My Neuro

2024-5 research findings report

Research

NEUROLOGICAL ALLIANCE
of IRELAND

REVEALING REALITY

About Revealing Reality

Revealing Reality is an independent research agency who work with regulators, government, charities, and private sector organisations.

Revealing Reality is experienced in conducting research with vulnerable groups in society, particular for charities involved in health and social care to ensure the experiences and perspectives of different people are placed at the heart of health and care policy.

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Introduction

Context and background

Neurological conditions impact the lives of thousands of individuals and families across Ireland, often bringing with them a complex mix of physical, psychological, and emotional challenges. For many, these conditions also result in financial strain and a need for specialised health and social care.

Yet, despite the scale and complexity of these challenges, many of these individuals struggle to receive the support they need. Delays in diagnosis, insufficient care, and limited availability of mental health and emotional support are just some of the issues that individuals with neurological conditions face. These gaps can leave individuals and their families feeling unsupported and uncertain about how to navigate life with a neurological condition.

This report seeks to shed light on the realities of living with a neurological condition in Ireland by drawing directly on the experiences of those most affected. Through a nationwide survey, adults and children living with neurological conditions shared their insights – including their experiences and reflections on services, as well as their overall experiences of living with neurological conditions.

Equally important are the voices of carers – family members, partners, and other individuals who provide essential, often unpaid, support for those with neurological conditions. Carers frequently encounter difficulties balancing these responsibilities with employment, their own health needs, and the emotional toll of caregiving. By exploring both perspectives, this research highlights the urgent need to design services that are flexible, person-centred, and truly responsive to the needs of this community.

About this research

To better understand the realities facing people with neurological conditions in Ireland, the Neurological Alliance of Ireland collaborated with Revealing Reality, an independent research and insight agency, to develop and deliver three surveys. These surveys were carefully designed to gather first-hand accounts from individuals living with neurological conditions and their carers.

The research set out to achieve the following key goals:

- **Capture the experiences of those affected by neurological condition(s):** The primary objective of this research is to gather in-depth insights into the lives and challenges of individuals living with neurological conditions in the UK, providing a comprehensive understanding of their needs
- **Be accessible and inclusive:** Designed with accessibility in mind, the surveys ensure they are easy to complete and accessible to a wide range of participants, accommodating individuals with diverse needs
- **Support advocacy, influencing, and service improvement:** The data will drive advocacy efforts, informing policies and campaigns aimed at ensuring public policy reflects the realities of living with neurological conditions and improving access to treatment, care, and support

This report presents the insights gathered through this research, providing a deeper understanding of the current landscape of care for those with neurological conditions and highlighting where attention is most needed when it comes to the improvement of healthcare, policymaking, and support.

How will the findings be used?

The My Neuro 2024/25 survey represents one of the most extensive efforts to gather insights from people living with neurological conditions in Ireland. With over 750 individual responses across the three surveys, it provides detailed information on key areas such as diagnosis, treatment, mental health, access to services, and the day-to-day experiences of individuals managing neurological conditions.

By highlighting the challenges reported by respondents, the data provides a strong evidence base to support ongoing efforts to improve services and strengthen support systems. These insights will play a central role in shaping the Neurological Alliance of Ireland's advocacy work, helping to ensure that the voices of people with neurological conditions are reflected in national policy and planning.

Overall, the findings from this research will be used to support NAI's efforts to ensure that services for people with neurological conditions in Ireland are informed by lived experience and focused on delivering better outcomes across the country.

Acknowledgments

We would like to thank everyone who participated in this survey. Whether you responded on your own behalf or as someone supporting a person with a neurological condition, your input has played a vital role in helping to build a clearer picture of the experiences and needs of people across Ireland.

The information you have shared with us is central to the Neurological Alliance of Ireland's efforts to bring about meaningful change and has helped to build a stronger evidence base that can be used to inform national policy, strengthen advocacy efforts, whilst supporting ongoing work to improve the design and delivery of neurological services. By highlighting the real-world challenges faced by individuals and families, your responses can lead the way to ensuring that future decisions about care and support are shaped by the voices of those with lived experience.

Overview of the survey

- The 2024/25 My Neuro Survey marks the first national effort to systematically gather large-scale insights into the experiences of people in the Republic of Ireland living with neurological conditions and those who care for them.
- Led by the Neurological Alliance of Ireland, alongside independent research agency Revealing Reality, the survey was designed to capture a broad and detailed understanding of how individuals interact with healthcare services and manage daily life with a neurological condition.
- The research included tailored surveys for both adults and children living with neurological conditions, as well as a dedicated version for carers. The inclusion of carers recognises the essential role they play and the specific challenges they face in supporting someone with a neurological condition.
  Responses were gathered over a four-month period, between 22 July and 15 November 2024, through an online survey. In total, the experiences of 861 individuals were captured.

Methodology

Survey design

The 2024/25 My Neuro Survey was developed using the previous UK-wide iteration as a reference point, while drawing on Revealing Reality's broader experience in designing national survey programmes – including work with organisations such as the Motor Neurone Disease Association. In general, the same questions were reflected in both the UK and Republic of Ireland surveys, though some additional questions were included in the Ireland version to reflect the specific context in Ireland where relevant.

The surveys were developed through a collaborative process between the partner alliances, including The Neurological Alliance, Wales Neurological Alliance, Neurological Alliance of Scotland, Northern Ireland Neurological Charities Alliance (niNCA), and Neurological Alliance of Ireland, and Revealing Reality. Key modifications in this iteration included the consideration of more accessible, age-appropriate language in the survey for children and young people, as well as the creation of a new, standalone survey for carers. These additions aimed to ensure that the experiences of a wider range of individuals could be accurately and sensitively captured.

A project steering group, made up of representatives from The Neurological Alliance member organisations alongside those from partner alliances, supported the design process. Their role was to ensure that the survey reflected the realities of people living with neurological conditions across the UK and Ireland. Their input helped shape the content and structure of the questionnaire, with a focus on ensuring relevance, clarity, and inclusivity.

To further ensure the appropriateness of the surveys, cognitive testing was carried out with five individuals, including both adults and children living with neurological conditions. Participants were asked to complete a draft version of the questionnaire and then provide detailed feedback on each question – including its wording, structure, layout, and length. The process was iterative: refinements were made after each session to improve clarity and usability, allowing subsequent testing to focus on new areas. The input from these participants was crucial in ensuring the final survey was accessible and appropriate. A summary of findings was shared with the Neurological Alliance of Ireland and the project steering group, and further adjustments were made based on this feedback. The updated versions were then re-tested to confirm their suitability.

Throughout the survey design process, Neurological Alliance of Ireland engaged closely with a lived experience reference group in order to inform the design of the Republic of Ireland surveys. This group, representing adults with a range of neurological conditions, played a vital role in informing the design of the surveys for an ROI audience.

The survey design process ran from April to June 2024, involving multiple stages of drafting, review, testing, and revision. Throughout this period, Revealing Reality worked closely with the Neurological Alliance of Ireland to finalise the question set, ensuring that it reflected the insights gathered from steering group discussions, participant feedback, and cognitive testing.

Dissemination

The survey was disseminated across the Republic of Ireland through a single online link promoted by the Neurological Alliance of Ireland through their website, social media channels, newsletters, and direct outreach networks.

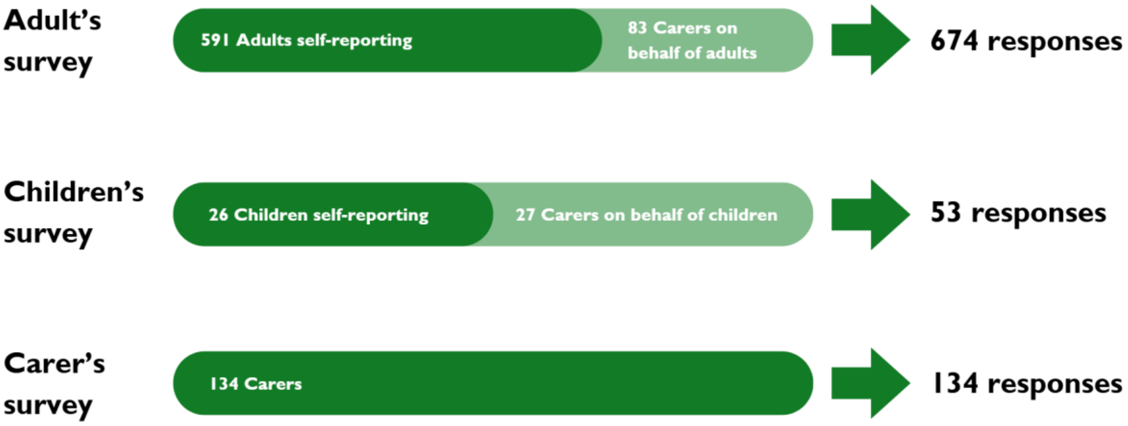
Data collection

Data for the surveys were gathered through responses directly from individuals living with neurological conditions, as well as by carers responding on behalf of someone they support. This approach was taken to ensure that the experiences of individuals who may have found it difficult or impossible to complete the survey themselves were still represented. Where carers completed the survey on behalf of another person, their responses were included in the dataset alongside direct responses wherever a comparable question was asked

It is important to note that not all questions from the adult survey were included in the version completed by carers. Some items were excluded where it was deemed inappropriate or unreliable for carers to answer on another person's behalf. Care was taken to ensure the integrity of the data, and limitations associated with proxy reporting were considered when interpreting the results.

