexplained hurdles she faced throughout her life.

This realisation followed a period of grieving for 'what might have been', had her neurodivergence been spotted younger.

Erin still hasn't received an official diagnosis of autism, although she was told by medical professionals she has 'high autism traits'.

Erin said: **"The online neurodivergent community is very supportive and knowledgeable, but it would be nice to have someone to talk to that is informed with up to date scientific and medical awareness to help someone through it."**

"At the moment you've only got the people around you. It can be a lonely, frustrating journey if you aren't around supportive people."

Case study:

Karen's fibromyalgia and FND story*



Karen, the CEO of a women's charity, has fibromyalgia, functional neurological disorder (FND) and post-traumatic stress disorder (PTSD).

During a neurological appointment in 2022, she was advised that her conditions had probably been caused by significant traumatic life events – in her case, experiencing domestic abuse.

Karen said she has seen this experience of developing neurological symptoms due to trauma reflected in other women she has worked with.

She believes greater understanding and research into the link between neurological conditions and trauma, including domestic abuse, is needed.

Karen said: **“We don't understand the full impact of physical abuse.”**

“We're currently failing to adequately support women, men and children who experience domestic abuse and who develop neurological symptoms.”

“We need more support, more understanding. We need to not have

symptoms blamed on mental health – that's really victim blaming.”

Karen's symptoms began 15 years ago when she began falling a lot while working for a homelessness charity.

She had already been diagnosed with PTSD in 2004 and spent four years going to the doctors to obtain a diagnosis for debilitating symptoms including chronic pain, stiffness which caused frequent falls, fatigue and cognitive problems like brain fog and memory loss.

Karen said her concerns about fibromyalgia were dismissed by her doctor, and she was told her symptoms were due to poor mental health.

In 2022 Karen was diagnosed with FND, a condition which interrupts the functioning of the nervous system.

She said she went through a 'grieving process' after being diagnosed with FND, as she had been without a correct diagnosis for the condition for 10 years.

At a recent appointment, Karen attempted to speak to a consultant about her concerns that the abuse may have been a trigger in developing neurological symptoms.

She said the medical professional didn't answer her questions, but instead said 'I can see you have PTSD, how is your mental health?'

Karen said:

“I was made to feel stupid, as though somehow the debilitating symptoms are not real.”

“The constant questioning of our own experiences and why this is happening is difficult enough, without medical professionals dismissing it as symptoms of poor mental health.”

“It's a horrible place to be.”

* Karen preferred to not be pictured

Section 4: Wider context

Public expectations versus our clients' reported experience

The #BrainSurvey findings illustrate a lack of information and support, delays to diagnosis and a negative impact on mental health. Despite this stark picture, evidence from a YouGov⁸ poll examining the public's perception of life with a neurological condition suggests there is a gap between the expectations and reality.

Respondents were asked if they developed a long-term medical condition, how confident they would be of having enough support from their friends and family to meet their emotional and physical needs.

- **59%** felt that they would have enough support.
- **20%** felt they would not have the support they needed.

These figures are sadly in stark contrast to the lived reality of our #BrainSurvey responders.

- **11%** told us that they felt they had enough support from friends and family
- **37%** reported feeling lonely and/or isolated.

The YouGov survey was commissioned by The Brain Charity to compare our clients' reported experiences versus the wider public's expectations.

In total 2,166 people were polled online in January 2023. Respondents were weighted by YouGov to ensure they were representative of the makeup of the UK adult population.

Respondents to the YouGov survey were also asked if they were confident any unexplained symptoms presented to their GP would be taken seriously.

