My Neuro Survey

2024-25 research findings report

Research

REVEALING REALITY

THE NEUROLOGICAL ALLIANCE
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Foreword

At least one in six of us across the UK lives with a neurological condition. That means every community, every workplace, every school and hospital includes people whose lives are shaped—every day—by symptoms like fatigue, pain, mobility challenges, memory loss, or seizures. Yet despite the scale of need, people affected by neurological conditions too often face long waits, poor coordination of care, and difficulty accessing the very services that are meant to help.

This report, based on over 10,000 voices, offers a powerful insight into what it means to live with a neurological condition in the UK today. The results are clear. People often wait years for a diagnosis and many report feeling left out of conversations about their care. Friends and family (also known as 'Carers') — many of them providing 50 hours or more of unpaid support each week — report feeling exhausted and overlooked. Mental health support is often out of reach. And for those who rely on multiple services, the system can feel fragmented and impossible to navigate.

As one person told us:

"I have been completely abandoned by NHS neurology for over 12 years."

It's a heartbreaking reminder that for too many, the system simply isn't working.

But there is also hope. Hope in the thousands who took the time to share their experiences. Hope in the commitment from our member organisations, from clinicians, and from policymakers who want to bring about much needed improvements to treatment, care and support. And hope in the possibility that by truly listening to what people have told us, we can build a health and care system that works—for everyone.

The survey's findings are a call to action. We must close the gap between the reality of services today and the support people need to live full and meaningful lives. That means supporting the neuro workforce, ensuring timely access to diagnosis and treatment, and recognising the vital role of unpaid carers. It means making mental health support accessible. And it means working in partnership with the voluntary sector to build a system that listens, responds, and adapts.

To every person who completed the survey: thank you. Your voice matters, and it will drive our shared mission to improve treatment, care, and support. To our member organisations and supporters across the UK: we are grateful for your continued dedication. Together, we will keep working until no one affected by a neurological condition feels forgotten or left behind.

Neurological Alliance of Scotland

Northern Ireland Neurological Charities Alliance

Georgina Carr, CEO, The Neurological Alliance of England

Wales Neurological Alliance

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Executive Summary

My Neuro Survey 2024/25 is the largest patient experience survey of people affected by neurological conditions across the UK. With over 10,000 responses from adults, children, and carers, this report offers insights into the challenges faced by those affected by neurological conditions and the individuals who support them.

The research had 3 main objectives:

1. Capture the experiences of those affected by neurological condition(s)
2. Be accessible and inclusive
3. Support advocacy, influencing, and service improvement

The findings highlight significant gaps in healthcare services, support systems, and mental health care for people affected by neurological conditions, while also identifying key areas where improvements can be made.

Diagnosis and access to healthcare

A significant proportion of adults affected by neurological conditions reported long delays in receiving a diagnosis, with over 1 in 5 waiting more than 5 years. Additionally, many individuals face inconsistent access to essential services such as neuropsychiatry, neurorehabilitation, and pain management. Only 1 in 3 adults affected by neurological conditions and their carers felt that the healthcare services they accessed met their needs, pointing to a gap in care and service delivery.

Impact on daily life

Neurological conditions significantly impact day-to-day life. Fatigue, mobility challenges, and mental health issues were the most commonly reported difficulties, affecting the majority of adults in the sample. Nearly half of adults reported having to stop working due to their condition, and 38% struggle with the costs associated with their condition. These challenges underline the profound effect that neurological conditions have on both personal and professional lives, exacerbating financial and emotional burdens.

The experience of children affected by neurological conditions

Children and young people affected by neurological conditions face substantial challenges, particularly around learning, mood, and socialising. Many reported feeling scared or nervous about healthcare appointments, indicating a need for more age-appropriate support and communication. Carers of children also face barriers to accessing mental health services and government-provided support, hindering their ability to provide effective care.

The experience of those caring for individuals affected by neurological conditions

Carers of individuals affected by neurological conditions face significant emotional and financial strain. Over 59% of carers reported that they had to reduce their work hours or leave their job entirely to accommodate caregiving responsibilities. Many carers spend 50 or more hours a week providing care and report limited mental health support.

Carers also highlighted gaps in support services, particularly in respite care and mental health support. While some services (such as equipment and home adaptations) were reported as meeting needs, many carers feel unsupported in their roles, underscoring the need for better access to services that can alleviate caregiving burdens.

Support services and gaps

Access to essential support services remains a major barrier across all groups. Mental health support, respite care, and financial assistance were often reported as inaccessible, and many carers feel they do not receive the support they need. This highlights a critical gap in the healthcare system, where individuals and carers struggle to access adequate care and support.

However, some services, such as home adaptations and specialist equipment, were reported as meeting needs by those who could access them. These findings highlight the need for a more coordinated approach to healthcare and support services to better serve people affected by neurological conditions and their carers.

Overall, this research reveals various support services are often failing to meet the diverse and complex needs of individuals living with neurological conditions. Gaps in diagnosis, mental health support, and access to care present significant challenges for both individuals and their carers. Addressing these gaps will ensure that individuals affected by neurological conditions and their carers receive the support they require, improving their quality of life and access to essential care.

Introduction

Context and background

Context and background to the research

In the UK, at least 1 in 6 people live with a neurological condition[1], affecting millions of lives across the country. For many individuals, these conditions often bring significant physical, emotional, and mental health challenges, as well as financial burdens and a need for specialist care. Access to the right treatment, care, and support is essential to improving the quality of life for people affected by neurological conditions and those closest to them, while also supporting them to manage their conditions effectively. However, many face considerable barriers, such as delays in diagnosis, a lack of sufficient care, and inadequate emotional and mental health support.

Understanding the experiences of those affected by neurological conditions is critical for identifying gaps in care and service provision. This research aims to increase understanding of the lives of those affected by providing a platform for their voices and aiming to capture insights into the challenges faced in managing neurological conditions. By capturing these experiences, the survey highlights the need for improvements in healthcare and support services, ensuring they are designed to meet the unique and varying needs of people affected by neurological conditions.

Additionally, this research aims to understand the experiences of those caring for or supporting someone with a neurological condition. Carers play a vital role in providing daily support, often facing challenges such as balancing caregiving with work, managing their own health, and coping with the emotional toll of caregiving. Throughout this report, we use the term ‘carer’ to refer to anyone who provides support and assistance to a person who cannot manage all aspects of their daily life due to an illness, disability or neurological condition(s). Carers can be family members, friends, partners, or neighbours – many are unpaid (but may receive financial support, such as Carer’s Allowance). The support provided can vary based on the needs of the person being cared for and may include tasks such as personal care, medical care and emotional support.

About this research

The Neurological Alliance has partnered with the Neurological Alliance of Scotland, the Wales Neurological Alliance, and the Northern Ireland Neurological Charities Alliance, along with an independent social research and insight agency, Revealing Reality, to produce and distribute 3 surveys. These surveys were designed to capture the experiences of adults, children, and young people affected by neurological conditions, as well as those who care for them.

The main goals of the survey were to:

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

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[1] https://www.neural.org.uk/backthe1in6/

This report presents the findings from these surveys, offering insight into the lived experiences of people affected by neurological conditions and helping guide future efforts in improving healthcare services, policy, and support systems across the UK.

How will the findings be used?

My Neuro Survey is the largest patient experience survey of people affected by neurological conditions and serves as the biggest single source of patient experience data when it comes to commissioning services for people affected by neurological conditions and lobbying to improve treatment, care, and support.

With over 10,300 individual experiences captured in the 2024/25 iteration, the survey findings provides valuable insights into areas such as diagnosis, treatment, mental health, access to support services, and the daily realities of living with a neurological condition.

The findings from this research will play a crucial role in supporting advocacy efforts. By revealing the systemic issues that people affected by neurological conditions face, the survey data provides evidence to drive campaigning and policy development. The results inform a wide range of work to improve services and influence public policy across the UK. This includes the newly established UK Neuro Forum, which aims to address these challenges and bring about much-needed change in the healthcare system.

In addition to influencing national policy, the evidence gathered offers actionable insights for individual clinics, helping to improve service delivery at the clinic level. Overall, My Neuro Survey serves as a powerful tool for both system-wide improvements and advocacy at national and local levels, supporting efforts to ensure that everyone with a neurological condition can access the care and support they need.

Acknowledgments

We would like to thank everyone who took the time to complete this iteration of My Neuro Survey. Your participation is invaluable, and your insights are crucial in helping us understand the experiences of those affected by neurological conditions. Whether you filled out the survey yourself or provided input on behalf of someone else, your contribution helps develop understanding of what challenges are being faced by individuals affected by neurological conditions and their carers.

By sharing your experiences, you have helped ensure that the Neurological Alliance's work in public policy reflects the realities of living with a neurological condition and that everyone has access to the treatment, care, and support they deserve.

Overview of the survey

General background

- My Neuro Survey 2024/25 is the fifth iteration of the My Neuro Patient Experience Survey. It collects insights into the lives of people affected by neurological conditions, covering their day-to-day. experiences and interactions with healthcare and other services. The Neurological Alliance England partnered with research agency Revealing Reality for this iteration of My Neuro Survey.
- This year was the first year where responses were obtained from those across the whole of the UK and the Republic of Ireland, with contributions from the Wales Neurological Alliance, Neurological Alliance of Scotland, and the Northern Ireland Neurological Charities Alliance (niNCA). While the first 3 iterations focused on England only, the 2021/22 survey expanded to the whole UK, and this year sees the addition of the Republic of Ireland. [2]
- Responses were gathered both online and through neurology, physiotherapy, and rehabilitation clinics (please see below for more details on dissemination). This is also the second iteration to include

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[2] Please note that this report includes findings based solely on data received from England, Wales, Scotland, and Northern Ireland. Findings from responses gathered in the Republic of Ireland are presented in a separate report.

children and young people, through a separate tailored version of the survey with questions designed to be easily understood by children and young people.

- This is the first year that a separate survey has additionally been developed to capture the perspectives of carers supporting someone with a neurological condition.
- The survey was open for 4 months, from 22 July 2024 to 15 November 2024, in total capturing the experiences of 10,342 individuals affected by neurological conditions and their carers.

Methodology

Survey design

The new iteration of the surveys was developed using the previous version as a guide, but drew on Revealing Reality's experience in running other national survey programmes.

The 2024/25 My Neuro Survey was developed through a collaborative process, building on previous iterations of the survey. This included the addition of more child-friendly language to the children and young people's survey and the creation of a new, separate survey for carers. During the design of the surveys, The Neurological Alliance England and Revealing Reality collaborated closely with a project steering group, which included representatives from The Neurological Alliance member organisations and included people affected by a range of neurological conditions, as well as healthcare professionals. These representatives ensured the questionnaire addressed the needs and experiences of those with a wide range of neurological conditions. Members represented all 4 UK nations – England, Scotland, Wales, and Northern Ireland – as well as the Republic of Ireland. Partner alliances, including the Wales Neurological Alliance, Neurological Alliance of Scotland, Northern Ireland Neurological Charities Alliance (niNCA), and Neurological Alliance of Ireland, also contributed.