Survey responses

In total, the experience of 861 of those with neurological conditions and their carers were collected.



Open-ended question

At the end of the surveys, respondents were given the opportunity to provide additional comments through an open-ended question. This invited individuals to share any further thoughts or reflections about their neurological condition(s), or their experiences with care, treatment, and support. Throughout this report, key themes from these comments have been highlighted with selected quotes that illustrate the experiences and perspectives shared by participants.

Caveats

- **Base sizes for analysis:** To ensure the reliability of the findings, subgroup analyses (such as by condition type or other demographics) have only been included where the number of respondents exceeds 30. This threshold was set to ensure that findings are robust and to minimise the risk of drawing conclusions from small samples, which have the potential to be biased. As a result, we have only been able to include a breakdown of the experiences of respondents with different conditions across 8 conditions in the adult survey and was not possible in the children's survey data. The specific conditions we have included will be listed in Chapter 1.
- **Sample representativeness:** While every effort was made to reach a wide and diverse range of individuals living with neurological conditions, it is not possible to confirm that the sample is fully representative of the broader population of people living with neurological conditions in Ireland. Findings should be interpreted with this context in mind.
- **Merger of responses where carers reported on behalf of children:** The children and young people's survey was designed separately to ensure it was age-appropriate. In some cases, carers completed the survey on behalf of children. Because the content of these two survey versions differs, responses have been analysed separately. Where possible, comparable questions were used alongside one another to bring together findings in a way that reflects the overall experiences of children and young people.

About this report

This report sets out the findings from the **2024/25 My Neuro Survey** from the Republic of Ireland. It provides detailed insight into the experiences of people living with neurological conditions, including children and young people, as well as the carers of those affected by these conditions. The report explores a range of key areas, including diagnosis, treatment, daily life, mental health, and access to health and support services.

The report is organised into eight chapters. The first three chapters provide an overview of the responses from each of the survey groups: adults, children and young people, and carers. Chapters 4 to 8 focus on five specific themes, each addressing a different aspect of life with a neurological condition in more detail.

A summary of each chapter is provided in the table below.

Chapter 1: Understanding the lives of adults with neurological conditions	This chapter presents findings on the experiences of adults living with neurological conditions, based on responses from these adults themselves as well as from carers responding on their behalf. It explores the impact of these conditions on physical and mental health, day-to-day life, and employment. The chapter also covers experiences with healthcare services, including diagnosis, treatment, and access to ongoing support.
Chapter 2: Understanding the lives of children with	This chapter focuses on the experiences of children and young people, drawing on both self-reported responses and those received from carers. It outlines the demographics of respondents and examines how neurological conditions affect their physical and emotional wellbeing, their experiences at school, in social settings,

neurological conditions	and in daily activities. It also includes findings on their experiences with healthcare services and professionals, and the availability of different types of support.
Chapter 3: Understanding the lives of carers and their experiences of caring	This chapter explores the experiences of carers who provide support to people with neurological conditions. It begins with an overview of the carers who took part in the survey, including demographic details and their relationships to the individuals they care for. The chapter then explores the challenges associated with caregiving, including emotional and practical barriers, as well as carers' experiences with available support services.
Chapter 4: Mental Health	This chapter explores the mental health of individuals with neurological conditions, including both adults and children. It reports on the prevalence of mental health challenges, access to mental health services, and the support individuals receive. It also explores the effectiveness of mental health support, in terms of whether it is meeting needs.
Chapter 5: Involvement in decision-making	This chapter considers the extent to which people with neurological conditions feel involved in decisions about their care, treatment, and support, as well as the involvement of carers in decisions for those they care for.
Chapter 6: Financial support	This chapter explores the financial impact of living with a neurological condition, including how these conditions affect financial stability, and assesses the use of and perceived adequacy of financial support for individuals and families.
Chapter 7: Children's transition to adults' care	This chapter focuses on the transition process for children aged 14–17 moving from paediatric to adult healthcare services, and whether children have support and information on this process.
Chapter 8: Access and confidence to participate in research	This chapter explores respondents' attitudes towards taking part in research about their condition(s), including their interest in participating and previous involvement.

Chapter 1: Understanding the lives of adults with neurological conditions

About the adult respondents and their condition(s)

Who responded to this survey?

The adult sample includes both adults who shared their own experiences of living with a neurological condition and adults whose experiences were shared by their carers. For ease of reading and to avoid repetition, we will refer to this group as "adults with neurological conditions" throughout the report. This term includes experiences shared by carers unless stated otherwise. The survey aimed to capture a wide range of perspectives from individuals across different age groups, genders, and neurological conditions, offering insights into the challenges and realities faced by adults living with neurological conditions in the Republic of Ireland.

Below is a summary of the key demographics of the adult sample:

72%	Female
27%	Male
1%	Other / Prefer not to say

5%	18-24
7%	25-34
21%	35-44
24%	45-54
23%	55-64
15%	65-74
5%	75+

1%	Black, Asian and Minority Ethnic groups
98%	White
1%	Other / Don't know / Prefer not to say

28%	Dublin
15%	Midlands
14%	South
11%	North East
9%	West
9%	South East
8%	Mid-West
6%	North West

What conditions were reached?

In total, the survey gathered responses from people living with a range of neurological conditions, covering 55 distinct conditions with at least one response each, provided either directly or on behalf of an adult. The most commonly reported conditions were:

1. Epilepsy – 19%
2. Migraine – 13%
3. Functional Neurological Disorder (FND) – 13%
4. Multiple Sclerosis (MS) – 12%
5. Parkinson's Disease – 12%

Please note that we only received 30 or more responses from / on behalf of adults with 8 conditions. Hereafter, any subgroup analysis by condition will only be done for the following conditions:

1. *Epilepsy*
2. *Migraine*
3. *Functional Neurological Disorder (FND)*
4. *Multiple Sclerosis (MS)*
5. *Parkinson's Disease*
6. *Dystonia*
7. *Fibromyalgia*
8. *Acquired Brain Injury*

How long respondents had been diagnosed

Overall, 70% of the sample of adults with neurological conditions indicated that they had been diagnosed with a neurological condition for more than four years.

Impact of neurological condition(s)

Impact of their neurological condition(s) on health

Fatigue was the most frequently reported health impact for adults with neurological conditions, with 93% of the sample indicating that it affected them to some degree[1]. The next most reported health impacts were **movement**, **thinking and memory**, **sleep**, **mood and mental health**, and **pain**.

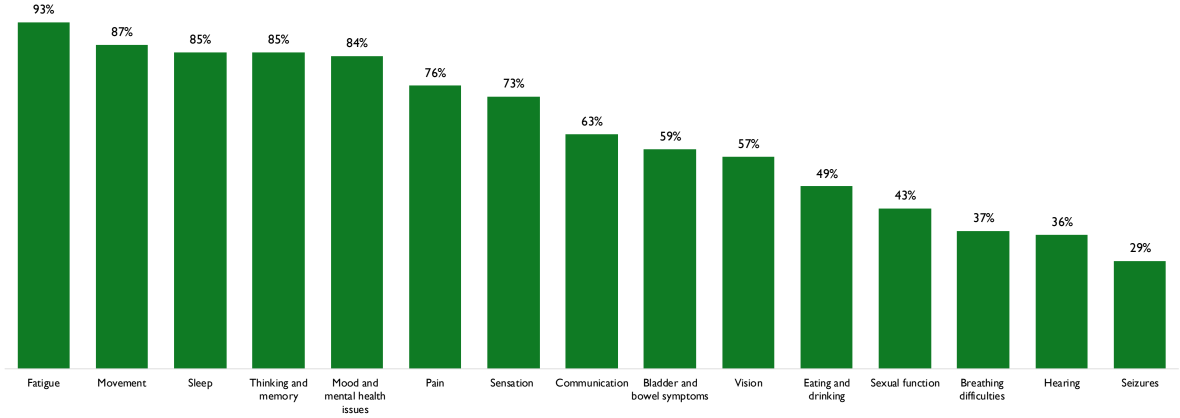


Chart: Which, if any, of the following ways does your neurological condition(s) impact your health? Please select all that apply (n=674)

Impact on daily life

Over half of the sample reported that their neurological condition(s) had an impact on their ability to engage in certain daily activities either "quite a lot" or "very much". Specifically:

- **56%** of adults reported that their condition(s) impacted their ability to **be active** at least quite a lot.
- **53%** reported that their condition(s) impacted their ability to **work or study** at least quite a lot.

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[1] This is based on those that reported that their neurological condition impacted their ability 'a little', 'somewhat', 'quite a lot', or 'very much'

- **51%** reported this degree of impact on their ability to **do fun things out and about**.