YouGov Survey

48%

agreed they would be taken seriously by their GP

29%

felt that they would not

The #BrainSurvey

27%

felt their concerns/symptoms had been taken seriously by their GP

44%

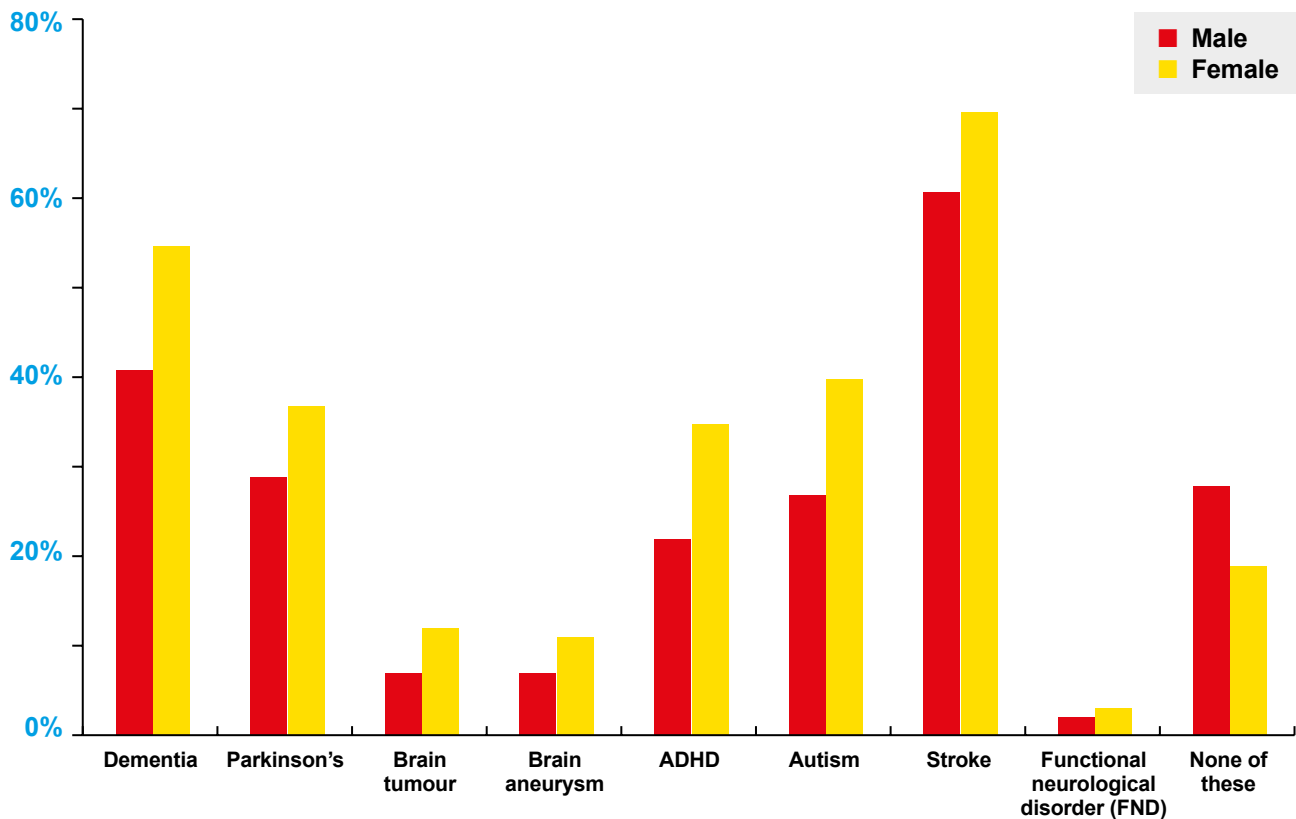
of respondents felt that their concerns/symptoms had been dismissed or not taken seriously

These figures suggest a lack of confidence in GPs, but again show the general public's expectation does not match the reality of our #BrainSurvey findings, which found 39% said their symptoms were not taken seriously by the GP.

This wider context shows the disparity between lived experience and public perception of how a diagnosis journey for a neurological condition would take place. It also provides some insight into how greater public awareness of neurological conditions is needed.

⁸ Total poll sample size 2,166 adults, fieldwork carried out in January 2023. Respondents weighted by YouGov to be representative of the UK population.