Cognitive testing was carried out with 5 individuals, including adults and children affected by neurological conditions. This process ensured the survey questions were accessible, clear, and effective in capturing the required information. Participants completed the draft questionnaire and provided detailed feedback on each question, including its wording, response options, layout, and length. The process was iterative, with changes made after each session when it was considered beneficial to improve the survey's clarity or effectiveness. This allowed subsequent sessions to focus on other aspects, avoiding repetitive feedback and ensuring comprehensive refinement. The participants' input was invaluable and greatly appreciated. Following these sessions, a report was shared with The Neurological Alliance England and the project steering group. Revisions were made based on the findings, and the updated questionnaire was then tested during the final cognitive testing interview to ensure it met the required standards.

The design process took place between April and June 2024 and involved drafting, reviewing, testing, and revising the questions. Revealing Reality worked closely with The Neurological Alliance to finalise the question set, ensuring it reflected the feedback and expertise of the steering group, and the insight gathered from the focus groups and cognitive testing interviews.

Dissemination

My Neuro Survey 2024-25 was distributed across the UK and Ireland through various channels to ensure it reached a wide and diverse group of respondents. The survey was promoted by The Neurological Alliance England and its partner organisations, including the Wales Neurological Alliance, Neurological Alliance of Scotland, Northern Ireland Neurological Charities Alliance (niNCA), and Neurological Alliance of Ireland. The dissemination approach ensured that the survey would be more accessible to a wide range of individuals' needs, and aimed to capture the experiences of people affected by neurological conditions, their carers, and children and young people affected by these conditions. To support dissemination and participation in Wales, the survey was translated into Welsh, with all survey links distributed in Wales offering the option to complete the survey in Welsh.

Online Distribution

Each participating clinic and organisation was provided with a unique link to the survey, enabling responses to be tracked to specific clinics and members, who were then able to distribute the survey directly within their networks.

Paper-Based Surveys

To improve accessibility of the survey, paper versions of the survey were distributed in clinics that provide services for people affected by neurological conditions across the UK. These paper surveys were accessible to all individuals who used the clinics, and were handed out without targeting specific patients, ensuring a random sample. Supporting organisations could also request paper versions of the survey for use at relevant face to face events. In total, 554 responses were captured through paper surveys.

Additionally, individuals were able to request a paper survey via email or phone from The Neurological Alliance England. This option was available with a prepaid return envelope, ensuring that individuals with limited access to digital devices could still participate.

Surveys completed over the phone

Individuals who were unable to complete the survey online or via paper had the option to complete it by phone with the Revealing Reality team. In total, 7 surveys were completed with individuals over the phone.

Additionally, a language line service was offered to ensure that individuals who could not complete the survey in English could call Revealing Reality, who would then arrange for the survey to be completed over the phone with a speaker of the participant's language. However, no one requested this service.

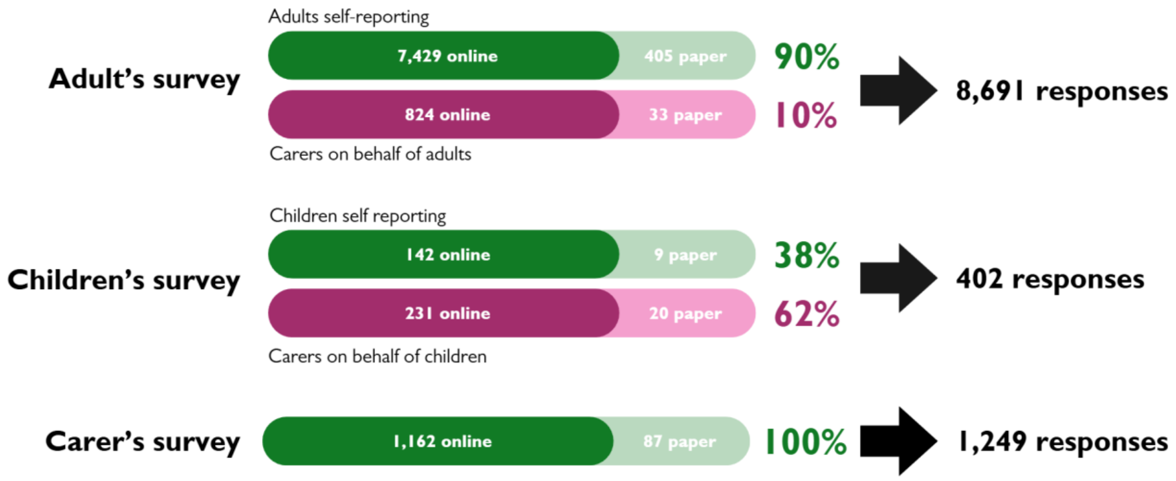
Data collection

The survey was open for 4 months, from 22 July 2024 to 15 November 2024. The data was collected through a combination of responses from individuals affected by neurological conditions and responses from carers completing the survey on behalf of those they care for, ensuring representation of those who may not be able to answer on their own behalf. These data points were merged where equivalent questions were asked.

It is important to note that not all questions given to adults were included in the section for carers responding on behalf of someone they support, as some questions would be difficult or inappropriate for carers to answer on behalf of another person. Additionally, responses from children and carers answering on a child's behalf could not be merged, as the language and questions in the children's survey did not align with those in the carers' survey. Therefore, the data for children and young people remains separate, except for a few key questions.

Survey responses

In total, the experience of 10,342 of those affected by neurological conditions and their carers were collected across the UK.



Open-ended question

The final question of the survey was open-ended, asking individuals to share any additional thoughts or reflections on their neurological condition(s), care, support, or treatment. Throughout this report, we have included key themes and included a selection of quotes that emerged from these responses.

Caveats

- **Base sizes for reporting and analysis**: In this report, we have limited our analysis and reporting of sub-groups (e.g., analysis by conditions or local health boards) to only where the base size is over 30 respondents. This ensures that the data presented is statistically robust and reliable. Therefore, when reporting on some sub-groups (e.g., when reporting on conditions facing particular challenges or performing specific analyses by condition), any conditions with a sample size below 30 have been excluded.
- **Sample representativeness:** This survey captured the responses of those who were made aware of the survey and who were willing and able to participate. This means the results are not necessarily representative of the entire population of people affected by neurological conditions in the UK. As a result, the findings should be interpreted with caution in relation to the broader population.
- **Merging of responses where carers answered on behalf of children:** As the children's survey was designed separately to be appropriate for children, the questions do not align with the questions in which carers reported on the experiences of children they care for. In the analysis of children's experiences, therefore, these 2 types of responses have been reported on separately, though have been combined to build a full picture of children's experiences where comparable questions were available.

About this report

This report presents the findings from the My Neuro 2024/25 Survey, focusing on the experiences of individuals living in the UK, and excludes data from the Republic of Ireland[3]. The report has been structured to provide in-depth insights into a range of topics, from diagnosis and treatment to daily life, mental health, and access to services and support

The report is divided into 8 chapters, each designed to understand different aspects of living with a neurological condition. Please see below for a detailed summary of each of the 8 chapters.

Chapter 1: Understanding the lives of adults affected by neurological conditions	This section examines the experiences of adults affected by neurological conditions, drawing on data reported both by individuals themselves and by carers on their behalf. It explores the impact of these conditions on physical and mental health, as well as their effects on daily life, and work/employment. Additionally, this section highlights interactions with health and care services, covering experiences with diagnosis, treatment, and access to essential support.
Chapter 2: Understanding the lives of children affected by	This section explores the experiences of children affected by neurological conditions, incorporating both self-reported insights and responses from carers on their behalf. It provides an overview of the children and young people who participated in the survey. It then examines the impact of neurological conditions on their health, daily lives, and

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[3] Findings based on data from the Republic of Ireland are presented in a separate report.

neurological conditions	emotional well-being, highlighting challenges they face at school, in social settings, and during daily activities. Finally, the section provides a summary of children's and carers' experiences with health and care services, including interactions with medical professionals and the support available for managing their conditions.
Chapter 3: Understanding the lives of carers and their experiences of caring	This chapter includes the experiences of those who provide care to individuals affected by neurological conditions. The section begins with an overview of the carers involved in the survey, detailing their demographic information and the relationships they have with the individuals they care for. The chapter then explores the experiences of carers. This includes looking at the impacts of caregiving, barriers to providing support, and reflections on experiences with support services.
Chapter 4: Mental Health	Chapter 4 focuses on the mental health experiences of both adults and children affected by neurological conditions, explores the prevalence of mental health issues, experiences with mental health services, and the challenges individuals face in managing their mental well-being.
Chapter 5: Involvement in decision-making	This chapter explores the involvement of adults, children, and young people affected by neurological conditions, as well as their carers, in decision-making related to their treatment, care, and support.
Chapter 6: Financial support	This chapter focuses on the financial challenges faced by individuals affected by neurological conditions. It looks at how living with a neurological condition impacts financial stability and the extent to which individuals can access the financial support they need.
Chapter 7: Children's transition to adults' care	This chapter focuses on the transition from children's to adult healthcare services for children aged 14-17 affected by neurological conditions.
Chapter 8: Access and confidence to participate in research	This chapter examines the attitudes and experiences of individuals affected by neurological conditions regarding participation in research. It explores the level of interest, and whether individuals have already taken part in research.

Chapter 1: Understanding the lives of adults affected by neurological conditions

About the adult respondents and their condition(s)

Who responded to this survey?

This survey aimed to reach a diverse group of individuals affected by neurological conditions across the UK, representing different ages, locations, and conditions. During data collection, good coverage was achieved across each nation, broadly aligning with national demographic figures. Whilst we cannot confirm how fully representative the sample is of all people affected by neurological conditions, the large and varied sample provides a comprehensive view of the experiences and challenges faced by adults affected by neurological conditions in the UK. The sample includes a wide range of conditions, effects, and demographics.

Below is a summary of the key demographic information:

68%	Female
31%	Male
1%	Other
0%	Prefer not to say

3%	18-24
7%	25-34
13%	35-44
20%	45-54
25%	55-64
19%	65-74
12%	75+

95%	White
1%	Black or Black British
1%	Asian or Asian British
1%	Mixed or multiple ethnic groups
1%	Other
1%	Don't know / Prefer not to say

80%	England
10%	Scotland
6%	Wales
3%	Northern Ireland

What conditions were reached?

In total, at least 1 response was collected from / on behalf of adults with **68 different conditions**. For a detailed summary of all 68 conditions reached, please refer to the technical report.