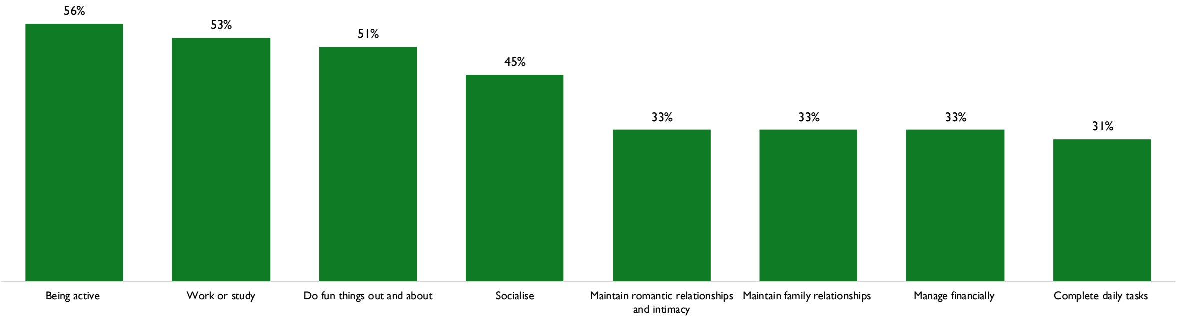

Chart: How does your neurological condition(s) affect your ability to do the following? (n=674)

Additionally, those with multiple neurological conditions were statistically significantly more likely to report a high impact of their condition on their daily life. **47%** of respondents with multiple conditions were categorised as experiencing a **high impact on daily life**, but in comparison only **30%** of those with only one condition experienced a **high impact on daily life**.

Note: Respondents were categorised into three groups measuring the extent of impact on their daily life, based on their responses to the statements in Q15: 'How does your neurological condition(s) affect your ability to do the following?'. Across the 8 areas of daily life explored in this survey question (answered by both adults and carers on behalf of adults), each response was assigned a numeric score: 'Not at all' = 0, 'A little' = 1, 'Somewhat' = 2, 'Quite a lot' = 3, and 'Very much' = 4. Respondents who selected 'I'm not sure' or 'Prefer not to say' were excluded from this coding.

An average score was then created across all 8 areas of daily life for each respondent. Respondents were categorised into the following three groups:

- **Low impact on daily life:** Average score ≤ 1.33 (rounded)
- **Medium impact on daily life:** Average score between 1.34 and 2.67 (rounded)
- **High impact on daily life:** Average score > 2.67 (rounded)

This approach enabled us to break down the severity of impact of adults' neurological conditions across different areas of their daily life.

Impact on work and employment

Adults with neurological conditions often reported difficulties related to work and employment[2].

Nearly half (47%) of adults with neurological conditions reported that they had stopped working due to their condition(s). Additionally, 1 in 5 (19%) agreed that they had to leave their job because of their employer's actions or inaction. Over 1 in 4 adults (27%) also reported experiencing discrimination at work due to attitudes toward their neurological condition(s).

For those who reported that they had to stop working because of their neurological condition, the following health impacts were most commonly reported as impacting them "*very much*" or "*quite a lot*" compared to those who disagreed with the statement *"I have stopped working because of my neurological condition*(s)":

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[2] Please note, this data is based solely on adults responding for themselves, not carers answering on behalf of adults.

- **75%** of this group reported that their condition impacted **fatigue**, compared to **55%** of those who did not report stopping work due to their condition.
- **59%** reported that their condition impacted **sleep**, compared to **29%** of those who did not report stopping work due to their condition.
- **58%** reported that their condition impacted **thinking and memory**, compared to **27%** of those who did not report stopping work due to their condition.

These figures suggest that individuals who had to stop working because of their condition were more likely to report significant health impacts in these areas.

In the survey open response question, adult respondents shared their experiences with work and employment. They highlighted two main areas of difficulty:

• **Reduction or loss of work due to health**	*"Was [self-employed] and had to give up my job due to neurological conditions associated with Lyme disease."* *"The pain [I] have endured and tiredness in both episodes were draining. I was out of work for 4 months most recently and [I] am now on reduced hours."*
• **Challenges in the workplace**	*"Despite absolutely loving my job, my workplace, a primary school, showed discrimination towards me and I have been very badly mistreated by them in recent years"*

However, not all adult respondents reflected negatively on their experiences at work, with some mentioning more positive experiences:

> *"[I] have also been very fortunate to meet amazing friends and colleagues who do not judge me for my condition and show equal respect and care."*
>
> *"[I'm] lucky enough that my [workplace] has made adjustments for me."*

Experience with healthcare services

Adults with neurological conditions in the Republic of Ireland reported varying levels of access to healthcare services. While some services were commonly used and largely met individuals' needs, others remained difficult to access or were associated with long waiting times. A more detailed breakdown and analysis of the findings in relation to access to and waiting times for key neurological services can be found in the NAI June 2025 report: ***'The Right Care in the Right Places: Access to Services for People with Neurological Conditions Across Ireland.'***

Most and least commonly used services

Among the adult respondents, the General Practitioner (GP) was by far the most commonly used healthcare service, with 88% of individuals reporting having accessed this service in the last 12 months. This was followed by neurologists (74%) and diagnostic scans such as MRIs or CTs (62%).

By contrast, a small number of adults had accessed more specialised or intensive forms of care. Palliative care (1%), end of life care (2%), and supported living or residential care (3%) were among the least used services across the sample[3].

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[3] *It is important to note that individuals receiving end-of-life or supported living/residential care may be underrepresented in an online survey.*

Services most often reported as inaccessible

For those who considered a service relevant to their condition, certain types of care were reported as particularly difficult to access. The three services adults most frequently reported being unable to access, despite considering them relevant to their condition, were:

1. **Inpatient neurorehabilitation (73%)**
2. **Neuropsychiatry (68%)**
3. **Outpatient neurorehabilitation (67%)**

Other services where respondents reported not being able to access them included counselling, occupational therapy, and pain services. Access challenges were especially severe for individuals who struggled to cope with daily life. Among those who described their day-to-day life as regularly or consistently difficult, 82% were unable to access inpatient neurorehabilitation – the most commonly reported service adults could not access. In contrast, 67% of those who felt capable or only occasionally faced difficulties reported the same issue. This indicates that those with the greatest need may face the greatest barriers to support.

Waiting times for key services

This report highlights waiting times for key services that are particularly relevant to the needs of people with neurological conditions[4]. The proportion of adults – including carers responding on behalf of an adult – who reported waiting more than seven months for the services that were applicable to them, or who were still waiting at the time of the survey:

- Audiology: 39% waited over seven months, 39% still waiting
- Care planning: 29% waited over seven months, 45% still waiting
- Community transport: 20% waited over seven months, 53% still waiting
- Continence supports: 31% waited over seven months, 38% still waiting
- Counselling: 20% waited over seven months, 50% still waiting
- Day services: 24% waited over seven months, 59% still waiting
- Dietician: 13% waited over seven months, 51% still waiting
- GP: 36% waited over seven months, 18% still waiting
- Home adaptations: 26% waited over seven months, 52% still waiting
- Inpatient Neurorehabilitation: 14% waited over seven months, 54% still waiting
- Neurologist: 59% waited over seven months, 26% still waiting
- Neuropsychiatry: 22% waited over seven months, 65% still waiting
- Neuropsychology: 27% waited over seven months, 58% still waiting
- Neurosurgery: 18% waited over seven months, 41% still waiting
- Occupational therapy: 25% waited over 7 months, 52% still waiting
- Orthotics: 11% waited over seven months, 61% still waiting
- Outpatient neurorehabilitation: 20% waited over seven months, 69% still waiting
- Paediatrician (carers only): 0% waited over seven months, 100% still waiting
- Pain services: 22% waited over seven months, 56% still waiting
- Personal assistant: 16% waited over seven months, 66% still waiting
- Physiotherapy: 34% waited over seven months, 50% still waiting
- Respiratory services: 27% waited over seven months, 54% still waiting
- Respite care: 18% waited over seven months, 56% still waiting
- Scans (e.g. MRI, CT): 44% waited over seven months, 44% still waiting
- Social worker: 14% waited over seven months, 64% still waiting

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[4] *Please note that fewer than 30 respondents answered this question for the following services: Spinal surgery, End of Life Care, and Palliative Care. These services have therefore not been included in this analysis.*

- Specialist nurse: 22% waited over 7 months, 58% still waiting
- Speech and language therapy: 27% waited over 7 months, 47% still waiting
- Supported living/residential care: 13% waited over seven months, 58% still waiting
- Wheelchair services: 18% waited over seven months, 62% still waiting

It is important to note that for those who indicated they were still waiting, the survey did not capture how long they had been waiting at the time of response. As a result, while the proportion of individuals still waiting for care indicates a potential access issue, the total duration of their wait is unknown.

These findings suggest that for many individuals, the path to timely, appropriate care remains blocked – particularly for rehabilitative, neurologist and psychological services.

How well services met needs

Accessing a service did not always mean that people felt their needs were met. While just over one in three adults (35%) agreed that the care they received from healthcare services met their needs, 43% disagreed.

Among those who had accessed services, some adults with neurological condition(s) were more likely to be described as meeting needs. Scans (89%), wheelchair services (85%), and audiology (82%) were most commonly reported as having met people's needs *(or the needs of the individual they support)*, followed by home adaptations (79%) and neurosurgery (79%).