Which neurological conditions did the public feel confident recognising the main symptoms for? (Source: YouGov)



Respondents to the YouGov survey were also asked which, if any, neurological conditions they felt confident recognising symptoms or warning signs for.

While high percentages felt they would be able to recognise the symptoms of a stroke, fewer believed they would know the warning signs of brain aneurysm, FND and ADHD. This is a

particular problem amongst men, with stroke being the only condition more than half of male respondents felt confident in recognising the main symptoms or warning signs of. This reinforces the need for greater awareness among the general public of symptoms associated with different neurological conditions in order to spot signs at an early stage.

Section 5: Recommendations

The impacts of the issues covered by this report, on people with neurological conditions, their families and the health and care services around them, suggests there is a clear need for an independent review to address the issues faced by those living with neurological conditions, both in receiving a first diagnosis and then in accessing the support and information they need through their treatment.

Recommendation 1:

The Brain Charity would like to see fuller consideration of the themes cited in this report through an independent review of the journey to and impact of diagnosis for people with neurological conditions.

An independent review could:

a. **Include what information, support and advice is given to patients at the Primary Care stage, during and beyond diagnosis**

b. **Examine how GPs and other primary care professionals can use training and other opportunities to maintain and strengthen their understanding of neurological conditions, adapt their processes and improve the quality of care patients receive**

c. **Explore how specialist mental health support can be provided for patients in a meaningful and timely manner**

d. **Identify how public awareness and understanding of neurological conditions might be improved, to influence people seeking help for themselves and their families sooner**

Recommendation 2:

In addition, as a member of the UK's Neurological Alliance, The Brain Charity supports the call for UK governments to set up a Neuro Taskforce, to address the current issues facing the 1 in 6 who live with neurological conditions.

A Neuro Taskforce would provide much needed leadership, scrutiny and co-ordination of multiple existing health initiatives, as well as a framework for greater collaboration to help tackle the issues raised in this report.

Accessibility

If you or someone you know requires this report in another format, such as large text, a different font or background colour or a different language, please email campaigns@thebraincharity.org.uk or call **0151 433 3485**.

A version of this report which is fully accessible with screenreader technology is also available on The Brain Charity's website via the link and QR code below.

Acknowledgements

The Brain Charity thanks the people with neurological conditions, their family members and carers, who took the time to complete the #BrainSurvey that made this report possible. We also thank those with lived experience who shared their own personal stories as case studies for the report.

The Brain Charity would also like to thank the members of our steering group, who have offered their advice, support and expertise both in designing the #BrainSurvey and in their guidance throughout the writing of this report and its recommendations. They include:

Dr Nicholas Silver, Consultant Neurologist at The Walton Centre NHS Foundation Trust, honorary clinical lecturer at the University of Liverpool and trustee of The Brain Charity

Emeritus Professor Gus Baker, patron of The Brain Charity, Chartered Consultant Clinical Neuropsychologist and Secretary General of the International Bureau for Epilepsy.

Sarah Oldnall, Suzie Goligher and Kim Hughes, volunteers at The Brain Charity with personal experience of neurological conditions.

This report is dedicated to the memory of **Janet Ireland**, Information and Advice Officer at The Brain Charity.

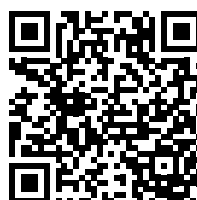
Contact

If you have any questions about the report, or would like to be involved in The Brain Charity's campaigning work, please email campaigns@thebraincharity.org.uk.

Webpage

To read more lived experience case studies and find out more about the methodology behind the report, please go to www.thebraincharity.org.uk/its-all-in-your-head or scan the QR code below.

QR code



Publisher

The Brain Charity
Publication date - September 2023



The Brain Charity: national support
for all neurological conditions
www.thebraincharity.org.uk

Norton Street
Liverpool
L3 8LR

@thebraincharity