The 5 most commonly reported conditions among adult respondents (both as reported by adults and carers on behalf of adults) were*:

1. Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) – 16% (n=1408 / 8620)
2. Multiple Sclerosis (MS) – 13% (n=1140 / 8620)
3. Migraine – 10% (n=837 / 8620)
4. Fibromyalgia – 9% (n=802 / 8620)
5. Functional Neurological Disorder (FND) – 9% (n=782 / 8620)

**Please note, that this does not necessarily mean that these 5 conditions are the most prevalent conditions in the UK, but rather the conditions that were most represented in the sample.*

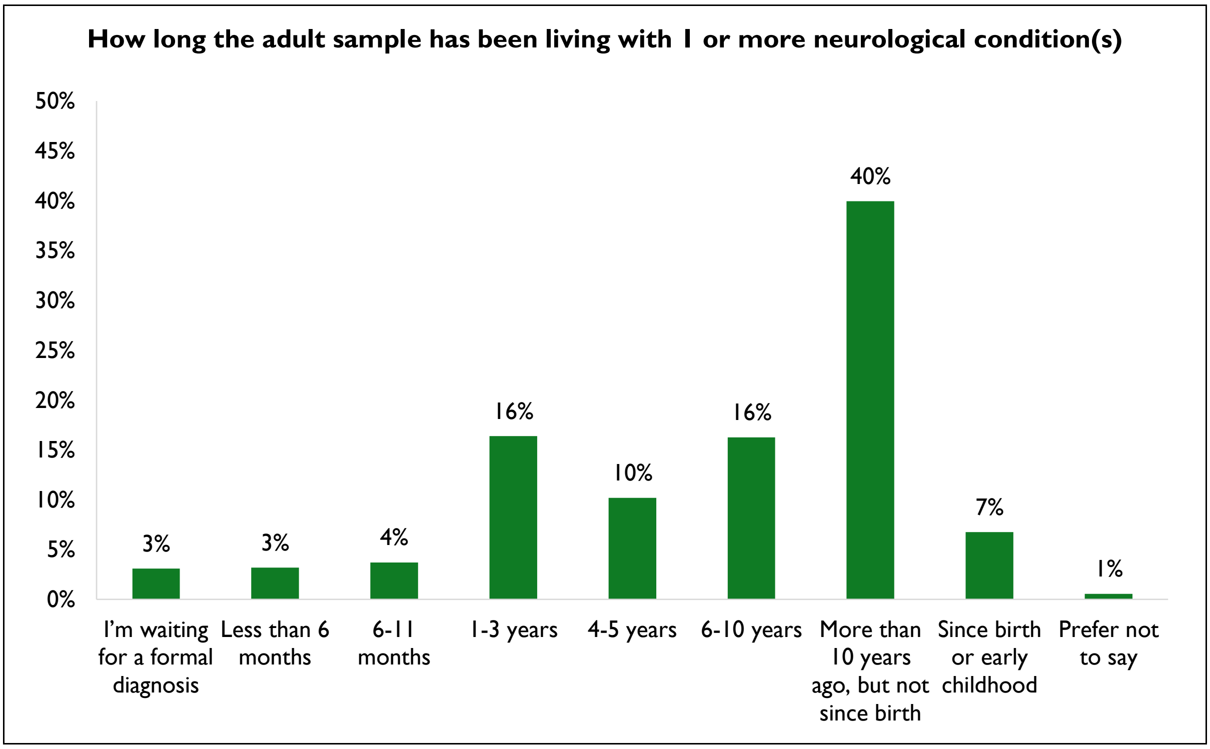
For an outline of the most prevalent conditions in the UK, please refer to Steinmetz et al. (2021)[4]

While the 5 most commonly reported conditions were generally consistent across the UK nations, some regional differences were observed. Notably, **Epilepsy** appeared among the most reported conditions in both Wales and Northern Ireland:

- England (n=6190): ME/CFS (17%, n=1041), MS (12%, n=757), Migraine (9%, n=579), Fibromyalgia (9%, n=571), FND (9%, n=533)
- Scotland (n=776): ME/CFS (20%, n=158), MS (15%, n=116), FND (15%, n=115), Fibromyalgia (11%, n=88), Migraine (11%, n=84)
- Wales (n=484): MS (27%, n=131), ME/CFS (12%, n=56), Epilepsy (9%, n=42), Migraine (8%, n=40), Dystonia (8%, n=39)
- Northern Ireland (n=258): FND (19%, n=48), Fibromyalgia (17%, n=44), ME/CFS (15%, n=38), Epilepsy (12%, n=32), Migraine (10%, n=27)

Duration of condition(s)

More than half of the adult respondents (*only those who self-reported*) had been living with at least 1 neurological condition for **over 5 years**. In contrast, only a small proportion (7%, n=493 / 7322) had received their diagnosis within the past year, and **3%** (n=226 / 7322) were still waiting for a diagnosis.



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[4] Steinmetz, J.D. et al. (2024). Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021. The Lancet Neurology, [online] 23(4). https://doi.org/10.1016/s1474-4422(24)00038-3.

Chart 1: *Adult survey Q: 'Please identify which neurological condition(s) you have and how long you have had a diagnosis for each condition'. This data was then coded for each respondent, using the duration of the condition they had reported as having for the longest time. Base n=7,322.*

Time to diagnosis

1 in 4 (26%, n=3053 / 12470) diagnoses[5] across the adult sample were received within 6 months of symptom onset. However, just over 1 in 5 (21%, n=2436 / 12470) were received following a wait of more than 5 years.

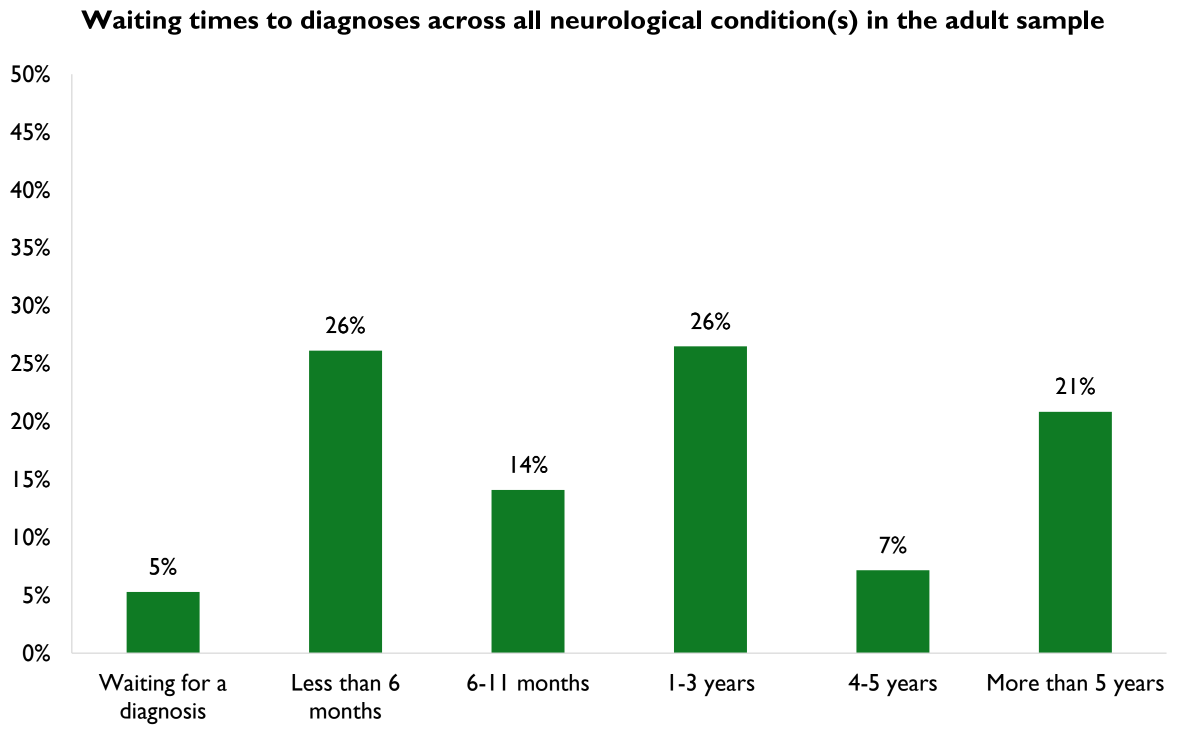

Chart 2: *Adult survey Q: 'How long after symptom onset did it take to receive diagnosis?' This data was then merged across conditions to work out the total spread of waiting times to diagnosis for all neurological conditions. Base n=12,470.*

For some conditions, the time to diagnosis was particularly prolonged. The 5 conditions (with base n at least 30) that had the highest proportion of adults where it took more than 5 years to receive a diagnosis were:

- Behcet's Disease – 49% (n=18 / 37)
- Autism – 44% (n=119 / 271)
- Charcot-Marie-Tooth Disease – 44% (n=39 / 89)
- Pernicious Anemia – 40% (n=52 / 131)
- Spondylosis – 38% (n=48 / 125)

For the 5 most frequently reported conditions in the sample (*ME/CFS, MS, Migraine, Fibromyalgia, and FND*), the proportion of respondents reporting a wait time of over 5 years to be diagnosed following symptom onset remained relatively consistent across the nations. However, there was a notably higher proportion of

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[5] We have used 'diagnoses' here as some respondents indicated that they had received more than one diagnosis. The total number of diagnoses reported across the adult sample was 12470.

respondents in Northern Ireland reporting longer wait times for Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS), with 42% (n=15 / 36) stating it took more than 5 years for diagnosis, compared to 27% (n=276 / 1018) in England, 25% (n=38 / 153) in Scotland, and 25% (n=14 / 55) in Wales.

Adult respondents shared their experiences with receiving diagnoses. The key challenges highlighted were:

- **Delays and difficulties in receiving a diagnosis**	*"It took me 3 years to feel well enough to pursue a referral, then a year waiting for the appointment…"*
- **Lack of information at diagnosis**	*"My GP [...] said 'I don't do Neurology' when I was first diagnosed..."* *"When I was first diagnosed I had a series of appointments...then was left alone to deal with it."* *"Complete lack of information diagnosed given website and forgotten."*
- **Misdiagnosis**	*"In March 2023 I found I had been misdiagnosed. I was using a wheelchair due to extreme pain in right leg...thinking it was MS..."* *"I was initially misdiagnosed with FND and found that once that is on your medical record, everyone attributes everything to it incorrectly without further investigations."*

Impact of their neurological condition(s)

Impact of neurological condition on health

Fatigue was the most frequently reported health impact for adults (*both self-reported and reported by carers)* affected by neurological conditions, with 93% (n=7936 / 8541) selecting this impact 'a little', 'somewhat', 'quite a lot', or 'very much'. This was followed by challenges related to **movement**, **sleep**, **mood and mental health**, **thinking and memory**, and **pain**.