Other services were less likely to be described as meeting needs. Pain services were only reported to be meeting the needs of half of those who were using them. Similar proportions said the same about care planning (51%) and inpatient neurorehabilitation (59%). These reflections may stem from a range of different experiences, including delays, limited availability, or a sense that the support provided didn't feel appropriate to their situation.

Barriers to accessing treatments and appointments

When exploring the barriers that adults with neurological conditions face in accessing treatment, affordability emerged as the most commonly reported issue. Over four in ten adults (43%) disagreed that they could afford the additional costs associated with the treatment for their condition. While transport and scheduling challenges were also raised, they were mentioned less frequently, with one in four adults (25%) said they did not have reliable transportation to attend appointments, and a similar proportion (27%) reported difficulties scheduling appointments.

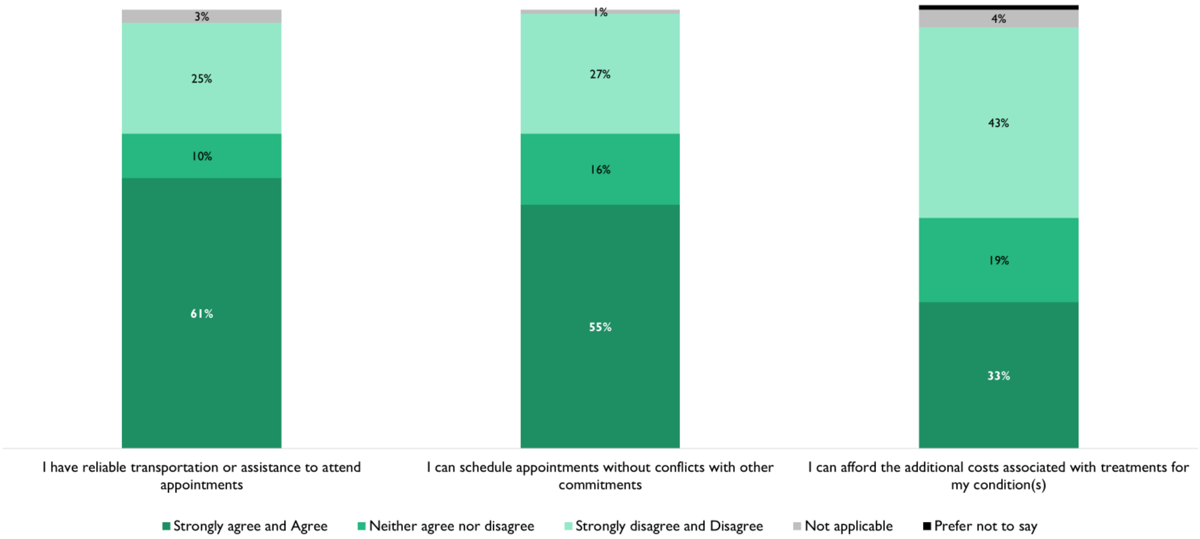
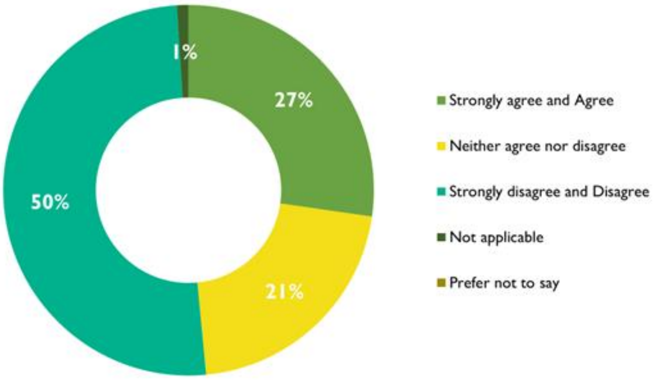


Chart: Thinking about your wider life, to what extent do you agree or disagree with the following statements regarding managing your condition(s)? (n=591)

Experiences affording treatment varied by age. Adults aged **35–44** were the most likely to report being unable to afford additional treatment costs, with **57%** saying they could manage these costs. This was followed by those aged **18–34** (48%), **55–64** (47%), and **45–54** (44%). In contrast, just over a quarter (**26%**) of those aged **65 and over** reported facing these financial challenges.

Experiences with affording treatments also varied by gender. Nearly half of all **women** surveyed (**49%**) reported struggling with the cost of treatment, compared to around a third of **men** (**32%**).

Reflections on experiences with healthcare services



Overall, adults in the sample expressed limited confidence in the healthcare system. Only **27%** agreed with the statement *"I feel supported by the health system,"* while **half (50%)** disagreed – indicating a widespread sense of disconnection or unmet need.

There were clear differences in how supported individuals felt by the healthcare system, depending on their condition. The data below highlights the proportion of adults who disagreed with the statement *"I feel supported by the health system"* – for conditions where there was a sufficient base size to report. Feelings of being unsupported were particularly high among those living with **Functional Neurological Disorder (FND)** and **Fibromyalgia**:

Individuals who felt unsupported by the healthcare system were significantly less likely to say that the care they received met their needs. While **71%** of those who *did* feel supported said their care met their needs, this dropped sharply to just **15%** among those who *did not* feel supported.

Reflections on communications with healthcare professionals

Overall, adults reported relatively positive experiences when it came to communication with healthcare professionals. **72%** said they felt comfortable communicating with healthcare staff, and **64%** were satisfied with the format of their appointments.

However, many adults also identified areas for improvement. **41%** said they did not have a consistent healthcare professional, meaning they often had to repeat information about their condition to different people. In addition, **43%** disagreed with the statement *"I am able to get follow-up appointments easily and when I need them,"* suggesting challenges in accessing ongoing care.

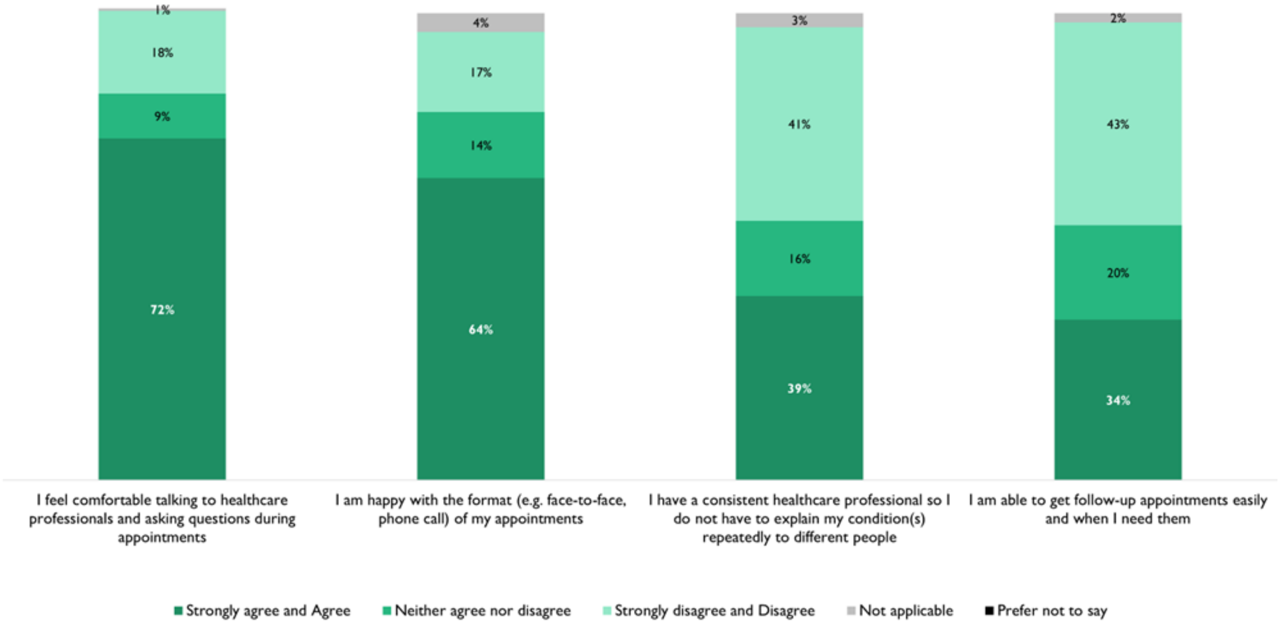


Chart: How much do you agree or disagree with the following statements? (n=591)

These issues were more common among adults with multiple neurological conditions. Only **32%** of this group reported having a consistent healthcare professional, compared with **42%** of those with a single condition. Similarly, **53%** of adults with multiple conditions said they struggled to access follow-up appointments, compared with **39%** of those with one condition.

There were also differences in how people experienced the impact of their condition depending on the consistency of their care. Among those **who did not have** a consistent healthcare professional, **44%** reported a high impact of their condition on daily life. In comparison, this was **16%** among those **who did have** a consistent healthcare professional.

In the open response question, reflections on healthcare were mixed, with some reflecting more positively on their experiences and other reflecting more negatively:

- **Positive reflections**

  "I have had excellent experience with HSE Physiotherapy services who recognised the red flags when I needed a second surgery."

  "[I'm] attending a Neuro Physio […] who has a great understanding of my condition and helped me so much"

  "Some specialists are amazing and very knowledgeable about the condition and take a holistic approach which is very comforting."

- **Negative reflections**

  "I have lots of neurological problems, I've waited years to be referred to neurologist."

  "I was discharged after three days with the statement, 'We don't know what to do with you!'-hardly comforting!"

  "I feel that the patients needs, opinions & requirements need to be listened to more & taken into consideration by all the medical service providers & the government - I feel that my life has become one long up hill battle constantly having to fight for what either myself or my partner needs."

Experience with support services

When asked about the sources of support they currently receive, adults most commonly pointed to **friends and family**, with **75%** reporting this as a source of support. Fewer adults said they received **financial support** (31%), and **1 in 5 (20%)** reported that they were **not currently receiving any support** for their neurological condition.

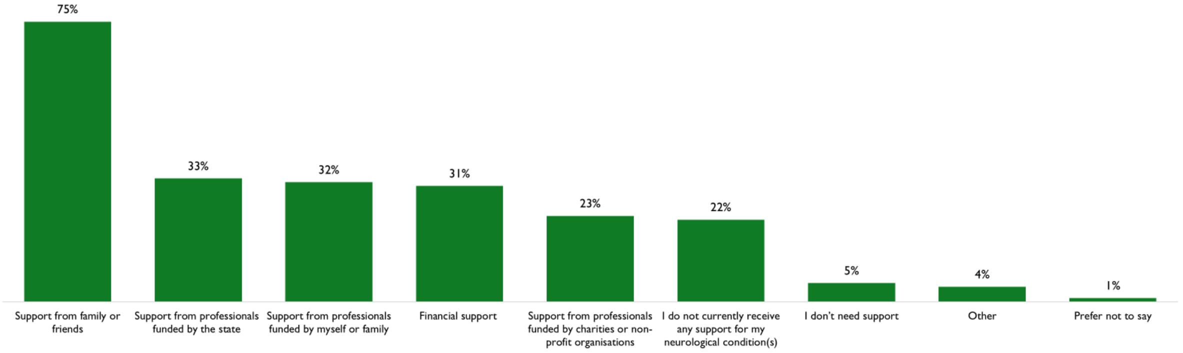


Chart: Which of the following types of support do you receive? (n=591)

A lower proportion of adults aged 18–34 reported being without support (11%), compared with older age groups, where figures ranged from 22% to 26%.

Information received

Adults in the sample reported a range of ways in which they had been offered or directed to information about their neurological condition in the last 12 months. The most common sources were **neurologists (41%)** and individuals' **own research (39%)**. Despite this, **over 1 in 5 adults (22%)** said they had **not received any information at all**.

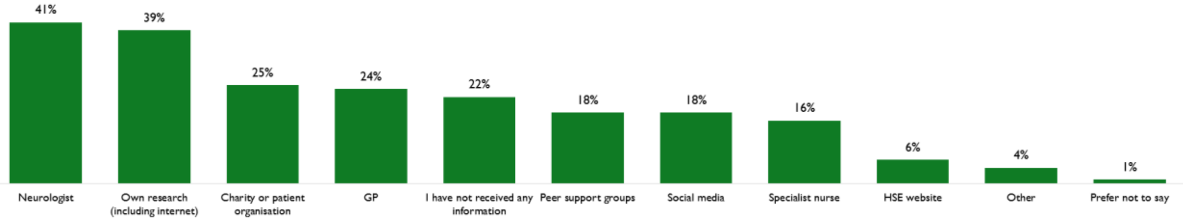


Chart: In the last 12 months, have you been offered or directed to any information about your neurological condition(s) by the following? (n=591)

Among those who had received information, the majority found it helpful. **61%** said the information they received was helpful, with **21%** describing it as *very helpful*. Just **6%** reported that the information was unhelpful, while **26%** were neutral.

There were some differences by gender: **68%** of men reported finding the information helpful, compared with **58%** of women.

Barriers to receiving support

Survey respondents were asked: *"If you haven't received the support you need, what are the main reasons why?"* The most common barrier reported was a **lack of awareness**, with just over **1 in 4 (26%)** saying they were **not aware of the support available**. In contrast, **financial barriers were less frequently selected**, with only **15%** selecting *"I could not afford support"* as a reason.

These barriers were more pronounced among adults who said they were **not currently receiving any support**:

- 42% of this group said they were not aware of available support, compared to 26% of the full sample
- 29% said they did not know how to access support, compared to 20% of the total sample
- 27% reported that they had asked for support but had not received any

These findings suggest that, for many adults, the gap in support may stem more from a **lack of accessible information and clear pathways to access**, rather than affordability.

As with reflections on healthcare, reflections on experiences with support services were also mixed:

- **Positive reflections** *“Charity organisations are sensational at providing support and advice.”*

- **Negative reflections** *“There is no support from the medical community, so I'm sorry I can't tell you more about supports.”*

  “I have only recently been diagnosed with […] so it is all very new to me but just feel like [I] was sent home with not enough information or support from healthcare professionals.”

  “There is no support from the Government.”

Chapter 2: Understanding the lives of children with neurological conditions

About the children and young people and their condition(s)

This section provides an overview of the key demographics of the children and young people included in the survey, which comprises both children who completed the child survey and carers who responded on behalf of a child. Please note that throughout this chapter, sub-group analysis is not possible due to small base sizes. In total, 26 children responded to the survey on their own, and 27 carers responded on behalf of a child.

[HOLD: summary infographic of key demographics children self-reporting (gender/age/ethnicity/region)]

[HOLD: summary infographic of key demographics of the children where a carer has answers on their behalf]

Background to condition(s) of the children in the sample

The survey captured responses from or on behalf of children and young people living with a wide range of neurological conditions – reaching the perspectives of **27 different conditions**.

The five most commonly reported conditions were:

- **Epilepsy** (25)
- **Autism** (10)
- **Acquired Brain Injury** (5)
- **Functional Neurological Disorder (FND)** (3)
- **Hydrocephalus** (3)

Among children who self-reported (n=26), the duration of their condition varied:

- **3** said they had lived with their condition for their whole life
- **10** reported having had it for **more than a year**
- **9** said they had had it for **around a year**
- **4** reported that their condition had developed **in the past few months**

Impact of their neurological condition(s)

Impact on health

Children and young people who completed the survey themselves most frequently reported that their condition affected **how they think and learn** (16 out of 26), **sleep and energy levels** (16), and **how they move around** (14). These were the most commonly selected impacts across the six areas of health assessed in the survey.

Carers responding on behalf of children also highlighted a wide range of impacts. Among the 27 carers, the most frequently reported areas of impact were*:

- **Mood and mental health** (25 out of 27 carers)
- **Sleep** (24)
- **Thinking and memory** (22)

**Please note, these figures reflect the number of carers who indicated that their child's condition impacted their health to some degree – whether a little, somewhat, quite a lot, or very much.*

How children feel as a result of their condition(s)

Children were asked how their health made them feel. Among the 26 children who responded:

- 15 said their health made them feel scared about the future
- 14 said it made them feel frustrated and angry, and the same number said it made them feel worried and stressed
- 11 reported feeling proud of myself for how I handle it

Experience with healthcare services

Most children in the sample had accessed healthcare services in the past year. Of the 26 children who self-reported, **24** said they had accessed healthcare in some form, with **7** reporting that they had seen a healthcare professional **more than 10 times** during that period.

Carers also reported on the types of services their children had used. The most commonly accessed services were:

- **GPs** (26 out of 27 carers)
- **Neurologists** (21)
- **Scans** (16)
- **Paediatricians** (16)
- **Occupational therapy** (15)

In contrast, there were a few services that no carers reported their child had accessed:

- **Personal assistant support** (0 out of 27)
- **Palliative care** (0)
- **End of life care** (0)

Carers were also asked which services they had **been unable to access** on behalf of the child. The most commonly reported were:

- **Counselling** (12 carers)
- **Home adaptations** (10)
- **Care planning** (10)

Reflections on experiences with healthcare services

Children were asked to reflect on their overall experiences with healthcare services, including how supported and understood they felt during appointments.

Among the 26 children who responded:

- **17** said they felt they needed **more support** from healthcare professionals.
- **12** reported feeling **mostly scared or nervous** before appointments.
- Only **9** said they felt **comfortable asking questions** to their doctor or healthcare professional.

Understanding and communication were also raised as areas for improvement. Just under half of the children – **12 out of 26** – agreed that healthcare professionals used words they could understand, and that they understood what was happening with their health.

Some children who provided responses on the open response question similarly reflected on areas for improvement. For example, one child described:

> *"Speak in terms and language that I understand. Show empathy"*

These responses suggest that while many children are engaging with healthcare services, there is room to strengthen how support, comfort, and communication are delivered in these interactions.

Carer's reflections

Carers were asked to reflect on whether the healthcare system – including both clinical and support services – was meeting the needs of the children they care for. Responses indicated mixed levels of satisfaction, with particular concerns raised around government-provided support and mental health services.