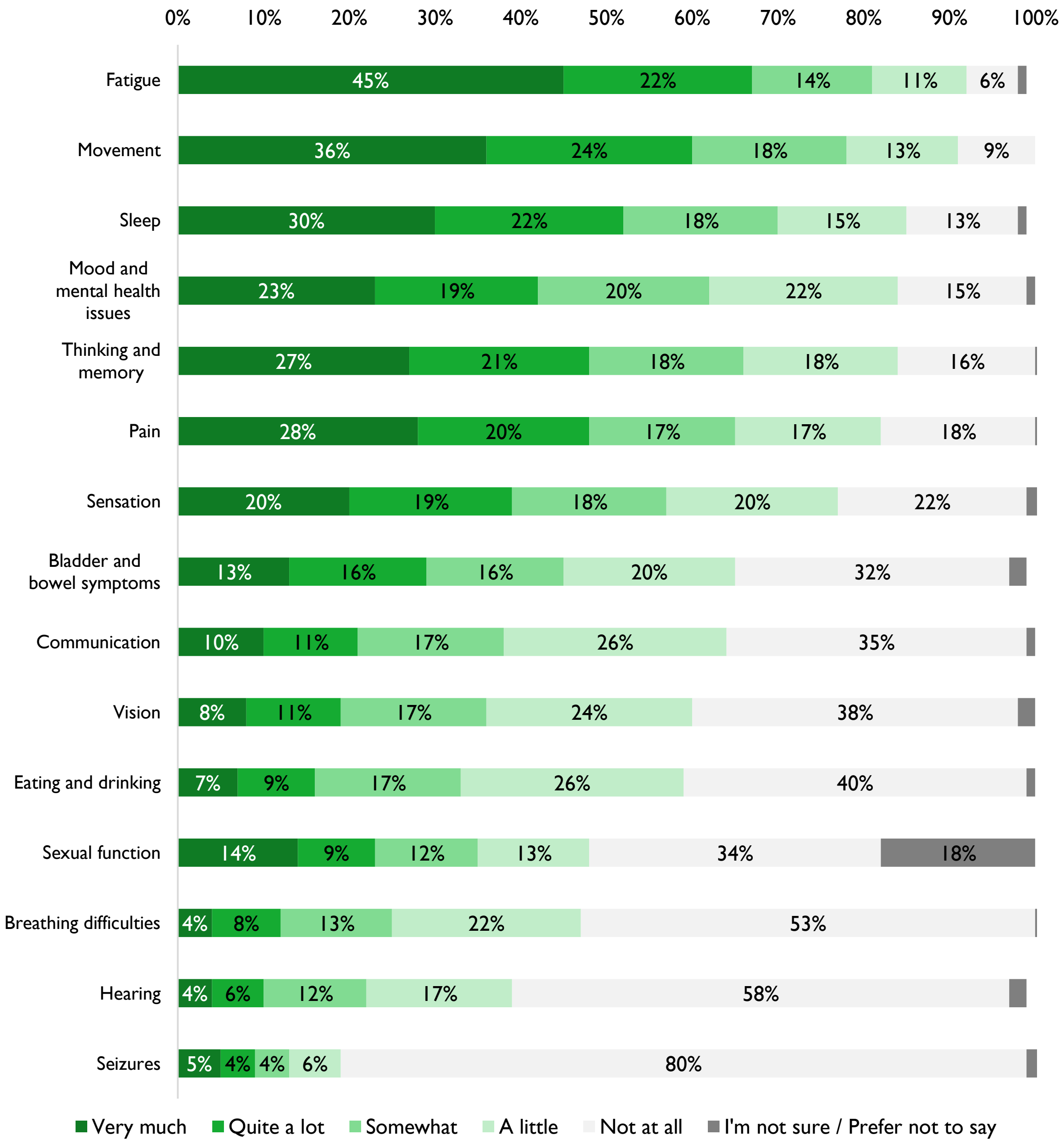

Extent to which adult respondents' neurological condition(s) impact on different areas of their health

***Chart 3:** Adult survey & carer on behalf Q: 'Which, if any, of the following ways does your neurological condition(s) impact your health?' Base n=8,472-8,558.*

The following conditions were reported by the highest proportion of individuals (either self-reporting or represented by their carers) as being '**very much**' affected by each specific health impact:

- **Fatigue (45% of the total sample, n=3855 / 8451):** Long Covid (89%, n=161 / 181), Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) (89%, n=1250 / 1408), and Fibromyalgia (83%, n=661 / 800)
- **Movement difficulties (36%, n=3100 / 8558):** Multiple System Atrophy (MSA) (71%, n=89 / 126), Progressive Supranuclear Palsy (PSP) (70%, n=173 / 248), and Corticobasal Degeneration (CBD) (69%, n=54 / 78)

- **Sleep issues (30%, n=2589 / 8534):** Fibromyalgia (60%, n=483 / 801), Restless Legs Syndrome (RLS) (60%, n=174 / 290), and Cluster Headache (59%, n=72 / 123)
- **Pain (28%, n=2365 / 8538):** Chronic Headache (76%, n=214 / 280), Cluster Headache (73%, n=89 / 122), and Fibromyalgia (73%, n=584 / 802)
- **Thinking and memory difficulties (27%, n=2293 / 8525):** Dementia (67%, n=58 / 86), Alzheimer's Disease (66%, n=23 / 35), and Long Covid Related Neurological Symptoms (59%, n=108 / 183)
- **Mood and mental health issues (23%, n=1975 / 8530):** Autism (52%, n=134 / 258), Cluster Headache (47%, n=58 / 123), and Chronic Headache (45%, n=127 / 281)

Impact on day-to-day life

More than half of adult respondents affected by neurological conditions, including those whose experiences were reported by their carers, indicated that their condition(s) significantly impacted their ability to be active, work/study, socialise, and engage in recreational activities, reporting this impact as either '**quite a lot**' or '**very much**'.

Extent to which adult respondents' neurological condition(s) impact on different areas of their day-to-day life

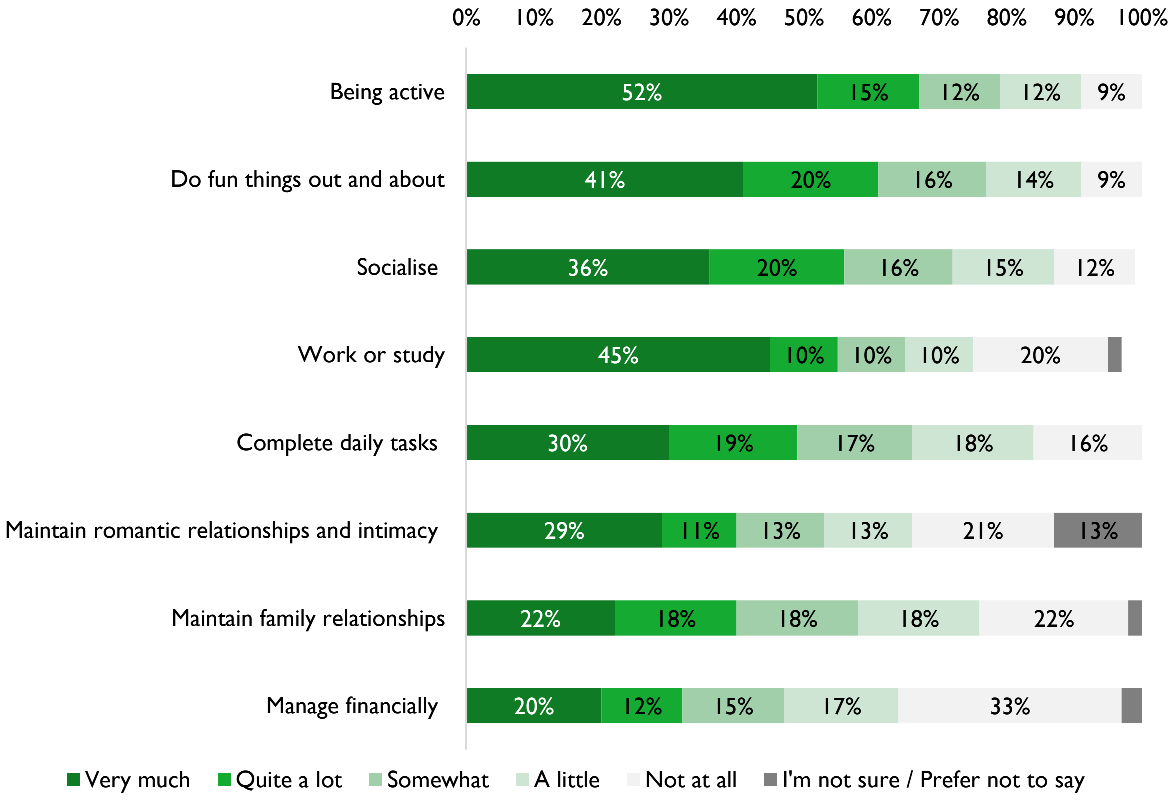


Chart 4: *Adult survey & carer on behalf Q: 'How does your neurological condition(s) affect your ability to do the following?' Base n=8,593-8,635.*

Those with multiple conditions were significantly more likely to report a higher impact on their daily life. 61% (n=1674 / 2752) of those with multiple conditions, including those self-reporting and those represented by their carers, were categorised as reporting that their condition(s) had a 'high impact' on daily life, compared to 40% (n=2253 / 5676) of those with just 1 condition.

Note: To assess the impact of an individual's neurological condition on their day-to-day life, respondents were categorised into 3 groups: 'low impact on daily life,' 'medium impact on daily life,' and 'high impact on daily life,' based on their responses to a series of statements. Across the 8 areas of daily life covered in the survey (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 the analysis.