- **18 out of 27** carers said that **government-provided personal and support services** did **not meet the needs** of the child they support.
- **18 carers** also felt that **mental health services** were **not adequately meeting their child's needs**.

Views on care from **medical and healthcare services** were more evenly divided:

- **12 carers** agreed that the care provided by these services **met their child's needs**
- **11 carers** disagreed

Experience with support services

Children were asked whether they were receiving support from sources outside their home, and if so, where that support was coming from.

The most frequently reported source of external support was specialist doctors, nurses, or allied health professionals, with 10 out of 26 children selecting this response. The second most common source of support was school, specifically for schoolwork, with 7 children indicating this as a form of support.

However, 7 children reported not receiving any support from outside their home.

Chapter 3: Understanding the lives of carers and their experiences of caring

About the carers

Relationship to the person they care for and background to their caring responsibilities

The majority of carers in the sample were **family members** of the individuals they support. Specifically:

- **41%** reported being the **parent/guardian** of the person they care for
- **40%** reported being the **spouse/partner**
- **10%** reported being the **child**
- **7%** were another **family member**

Main carer or shared role:

The majority of carers reported being the primary individual responsible for supporting the person that they care for. The following breakdown highlights the extent to which carers are primarily or jointly responsible for the care of the person they support:

- **69%** of the sample identified as the **main carer** for the person they care for
- **20%** reported sharing the main caring role with someone else
- **10%** reported helping, but someone else was the main carer

Caring hours and long-term commitment

Carers were asked how many hours per week they spent caring for the person they support. Over **half of the sample** reported that they spend **50 or more hours per week** providing care. This highlights the substantial and ongoing commitment that many carers were making in the sample.

In addition, **20% of carers** reported supporting **more than one person**, further emphasizing the broad scope of caregiving responsibilities some individuals manage.

When asked how long they had been in their caregiving role, the most common response was **1-5 years**, with **51%** of carers selecting this option. However, a significant portion of carers had been providing care for much longer, with **26%** reporting they had been caring for over **10 years**. This suggests that for many, caregiving is a long-term commitment that requires sustained effort and dedication.

Intensity of care

The level of dependence of the person being cared for is a crucial factor in understanding the demands placed on carers. According to the survey, **92%** of carers reported that the person they care for relies on them to some degree[5] for assistance with daily activities.

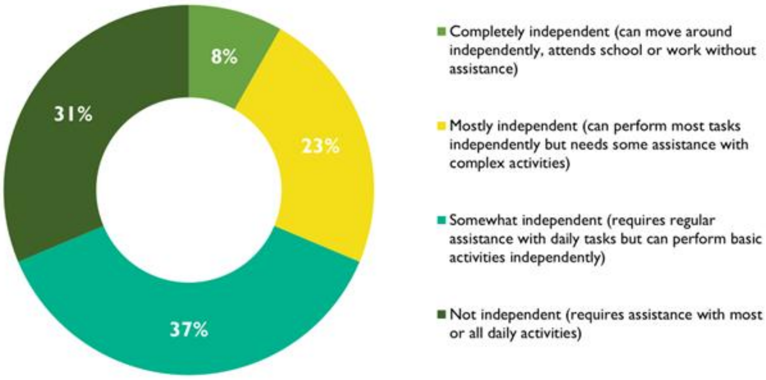


Chart: How independent would you say the person you care for is in their daily activities without your assistance? (n=134)

31% of carers stated that the individual they support is **not independent** and requires assistance with **most or all daily activities**. This points to the high level of support required by a significant proportion of the carers in the sample. Meanwhile, **37%** of carers reported that the person they care for is **somewhat independent**, still requiring regular assistance with daily tasks but able to perform basic activities on their own.

Carer’s experiences

This section explores the challenges and experiences faced by carers who provide support to individuals with neurological conditions. It examines the ability of carers to meet the needs of those they support, the impact caregiving has on their own health and wellbeing, and the effects on their confidence, work, and financial stability. Additionally, it highlights the barriers to providing care and the support available to carers in these demanding roles.

Carers’ ability to meet the needs of those they care for

Carers were asked about the types of care they provide to those they support. **Emotional care** was the most commonly reported form of support, with **91%** of carers selecting this option. **Financial care** followed, with **71%** of carers reporting they provide this type of support, and **66%** providing **physical care**.

Despite the challenges of daily life, many carers expressed confidence in their ability to meet the needs of the individuals they support. Specifically:

- **75%** of carers agreed they could meet the **day-to-day needs** of the person they care for
- **67%** agreed they were able to meet the **health and wellbeing needs** of the person they support

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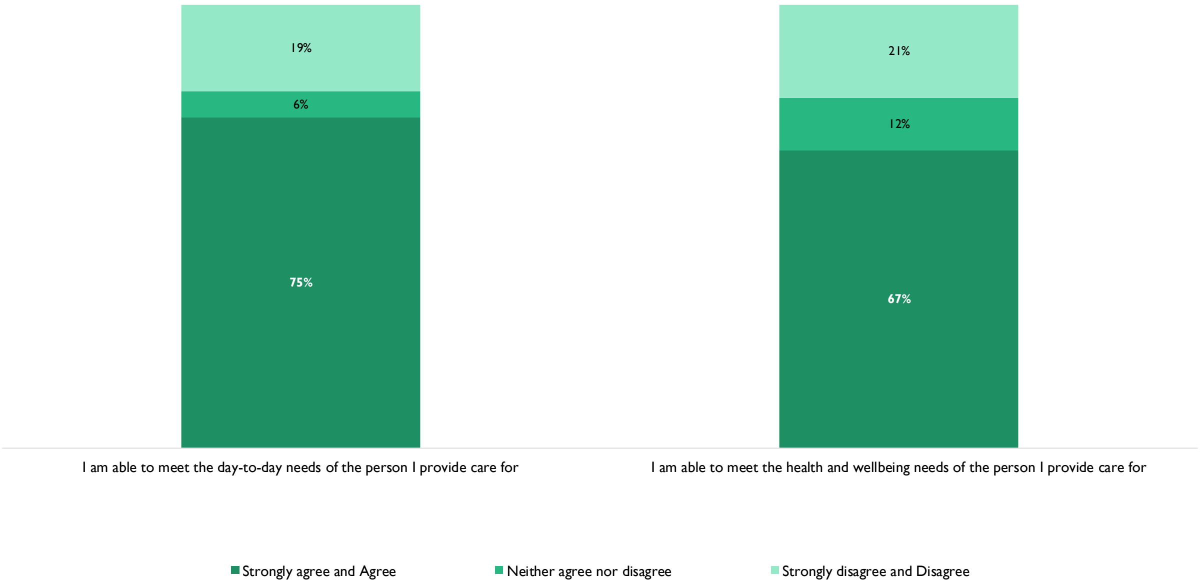
[5] This is based on the proportion of carers that selected that the person they care for is ‘Not independent (requires assistance with most or all daily activities)’, ‘Somewhat independent (requires regular assistance with daily tasks but can perform basic activities independently)’, or ‘Mostly independent (can perform most tasks independently but needs some assistance with complex activities)’



Managing their own health and wellbeing

While many carers expressed confidence in their ability to meet the needs of the individuals they care for, managing their own health and wellbeing proved to be a greater challenge. **51%** of carers reported that they could manage their **own day-to-day needs**, but **33%** disagreed with this, indicating a significant struggle to balance personal and caregiving responsibilities.

Carers who also had their own **long-term condition** were particularly challenged in managing their own needs. Only **43%** of those with a long-term condition felt they could manage their day-to-day needs, compared to **61%** of those without a long-term condition. This highlights the compounded difficulty faced by carers who are also managing their own health issues while providing intensive care to others.

More than half (**51%**) of carers said they **sometimes find day-to-day life challenging**, while **27%** said they **regularly find it challenging**. Only **10%** of carers reported feeling **confident and capable** in managing their day-to-day lives.

In the survey, carers were given the opportunity to reflect on their experiences of caring for someone with a neurological condition(s). Some reflected on the emotional and physical strain of caring:

> *“Just for me as a partner. Everyday is different […], myself [I] feel drained and have found that [I’m] getting bad anxiety attacks after my partners last seizure.*
>
> *“As my child get older, his behaviour is getting increasingly difficult to deal with and can be very draining especially on school holidays”*
>
> *“All [I] see in the future is worry.”*

These challenges indicate that while carers prioritise the needs of those they support, their own wellbeing may often be taking a back seat, and a significant proportion report struggling to manage their personal and caregiving responsibilities simultaneously.

93% of carers reported that **lack of access to healthcare professionals** affected their ability to provide care, either *a little*, *somewhat*, *quite a lot*, or *very much*. Similarly, **83%** indicated that **financial constraints** also impacted their caregiving experience.

Additionally, **79%** of carers said that a **lack of knowledge or training** in managing specific neurological conditions was a barrier to providing optimal care. On the other hand, **educational commitments (38%)** and **working full time (53%)** were less commonly identified as barriers.

Impact of caring on work and financial stability

Carers' responsibilities also had a profound effect on their work and financial stability. More than half of carers (**59%**) reported that they had **cut back on other expenses**, while **59%** also indicated that they had **reduced their work hours** or **left their job entirely** due to caregiving responsibilities.