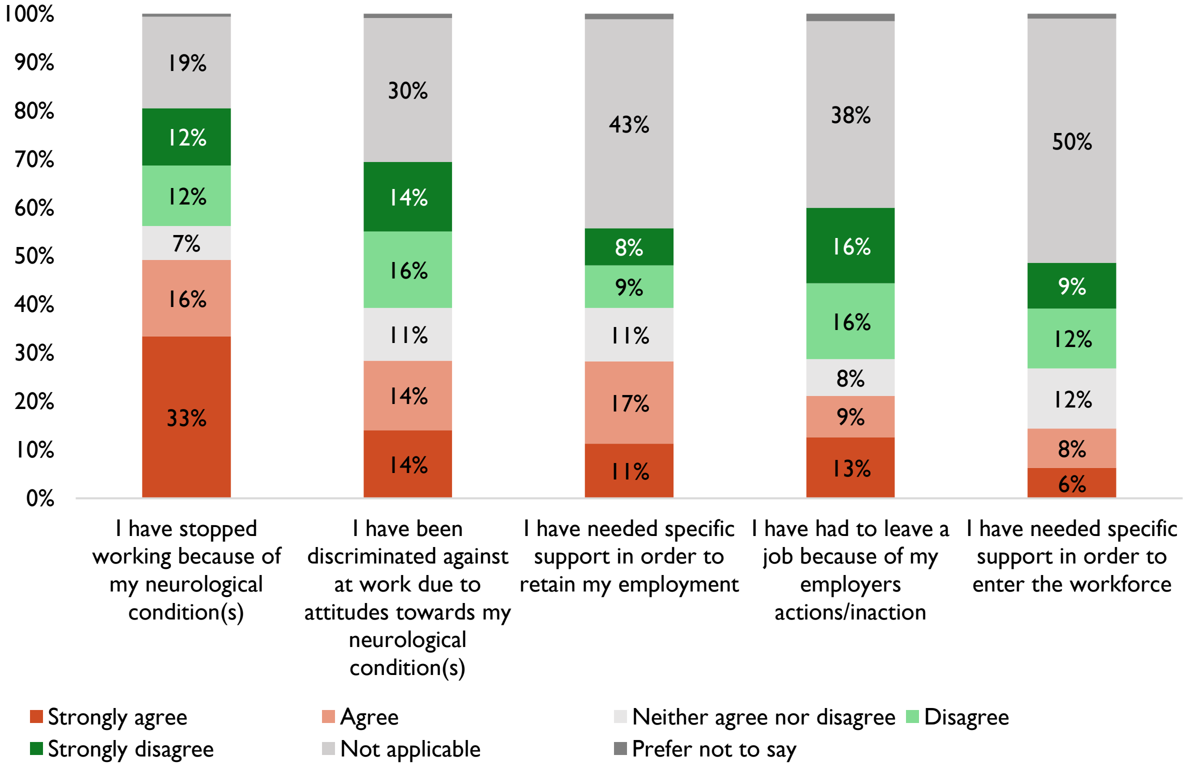
An average score was then calculated across all 8 statements for each individual. Respondents were categorised as follows:

- **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

This approach allows us to group respondents based on the severity of the impact their neurological condition has on their daily life.

Impact on work and employment

Adult respondents affected by neurological conditions frequently reported difficulties related to work and employment. Just under half of the sample (49%) indicated that they had stopped working because of their condition.



Extent to which adult respondents agreed or disagreed with different statements about their experiences of work and employment

***Chart 5:** Adult survey Q: 'To what extent do you agree or disagree with the following statements?' Base n=7,738-7,749.*

Additionally, **1 in 4** adults reported experiencing discrimination at work due to their neurological condition.

The conditions with the highest proportion of individuals agreeing with the statement *“I have stopped working because of my neurological condition”* were:

- Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) (74%, n=1006 / 1351)
- Long Covid Related Neurological Symptoms (73%, n=125 / 172)
- Fibromyalgia (72%, n=564 / 778)
- Functional Neurological Disorder (FND) (69%, n=502 / 730)
- Restless Legs Syndrome (RLS) (68%, n=188 / 278)

Adult respondents shared their experiences with work and employment. The key challenges highlighted were:

- **Reduction or loss of work due to health**	*“I can't work in my trained field and am trying my best to stay a part of society but the treatment for my condition is just not there."* *"I am self employed as I cannot get benefits, apparently not eligible despite having moderate CFS, Fibromyalgia and Long COVID... I'm in a lot of debt, working is very difficult and my life is thoroughly depressing.”*
- **Attempts to return to work that worsened health**	*"I asked […] for help (via my GP), and they said to phase back to normal at work. That made me very ill..."* *"Each new symptom arose when work put me down for a morning start to phase me back to normal..."*
- **For those that do work, struggling to cope**	*“I work (down to 4 days not 5 and term time only) but I don’t do any housework and often lose my evenings, weekends and a lot of the holidays to exhaustion. It is only because of the support of my husband that [I] can manage.”*

Experience with healthcare services

In the survey, adults affected by neurological conditions and their carers (answering on their behalf) were asked to share their experiences with a range of healthcare services. Specifically, participants were asked whether they or the person they care for had used any of 31 services for their neurological condition(s), and if so, whether those services met their needs. Respondents could also indicate if they or the person they care for had been unable to access a service, if it wasn’t relevant to them, or if they didn’t know what it was.

Most and least commonly used services

The 5 most commonly used services were:

- GP (74%, n=6286 / 8460)
- Neurologist (59%, n=5018 / 8470)
- Scans (e.g., MRI, CT) (50%, n=4223 / 8409)
- Physiotherapy (38%, n=3213 / 8404)
- Specialist nurse (29%, n=2463 / 8393)

The least used services were:

- End of life care (2%, n=145 / 8323)

- Palliative care (2%, n=145 / 8312)[6]
- Respite care (2%, n=192 / 8335)

What is palliative care?

"Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual." (World Health Organization, 2020)[7]

Services most often reported as inaccessible

When focusing only on those who considered a service relevant *(i.e., excluding respondents who selected 'not relevant'),* many still reported difficulties accessing certain services. The 5 services most commonly reported as inaccessible were:

- Neuropsychiatry (69%, n=1030 / 1486)
- Respite Care (66%, n=620 / 944)
- Inpatient Neurorehabilitation (64%, n=767 / 1192)
- Neuropsychology (61%, n=1108 / 1804)
- Personal Assistant (61%, n=893 / 1464)

In general, adults affected by neurological conditions that reported difficulty accessing various services were more likely to say they found everyday life challenging. For example, among those who were unable to access neuropsychiatry, 83% (n=710 / 860) said they found daily life challenging, selecting either 'I find every day challenging' or 'I regularly find day-to-day life challenging' – this was higher than the proportion of the total sample who gave this response (57%, n=4466 / 7776).

Access difficulties were especially pronounced among adults and carers answering on their behalf with certain conditions. In particular, those with ME/CFS frequently reported being unable to access multiple services despite wishing to. Among all of the 5 services most frequently reported as inaccessible, respondents with ME/CFS were among the three conditions most likely to report issues with access:

- Neuropsychiatry: ME/CFS (83%, n=197 / 236), Chronic Headache (78%, n=62 / 79), Long Covid-Related Neurological Symptoms (78%, n=46 / 59)
- Respite Care: ME/CFS (88%, 192 / 218), Fibromyalgia (86%, n=97 / 113), Chronic Headache (80%, n=35 / 44)
- Inpatient Neurorehabilitation: Autism (89%, n=34 / 38), ME/CFS (87%, n=163 / 188), Long Covid-Related Neurological Symptoms (84%, n=38 / 45)
- Neuropsychology: ME/CFS (78%, n=207 / 267), Chronic Headache (71%, n=63 / 89), Fibromyalgia (71%, n=174 / 246)

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[6] It is important to note that individuals receiving end-of-life or respite care may be underrepresented in this survey, as individuals receiving this type of support may find surveys less accessible. In addition, awareness of what palliative care is and who it serves, may be relatively low; public understanding of 'palliative care' is often limited to critical or end-of-life stages, rather than being seen as care received upon the diagnosis of a terminal condition, which may restrict access. This could also reflect the survey responses, as the 5 most commonly reported conditions in the sample are generally not associated with the need for palliative care.

[7] Definition taken from World Health Organization. For more information, please visit: https://www.who.int/news-room/fact-sheets/detail/palliative-care

- Personal Assistant: Long Covid-Related Neurological Symptoms (77%, n=37 / 48), ME/CFS (77%, n=351 / 457), Chronic Headache (76%, n=62 / 82)

While access challenges were broadly similar across the UK nations, rates were slightly higher in Northern Ireland for several key services:

- England: Neuropsychiatry (69%, n=715 / 1040), Respite Care (67%, n=444 / 665), Inpatient Neurorehabilitation (64%, n=544 / 850)
- Scotland: Neuropsychiatry (68%, n=108 / 159), Respite Care (67%, n=76 / 114), Inpatient Neurorehabilitation (64%, n=71 / 111)
- Wales: Neuropsychiatry (73%, n=60 / 82), Inpatient Neurorehabilitation (68%, n=50 / 74), Personal Assistant Support (67%, n=50 / 75)
- Northern Ireland: Inpatient Neurorehabilitation (82%, n=36 / 44), Neuropsychiatry (80%, n=47 / 59), Neuropsychology (71%, n=53 / 75)

How well services met needs

Even when services were accessible, this did not always translate into a satisfactory experience. Overall, only 1 in 3 adults affected by neurological conditions and their carers reported that the healthcare services they accessed met their needs.

Extent to which adult respondents felt that their care from medical and healthcare services met their needs

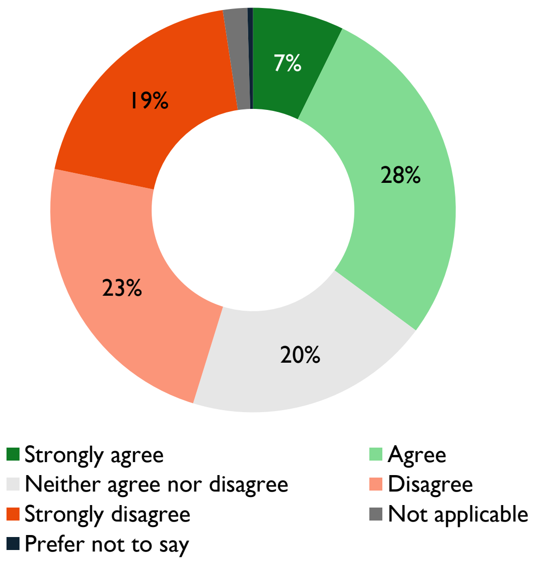

Chart 6: *Adult survey & carer on behalf Q: 'How much do you agree or disagree with the following statements? 'My care from medical and healthcare services meets my needs' Base n=8615.*

The extent to which adults and their carers felt healthcare services had met their needs varied across different services they had accessed.

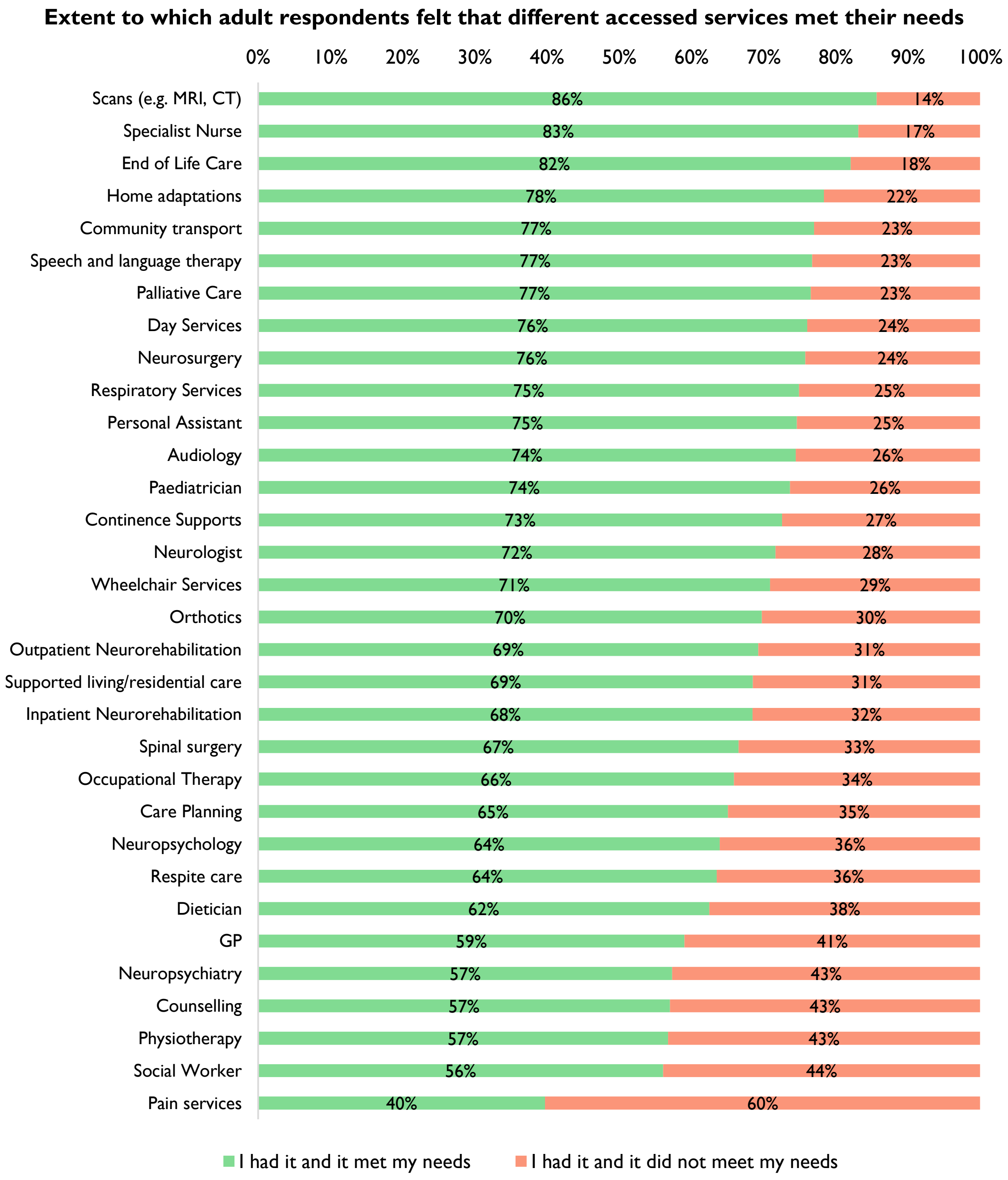

Chart 7: *Adult survey & carer on behalf Q: 'In the last 12 months, have you used any of the following services for your neurological condition(s)?' This was then coded to only include the responses of those that indicated they were able to access the service. Base n=38-6286.*

The 5 services most frequently reported as meeting needs were:

- Scans (e.g., MRI, CT) (86%, n=3618 / 4223)
- Specialist nurse (83%, n=2048 / 2483)
- End of life care (82%, n=119 / 145)
- Home adaptations (78%, n=1598 / 2039)
- Community transport (77%, n=422 / 548)

The services least likely to meet needs were:

1. **Pain Services:** 40% (n=520 / 1308) of respondents who accessed this service felt it met their needs. These services showed particularly low satisfaction among groups for whom pain is often a central and persistent symptom[8]:

Fibromyalgia	23% (n=70 / 310)
ME/CFS	23% (n=62 / 271)
Cluster headache	24% (n=10 / 42)

2. **Social Worker**: 56% (447 / 797) felt this service met their needs. Satisfaction was lower among the following conditions:

ME/CFS	39% (n=47 / 121)
Migraine	43% (n=33 / 77)
Fibromyalgia	47% (n=38 / 81)

3. **Physiotherapy**: 57% (n=1824 / 3213) reported that this service met their needs. Lower satisfaction was reported among the following conditions:

ME/CFS	29% (n=128 / 438)
Long Covid-related neurological symptoms	32% (n=25 / 78)
Restless legs syndrome	33% (n=40 / 122)

Barriers to accessing treatments and appointments

In addition to challenges with service availability, many adults affected by neurological conditions reported facing practical and financial barriers to accessing care. The most commonly reported barrier was the cost of treatment – with 38% (n=2972 / 7759) of the adults affected by neurological conditions in the sample concerned about affording the additional expenses associated with their condition.

Travel and scheduling challenges were mentioned less often but still affected a significant number of people. Around 21% (n=1647 / 7765) said they did not have reliable transport or assistance to attend appointments, while 23% (n=1769 / 7755) reported difficulties scheduling appointments that didn't clash with other commitments. Additionally, 57% (n=894 / 1569) of adults who indicated that community transport services

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[8] Please note that the breakdown by condition only includes those conditions for which at least 30 respondents reported being able to access the service.

would be relevant to them reported being unable to access these services This finding showed no significant variation by nation.

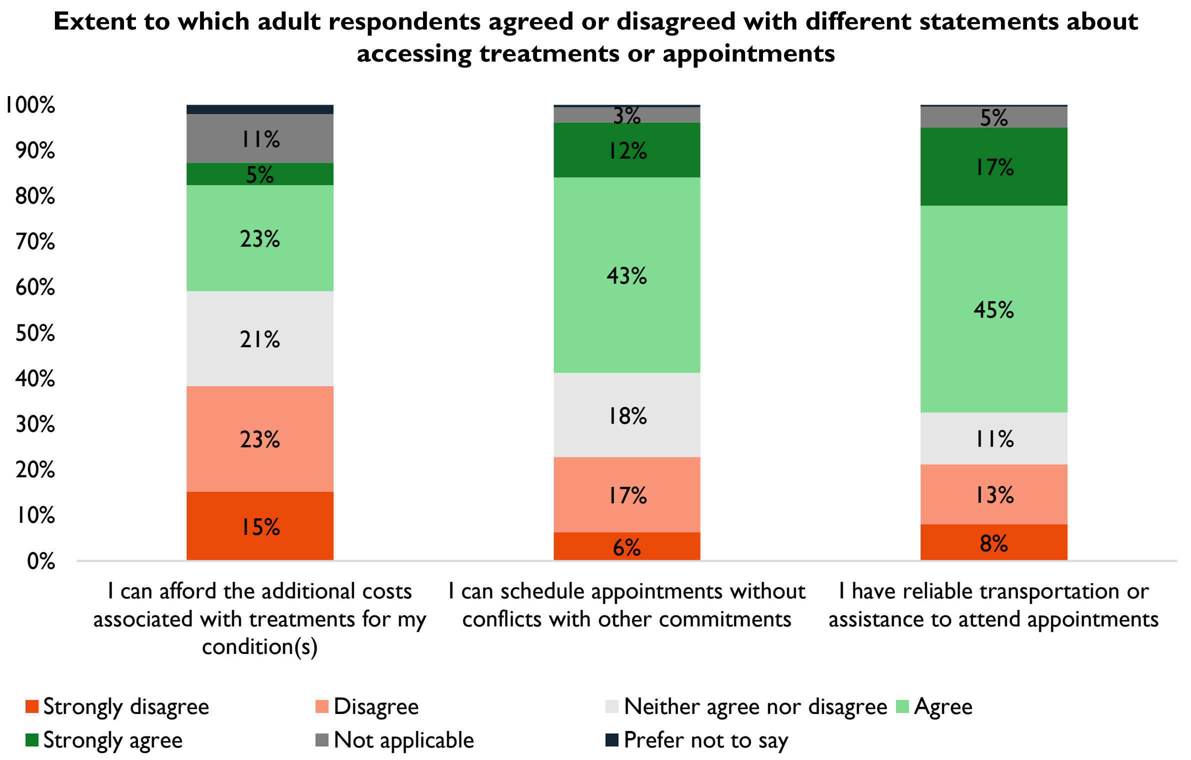

Chart 8: *Adult survey Q: 'Thinking about your wider life, to what extent do you agree or disagree with the following statements regarding managing your condition(s)?' Base n=7,755-7,765.*

Some demographic and regional groups were more affected by financial barriers:

- **By country**: In Northern Ireland, 48% (n=111 / 233) of respondents disagreed they could afford treatment costs – higher than Wales (39%, n=168 / 429), Scotland (40%, n=273 / 685), and England (38%, n=2146 / 5611)
- **By health board / Integrated Care Board:** the local health commissioners which had the highest proportion of individuals reporting financial barriers were:
    - NHS Lincolnshire ICB (England) (55%, n=30 / 55)
    - NHS Lanarkshire (Scotland) (52%, n=29 / 56)
    - NHS Cambridgeshire and Peterborough ICB (England) (51%, n=50 / 98)
    - Eastern Health Board (Northern Ireland) (48%, n=58 / 121)
    - Northern Health Board (Northern Ireland) (48%, n=19 / 40)
- **By age**: 48% (n=1684 / 3506) of those under 54 disagreed they could afford additional treatment costs, compared to 30% (n=1282 / 4229) of those aged 55+
- **By gender**: 42% (n=2286 / 5489) of women disagreed, compared to 29% (629 / 2156) of men
- **By ethnicity**: Over half (51%, n=148 / 290) of respondents from Black, Asian and Minority Ethnic groups disagreed, compared to 38% (n=2781 / 7370) of white respondents

Reflections on experiences with healthcare services

In general, adults affected by neurological conditions did not report feeling supported by the healthcare system. Only 32% (n=2502 / 7762) agreed that they felt supported, while nearly half (48%, n=3714 / 7762) disagreed.

Despite this, half (50%, n=3875 / 7751) of adults affected by neurological conditions in the sample reported feeling involved in decisions about their treatment, care, and support plan. Furthermore, over half (61%, n=4745 / 7754) agreed that they understood their condition(s) and the treatment options available.