Carers of children were particularly affected in this regard, with **78%** of them saying they had to reduce work hours or leave their job entirely, compared to **52%** of carers of adults.

Financial instability also emerged as a key issue. **Only 9%** of carers reported being able to **advance in their careers**, with **62%** disagreeing with the statement *"I am able to advance in my career."*

Barriers to providing care

Carers most frequently reported that **lack of access to healthcare professionals** affected their ability to provide care, with **93%** of carers selecting this as a barrier. **Financial constraints** followed closely, with **83%** of carers agreeing that financial limitations impacted their caregiving. **79%** of carers also cited a **lack of knowledge or training** in managing the specific neurological condition(s) they were supporting as a significant challenge.

Less frequently reported barriers included **educational commitments (38%)** and **working full time (53%)**, but these still presented challenges for a portion of the sample.

Support for carers

Despite the importance of their role, **less than 2 in 10 carers (19%)** reported feeling **supported** in their caregiving role. The majority (**64%**) disagreed with the statement *"I feel supported in my caring role."*

When asked about support services, carers reported significant difficulty accessing services that were relevant to their needs:

- **73%** of carers were unable to access **mental health and wellbeing support**
- **70%** struggled to access **transport services** for appointments and activities
- **63%** reported being unable to access **respite care**

Interestingly, carers who found **day-to-day life challenging** were particularly affected by the lack of **respite care** – **48%** reported being unable to access this service, compared to **29%** of those who felt **confident and capable** in their day-to-day life.

When it came to services that did meet their needs, carers identified **equipment and home adaptations** as the most successful. **70%** of those who accessed these services felt they met their needs.

In contrast, **financial support** was the least helpful service, with only **42%** of carers reporting that the financial support they received met their needs. This was reflected in some of the open responses in the survey, too – one carer, for example, described their experience as follows:

> *"Disappointed that our country only offers benefit for two years before means testing. Then I am means tested from which I then did not qualify. It demeans my contribution as a carer."*

Chapter 4: Mental Health

Prevalence of mental health across the adults' sample

Mental health conditions were commonly reported among adults living with neurological conditions. Approximately **1 in 3 adults** (32%) in the sample reported having a diagnosed mental health condition.

Additionally, **mood and mental health issues** were a prevalent effect of neurological condition(s), with **84% of adults** indicating that their neurological condition(s) impacted their mood and mental health to some degree. This includes responses of "a little," "somewhat," "quite a lot," and "very much."

Notably, individuals with a diagnosed mental health condition were more likely to report that their neurological condition 'very much' affected their mood and mental health compared to those without a diagnosed mental health condition. Specifically, **40%** of those with a mental health condition reported a "very much" impact, compared to just **14%** of those without one.

In the survey open response question, some adults reflected on the impact of their condition(s) on their mental health:

> *"When I was diagnosed, my mental health took a dive, and my symptoms exacerbated."*
>
> *"With grade 3 astrocytoma the main impact has been mental health by far"*

Additionally, adults from lower income households more frequently reported that their neurological condition impacted their **mood and mental health** 'quite a lot' or 'very much,' though this finding was not statistically significant. The distribution by household income was as follows:

- **Less than €20,000**: 45%
- **€20,000 - €34,999**: 41%
- **€35,000 - €49,999**: 32%
- **€50,000 - €74,999**: 36%
- **€75,000 - €99,999**: 28%
- **€100,000 or more**: 31%

Adults' overall experiences with mental health services

Adults with neurological conditions expressed mixed experiences with mental health services.

Less than half of adults (48%) agreed that they had someone to talk to about their mental health and wellbeing. A quarter of respondents (26%) reported that they did not feel comfortable raising or discussing their mental health with their healthcare professional.

Among those who considered mental health services relevant, half (50%) reported that these services did not meet their needs. Furthermore, compared to medical and healthcare services, adults were less likely to perceive any improvement in mental health services over the past year. Only **17%** of respondents agreed that their care in mental health services had improved since the previous year, compared to **27%** of those who reported improvement in medical and healthcare services.

Adults with multiple neurological conditions, as well as those with a diagnosed mental health condition, were more likely to report that mental health services were not meeting their needs. Specifically, **58%** of those with multiple conditions disagreed that mental health services met their needs, compared to **46%** of those with only one condition. Similarly, **59%** of adults with a mental health condition disagreed that mental health services met their needs, compared to **45%** of those without a mental health condition.

Adults' experiences with counselling

Counselling services were considered relevant to just over half of the adults with neurological conditions in the sample, with **52%** of adults reported that counselling was relevant to them. Of this group, however, **43%** reported that they had been unable to access counselling services.

For those who had accessed counselling, **66%** reported that it met their needs (or the needs of the person they cared for), while **34%** stated that the service had not met their needs.

Among those who stated that counselling services had not meet their needs, a higher proportion reported that their condition(s) had a high impact on their daily life[6], with this group also being more likely to report finding daily life challenging. **58%** of those that had received counselling and felt that it had met their needs reported they felt confident and capable in their daily life or only sometimes finding day-to-day life challenging, compared to just **23%** of those that had received counselling and reported that it had not met their needs, and **34%** of those that had not been able to access counselling services. Similarly, **63%** of those who felt counselling had not meet their needs reported a high impact on their daily life, compared to just **30%** of those who felt counselling met their needs.

In the open response question, some respondents described difficulties accessing counselling:

> *"I am also paying for counselling as I am on a waiting list and it could take 15-18 months."*
>
> *"I was never offered counselling or any kind of support after my diagnosis"*
>
> *"I was told over a year ago by a neurologist that cognitive behaviour therapy might help. Although I am still waiting for psychology/counselling for this"*

However, some respondents who had accessed counselling reflected positively on the treatment they had received. For example, one respondent expressed that they found counselling helpful, but would have liked more of it:

> *"HSE funded counselling through GP was very helpful but not long enough (max 12 sessions)"*

Mood and mental health issues in the children's sample

Mood and mental health challenges were also commonly reported as an impact of neurological conditions among children in the sample.

- **25 out of 27 carers** reported on behalf of the child they support that their neurological condition(s) impacts on their mood and mental health to some degree.
- **12 out of 26 children** self-reported that their condition(s) affected their mood.

Additionally, when asked about how their health makes them feel, only **2 children** reported feeling "hopeful about the future," with **15 children** reporting feeling "scared about the future."

Children's experiences with mental health services and counselling

Support from Child and Adolescent Mental Health Services (CAMHS) was the second least frequently reported support received outside the home, with only **3 out of 26 children** self-reporting having received support from CAMHS.

Carers of children also often reported that mental health services and counselling were not meeting the needs of the child they support. Among those who considered mental health services relevant, only **2 out of 24 carers** reported that the care received from mental health services met the child's needs.

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[6] For an explanation of how this variable was coded, please refer to the explanation in *Chapter 1: Understanding the lives of adults with neurological conditions*, under subheading '*Impact of neurological condition(s)*'.

Chapter 5: Involvement in decision-making

Adults' reflections on their involvement with decision-making

In general, adults with neurological conditions reported being involved in the decision-making process regarding their condition and treatment. **57%** of adults agreed that they felt involved in decisions about their treatment, care, and support plan. Additionally, **67%** of adults reported understanding their condition(s) and the treatment options available to them.

Men were more likely to agree with both statements: **66%** of men agreed that they felt involved in decisions, compared to **55%** of women. Similarly, **74%** of men agreed that they understood their condition and treatment options, compared to **65%** of women.

Adults with higher household incomes were also more likely to report understanding their condition and treatment options. The breakdown by income is as follows:

- **73%** of those with an income of €100,000+ agreed
- **74%** of those with an income of €75,000-€99,999 agreed
- **70%** of those with an income of €50,000-€74,999 agreed
- **65%** of those with an income of €35,000-€49,999 agreed
- **64%** of those with an income of €20,000-€34,999 agreed
- **57%** of those with an income of less than €20,000 agreed

In general, adults who felt involved in their healthcare decisions were also more likely to report higher levels of satisfaction with their healthcare experience. **54%** of those who felt involved in decisions about their treatment, care, and support plan reported being happy with their healthcare in the last 12 months, compared to only **7%** of those who did not feel involved in these decisions.

Carers' involvement in decision-making for the adults they support

The majority of carers of adults in the sample reported being closely involved in decision-making regarding the person they care for. **51%** of carers stated they were fully involved in all decision-making, while **39%** reported being involved in most decisions, with the person they care for making the final choice. **8%** of carers indicated they were involved in some decisions, but others were made by the person they care for or other professionals. Only **1%** of carers reported that they were not involved in any decisions about the person they care for.

Children's feeling of involvement in decisions about their health

More children in the sample reported feeling involved in decision-making about their health than not. **12 children** disagreed with the statement that they do not always feel involved in decisions about their health, while only **7 children** agreed with this statement.

Carers' role in decisions for the children they support

Most carers of children in the sample reported being fully involved in all decision-making for the child they care for, with **21 out of 27 carers** reporting this. Additionally, **5 carers** reported being involved in most decisions, but the child they care for makes the final choices, and **1 carer** stated they make some decisions, but others are made by the child or other professionals.

Chapter 6: Financial support

Adults' experiences with finances

1 in 5 adults (18%) in the sample reported that their condition(s) **"very much"** impacted their ability to manage financially.

This issue was more pronounced among individuals with multiple conditions, with **30%** of those with multiple conditions reporting their neurological condition **"very much"** impacted their financial management, compared to **13%** of those with just one condition.

Additionally, adults who reported multiple impacts on day-to-day life from their condition(s) were significantly more likely to also report difficulties with work or study. For instance, **73%** of adults who reported a **high impact** on daily life also reported having stopped working due to their neurological condition. In comparison, **51%** of those reporting a **medium impact** on daily life, and **19%** of those reporting a **low impact** on daily life, agreed that they had to stop working due to their condition.[7]

Over **4 in 10 adults (46%)** disagreed that they could afford the additional costs associated with their treatment, indicating a substantial financial burden of neurological condition(s) for almost half of the sample.

Financial support

Around **1 in 3 adults (36%)** with neurological conditions reported receiving financial support. Those who received financial support were more likely to report that their neurological condition(s) significantly affected their ability to manage financially. Specifically, 28% of individuals receiving financial support indicated that their condition(s) "very much" impacts their ability to manage financially, compared to only 13% of those not receiving financial support.

Individuals with lower incomes were more likely to report receiving financial support.

Additionally, around **1 in 3 adults** reported self-funding support from professionals, either using their own resources or assistance from family members. This group was more likely to report earning a higher income.

In the survey, some adults reflected on financial difficulties related to their condition(s), and felt that financial support was limited, difficult to access, or not meeting their needs:

> *"After reducing my work hours considerably due to the condition, my income has reduced significantly, however the financial supports are limited (of the ones I'm aware of) , more support in this area would be welcomed."*
>
> *"We have zero social life or disposable income - we cannot afford to do anything 'extra'. We are in financial crisis; outgoings exceed income: […] cost for prescription medications/supplements not covered by GMS/LTI"*
>
> *"Financial insecurity and housing insecurity for people with disabilities is something the Irish government put further supports into to ensure people who are disabled an unable to earn an income can actual live, access services/amenities and communities as well as making [access] to medical services more functional."*
>
> *"I also had to go back to work with 3 months left of chemo because I had used up my sick pay, and I didn't qualify for social welfare or any other support."*

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[7] For an explanation of how this variable was coded, please refer to the explanation in *Chapter 1: Understanding the lives of adults with neurological conditions*, under subheading '*Impact of neurological condition(s)*'.

Chapter 7: Children's transition to adults' care

Among the **12 children and young people aged 14 to 17** who responded to the survey, **9** reported that they had not received any information about moving to adult care.

Of these 9 children who had not received information, **3** expressed a desire to know more about the transition process, while **4** were unsure of where to obtain this information.

Chapter 8: Access and confidence to participate in research

Adults’ access and confidence to participate in research

The majority (72%) of **adults with neurological conditions** in the sample expressed interest in participating in research related to their condition(s). However, despite this high level of interest, only **1 in 3** (33%) of these adults had already participated in research. Overall, **29%** of adults reported having already taken part in research, indicating a gap between interest and actual involvement.

Children’s access and confidence to participate in research

Among the **children with neurological conditions** in the sample, **12 out of 26** expressed interest in participating in research related to their condition(s). However, only **3 children** reported having already taken part in research.

Of the children who had already taken part in research, **2 out of these 3 children** indicated that they were not interested in participating in any further research.

Conclusion

This report presents the findings of the 2024/25 My Neuro Survey – the first national initiative of its kind to gather large-scale, detailed insights into the lives of people living with neurological conditions in the Republic of Ireland, as well as those who care for them. Commissioned by the Neurological Alliance of Ireland and delivered in collaboration with Revealing Reality, this research was designed to address a critical evidence gap. Despite the growing number of people living with neurological conditions and the complexity of their needs, very little robust, person-centred data has existed to reflect their experiences. This research was developed to change that – capturing not just clinical and service-based outcomes, but also the wider social, emotional, financial, and day-to-day realities of life with a neurological condition.

Through over 860 responses – from adults, children and young people, and carers – this work provides a comprehensive and often sobering picture of the current landscape. The findings highlight a system that is struggling to deliver timely, appropriate, and effective support. Many respondents describe significant delays in receiving a diagnosis, long waits for essential services, and a lack of access to vital supports such as neurorehabilitation, mental health care, and specialist therapies. Even where services are accessed, they do not always meet individual needs, and communication with healthcare professionals can be inconsistent.

Financial pressure is a recurring theme across the sample. Many respondents – both those living with neurological conditions and those providing care – report having to reduce or leave paid employment. A substantial number say they are unable to afford the additional costs associated with treatment and support, with some forgoing essential care as a result. While financial support is available in some cases, it is not always sufficient or accessible, and gaps remain in how individuals are guided through systems of support.

Carers play a vital but often under-recognised role in sustaining the wellbeing of people with neurological conditions. This research shows clearly the intensity of that role – with many carers providing high levels of unpaid care for 50 or more hours per week. Despite their crucial contribution, most do not feel supported in their role. Many report deteriorating health and wellbeing, challenges with employment and financial stability, and barriers to accessing respite, training, or emotional support. These findings raise urgent questions about how carers are recognised and resourced within the broader system of care.

Mental health also emerged as a key area of concern. A significant proportion of adults and children report that their neurological condition affects their mood, confidence, and emotional wellbeing – yet access to appropriate mental health support is limited. Among those who could access counselling or mental health services, many felt these did not meet their needs. This points to a broader challenge: integrating mental health care as a core component of neurological care, rather than treating it as an add-on.

Despite these challenges, the report also shows clear signals of strength, agency, and engagement among people with neurological conditions. Many express a desire to be more involved in decisions about their care, to access better information, and to participate in research. Their experiences and reflections show how much more could be achieved with services that are genuinely person-centred, coordinated, and responsive to individual needs.

Taken together, these findings present a strong case for action. They demonstrate the need to redesign and resource services to ensure they are accessible, inclusive, and built around the lived experiences of those who use them. Policymakers, service providers, and advocacy organisations now have a valuable evidence base to inform their efforts – and a clear mandate to act. At the heart of this report is a simple but urgent message: that the voices of people with neurological conditions and their carers must be central to shaping the future of neurological care in Ireland.

Appendix

Appendix 1: Total number of responses received by condition, from adults affected by neurological conditions and carers responding on their behalf

Epilepsy	126
Migraine	90
Functional Neurological Disorder (FND)	89
Multiple Sclerosis (MS)	84
Parkinson's Disease	83
Dystonia	68
Fibromyalgia	50
Acquired Brain Injury	36
Chronic Headache	27
Stroke / Tia	24
Awaiting diagnosis	21
Brain Tumour	19
Restless Legs Syndrome (Rls)	19
Autism	17
Peripheral Neuropathy	17
Essential Tremor	16
Long Covid Related Neurological Symptoms	16
Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS)	16
Progressive Supranuclear Palsy (PSP)	11
Cluster Headache	10
Dementia	10
Poliomyelitis/Post-Polio Syndrome	9
Carpal Tunnel Syndrome	8
Brain Aneurysm	7
Cavernoma	6
Motor Neurone Disease (MND)	6
Spondylosis	6
Alzheimer’s Disease	5
Ataxia	5
Charcot-Marie-Tooth Disease	5
Chiari Malformation	5
Multiple System Atrophy (MSA)	5
Corticobasal Degeneration (CBD)	4
Hydrocephalus	4
Acoustic Neuroma	3
Encephalitis/Autoimmune Encephalitis	3
Myasthenia	3
Pernicious Anemia	3
Spina Bifida	3

Autoimmune Encephalitis	2
Dravet Syndrome	2
Huntington's Disease	2
Idiopathic Intracranial Hypertension	2
Meningitis	2
Muscular Dystrophy	2
Spinal Tumour	2
Chronic Inflammatory Demyelinating Polyneuropathy	1
Cerebrospinal Fluid (CSF) Leak	1
Familial Dysautonomia	1
Guillain-Barre Syndrome	1
Hemifacial Spasm	1
Neurofibromatosis	1
Neuromyelitis Optica	1
Periodic Limb Movement Disorder Of Sleep (Plmd)	1
Ring 20	1
Vasculitis	1

Appendix 2: Total number of responses received by condition, from children and young people affected by neurological conditions and carers responding on their behalf

Epilepsy	25
Autism	10
Acquired Brain Injury	5
Functional Neurological Disorder	5
Hydrocephalus	3
Autoimmune Encephalitis	2
Cerebral palsy	2
Meningitis	2
Muscular Dystrophy	2
Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS)	2
Tourette syndrome	2
Ataxia	1
Brain tumour	1
Chiari Malformation	1
Chronic Headache	1
Dystonia	1
Encephalitis / Autoimmune encephalitis	1
Essential Tremor	1
Fibromyalgia	1
Lennox Gasteut Syndrome	1
Multiple Sclerosis (MS)	1
Restless Legs Syndrome (Rls)	1
Spina Bifida	1
Spinal muscular atrophy	1