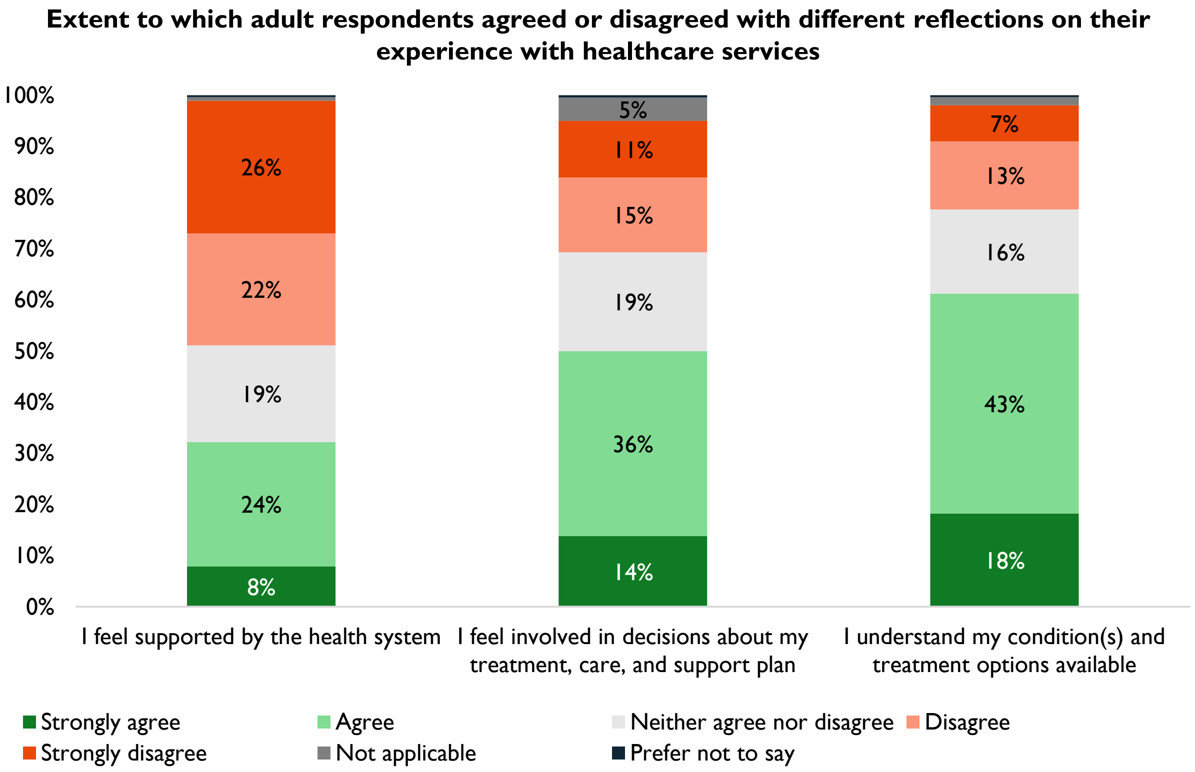

Chart 9: *Adult survey Q: 'Thinking about your wider life, to what extent do you agree or disagree with the following statements regarding managing your condition(s)?' Base n=7,751-7,762.*

Who reports feeling unsupported by the healthcare system?

The sense of lacking support was particularly prominent in Northern Ireland, where 64% (n=148 / 233) of adults affected by neurological conditions disagreed with the statement *"I feel supported by the healthcare system"*, compared to 44% (n=190 / 429) in Wales, 53% (n=365 / 685) in Scotland, and 48% (n=2705 / 5611) in England.

Additionally, a higher proportion of adults who reported a *high impact* of their neurological condition on their daily life (67%, n=2271 / 3369) disagreed with this statement, compared to those with a *low impact* (23%, n= 436 / 1929).

Conditions with the highest proportion of individuals agreeing that they felt supported by the healthcare system included:

- Motor Neurone Disease (MND) (73%, n=27 / 37)
- Myasthenia (61%, n=88 / 144)
- Muscular Dystrophy (57%, n=25 / 44)

In contrast, individuals with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) (87%, n=1169 / 1351), Long Covid Related Neurological Symptoms (81%, n=139 / 172), and Fibromyalgia (77%, n=596 / 779) were most likely to feel unsupported, disagreeing with the statement 'I feel supported by the healthcare system'.

Adults who reported feeling the care provided by medical and healthcare services did not meet their needs were also more likely to say that they felt unsupported by the healthcare system. Only 9% (n=257 / 2713) of those who did not feel that their care meets their needs agreed that they felt supported, compared to 72% (n=1950 / 2713) of those who did feel their care meets needs.

Reflections on communications with healthcare professionals

Overall, adults in the sample generally reflected positively on their communication with healthcare professionals. A majority (71%, n=5516 / 7755) reported feeling comfortable talking to healthcare professionals and asking questions during appointments. Nearly 3 in 5 (58%, n=4464 / 7741) agreed that healthcare professionals explained medical information clearly and in a way they could understand. Around half (47%, n=3601 / 7739) felt that their preferences and priorities were considered when discussing treatment options, and 48% (n=3706 / 7738) felt comfortable raising and discussing mental health concerns with their healthcare professional.

However, some areas of communication could be improved. Only 36% (n=2766 / 7735) of respondents agreed they had a consistent healthcare professional, meaning they didn't have to repeatedly explain their condition(s) to different people. Additionally, only 27% (n=2120 / 7730) reported being able to easily secure follow-up appointments when needed. These findings highlight challenges in the continuity of care for adults affected by neurological conditions, as many respondents reported encountering inconsistent healthcare professionals and difficulties with follow-up appointments.

Differences based on condition

There were notable differences in how individuals reflected on their communication with healthcare professionals, with individuals with some conditions having higher levels of comfort than others. The 5 conditions where adults were most likely to feel comfortable speaking with healthcare professionals, and agreed with the statement 'I feel comfortable talking to healthcare professionals and asking questions during appointments' were:

- Muscular Dystrophy (98%, n=43 / 44)
- Motor Neurone Disease (MND) (95%, n=35 / 37)
- Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) (91%, n=92 / 101)
- Myasthenia (91%, n=130 / 143)
- Parkinson's Disease (87%, n=488 / 559)

In contrast, the 5 conditions where the lowest proportion of adults agreed that they felt comfortable talking to healthcare professionals included:

- Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) (45%, n=613 / 1351)
- Autism (45%, n=89 / 196)
- Pernicious Anemia (48%, n=60 / 125)
- Fibromyalgia (52%, n=403 / 779)
- Long Covid-Related Neurological Symptoms (52%, n=89 / 172)

Time to discuss concerns during appointments

Adults with multiple neurological conditions, those still waiting for a diagnosis, and younger respondents were more likely to feel they did not have enough time to discuss all their concerns during appointments. Specifically:

- 51% (n=1246 / 2444) of adults with multiple conditions indicated that that they did not have enough time, compared to 32% (n=1658 / 5116) of those with just 1 condition
- 55% (n=278 / 505) of those awaiting a diagnosis reported not having enough time, which is higher than the overall sample

- 48% (n= 360 / 754) of respondents under 34 reported not having enough time, compared to 37% (2612 / 6969) of those aged 35 and older, and only 19% (n= 136 / 727) of those aged 75 or over disagreed

Adult respondents shared their experiences with accessing healthcare services. The key challenges highlighted were:

• **Services not available or don’t exist locally**	*"There is almost no support or treatment available for ME/CFS."* *"There is a lack of health and social support locally for people with learning disabilities and physical disabilities."* *“Sadly there is no local support for FND in my local area. I have not had access to a neurologist, OT or speech therapist despite severe difficulties in these areas”*
• **Long wait times or no follow-up after referral**	*"My last appointment with a neurologist was in July 2012... I have been completely abandoned by NHS neurology for over 12 years."* *"I have a provisional diagnosis of FND I'm still waiting for EEG and then follow up with neurologist."*
• **Forced to pay privately for care**	*"I gave up on waiting for NHS appointments so have been seeing specialist doctors privately via private medical offered by my work place."* *"I pay privately for home care... apparently don’t qualify for any personal care as it’s now reserved for terminally ill."*

Experience with support services

In the adult survey, people affected by neurological conditions were asked ‘Which of the following types of support do you receive?’ The majority of adults affected by neurological conditions report receiving support from **friends and family**, with 78% (n=6040 / 7766) indicating this source of assistance. Just under half (45%, n=3469 / 7766) reported receiving **financial support**, while a small proportion (5%, n=380 / 7766) reported not needing any support. However, **1 in 5 adults** (20%, n=1553 / 7766) stated that they do not receive any support for their neurological condition(s).

Proportion of adult respondents that indicated they received support from various sources

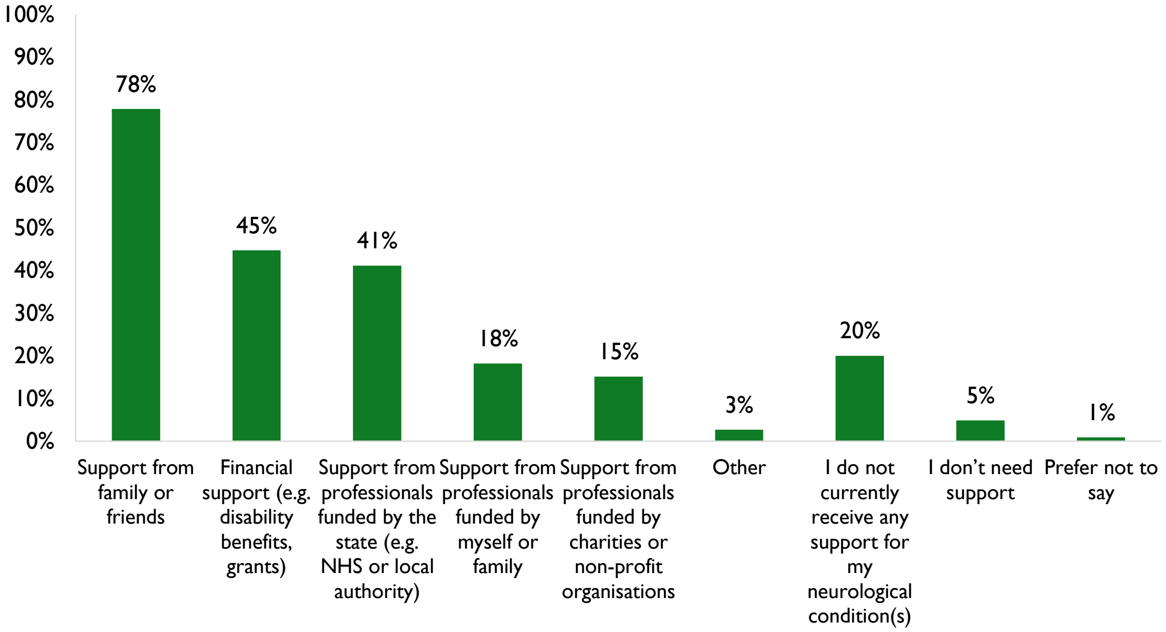

Chart 10: *Adult survey Q: 'Which of the following types of support do you receive?' Base n=7,766.*

For those adults affected by neurological conditions who reported not receiving support, specific conditions and demographics were more likely to be associated with this lack of support. Among conditions with a sufficient number of responses[9], the highest proportions of individuals reporting receiving no support were found in those with the following conditions:

- Pernicious Anemia (37%, n=46 / 125)
- Cavernoma (33%, n=21 / 64)
- Essential Tremor (29%, n=91 / 309)

The proportion of adults receiving financial support varied by UK nation. For example, respondents from Scotland (58%, n=396 / 685), Wales (50%, n=215 / 427), and Northern Ireland (57%, n=132 / 233) reported higher rates of financial support compared to England (43%, n=2417 / 5612).

In contrast, self-funding professional support was less common, with only 1 in 6 (18%, n=1415 / 7766) of adults reporting they were self-funding this support. A significant income disparity was seen in this group: 26% (n=393 / 1538) of adults with an annual household income of £50,000 or more reported self-funding support, compared to just 15% (n=284 / 1945) of those earning under £20,000.

Information received

Adults reported several ways they had been offered or directed to information about their condition in the past year. The most common method was through self-research, with 39% (n=2975 / 7725) of the sample indicating they had used this approach.

Neurologists were the second most frequently reported source of information, with just under a third of respondents (32%, n=2497 / 7725) mentioning them as a source. However, over a quarter (27%, n=2069 /

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[9] 'Sufficient number of responses' refers to conditions where there were at least 30 participants, ensuring that the data is reliable and meaningful for analysis.

7725) of the sample indicated that they had not received any information about their neurological condition(s) in the last 12 months.

Proportion of adult respondents that indicated they were offered or directed to information in the last 12 months through various sources

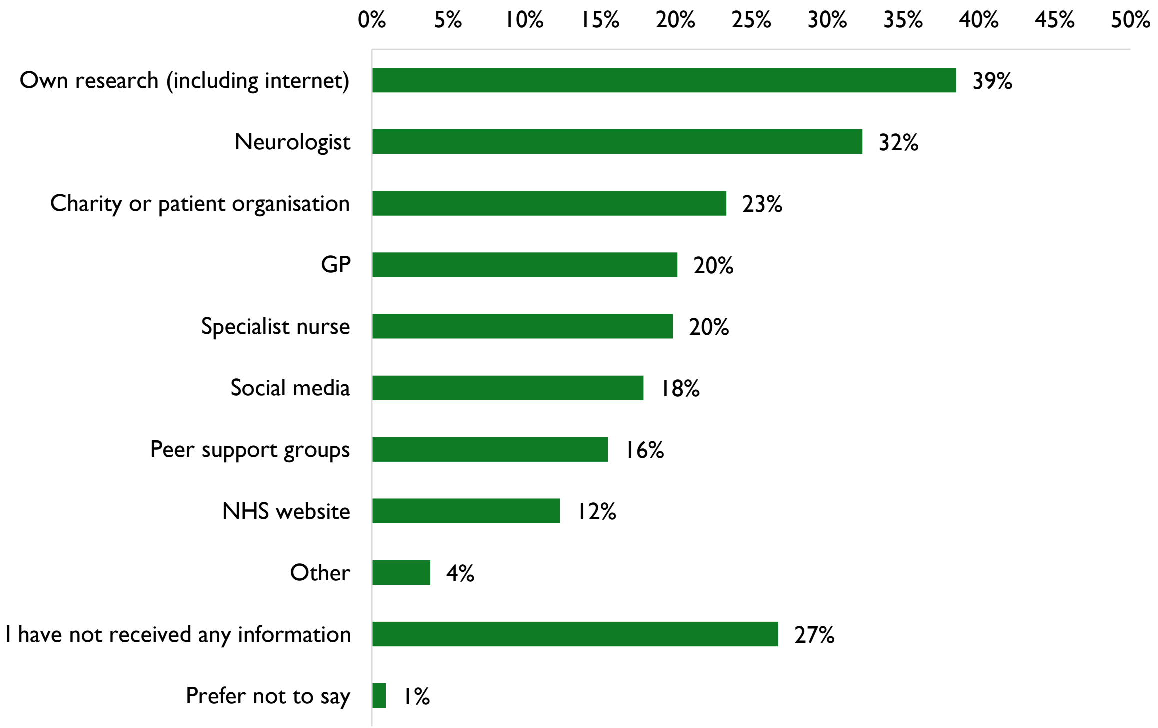

***Chart 11:** Adult survey Q: 'In the last 12 months, have you been offered or directed to any information about your neurological condition(s) by the following?' Base n=7,725.*

For those who did receive information, most found it helpful. Over half (57%, n=4382 / 7685) of the respondents felt the information was 'helpful' or 'very helpful', with just under 1 in 5 (18%, n=1421 / 7685) reporting that it was 'very helpful'. Only 8% (n=611 / 7685) of the sample felt the information they received was 'unhelpful' or 'very unhelpful'.

Barriers to receiving support

When asked why they have not received the support they need, the most common reason reported by adults was that they were not aware of available support, with just over a quarter (28%, n=2133 / 7625) citing this as a barrier to receiving support.

Proportion of adult respondents that indicated they had not received support for various reasons

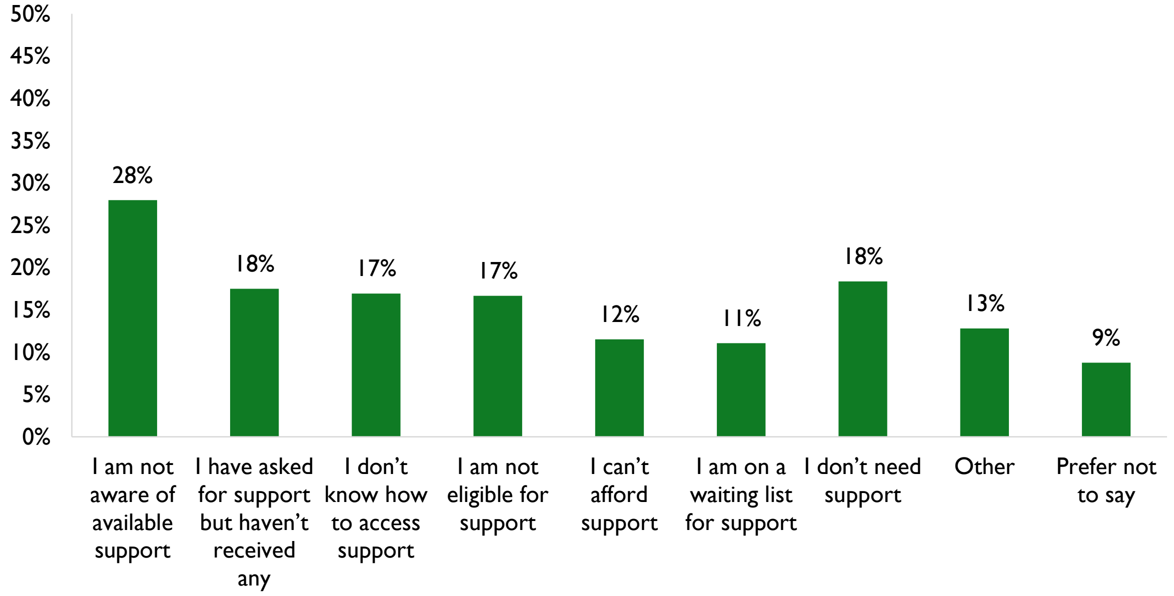

Chart 12: *Adult survey Q: 'If you haven't received the support you need, what are the main reasons?' Base n=7,625.*

Just under 1 in 5 adults (18%, n=1402 / 7625) felt they didn't need support, while a smaller proportion (12%, n=903 / 7625) reported that they could not afford support. Those that were receiving **financial support** were more likely to report affordability as an issue, with 15% (n=517 / 7618) of this group selecting the 'cannot afford support' response option.

Among adults who reported that they are not currently receiving support for their neurological condition, the most commonly selected reasons were:

- 38% (n=593 / 7618) said they are "*not aware of the available support*".
- 24% (n=375 / 7618) indicated that they "*have asked for support but haven't received any*".
- 23% (n=360 / 7618) reported that they "*don't know how to access support*".
- 13% (n=206 / 7618) selected that they "*can't afford support*".

These findings highlight that awareness and accessibility of support services are the primary barriers, with a smaller proportion of individuals facing financial constraints in accessing care.

Chapter 2: Understanding the lives of children and young people affected by 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.

A total of 402 responses were collected from, or on behalf of, children and young people affected by neurological conditions. This includes 151 children self-reporting, and 251 carers responding on behalf of a child/ young person. Where information on the respondent's nation was available, this breaks down as: 233 responses from England, 67 from Scotland, 30 from Wales, and 16 from Northern Ireland.

<u>Demographics of the children's sample – those that self-reported:</u>

46%	Girl
50%	Boy
1%	Other
3%	Prefer not to say

15%	Younger than 7
22%	7-10
18%	11-13
44%	14-17

91%	White
3%	Black or Black British
1%	Asian or Asian British
4%	Mixed or multiple ethnic groups
1%	Other
1%	Don't know / Prefer not to say

78%	England
9%	Scotland
10%	Wales
4%	Northern Ireland

Demographics of the sample – those where carers answered on behalf of a child:

50%	Female
48%	Male
1%	Other
0%	Prefer not to say

20%	0-5
44%	6-12
36%	13-17

91%	White
2%	Black or Black British
1%	Asian or Asian British
4%	Mixed or multiple ethnic groups
0%	Other
1%	Don't know / Prefer not to say

61%	England
26%	Scotland
8%	Wales
5%	Northern Ireland

**Please note: Similar to the adult sample, the findings in this section are based on both children completing the survey themselves and carers answering on behalf of the children they support or care for. Children were provided with a bespoke, child-friendly version of the survey designed to be accessible and understandable for a wide range of ages. Carers, on the other hand, completed the carers' survey, which was not directly comparable to the wording and framing of the questions asked in the children's survey. Both sets of data have been included in this chapter, with clear distinctions made throughout to indicate which sample is being reported on.*

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

The survey captured responses from children and young people, as well as their carers who responded on their behalf, living with **49 different neurological conditions**. The most commonly reported conditions were *(across both children and young people self-reporting, and carers on their behalf):*

Autism (24%, n=95 / 390)

Epilepsy (22%, n=85 / 390)

Hydrocephalus (19%, n=73 / 390)

Spina Bifida (13%, n=52 / 390)

Cerebral Palsy (11%, n=43 / 390)

Please note, 17% (n=66 / 390) of children or carers reported a condition not listed in the options by selecting "other[10]".

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[10] The three most frequently specified 'other' conditions were Tourette's Syndrome, ADHD (Attention Deficit Hyperactivity Disorder), and PANDAS/PANS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections), despite Tourette's Syndrome being listed as a response option.

Regarding the duration of their condition(s), 1 in 3 (35%, n=53 / 151) children and young people self-reported that they have had their neurological condition their whole life. Another third (38%, n=58 / 151) indicated they had been living with their condition for more than a year.

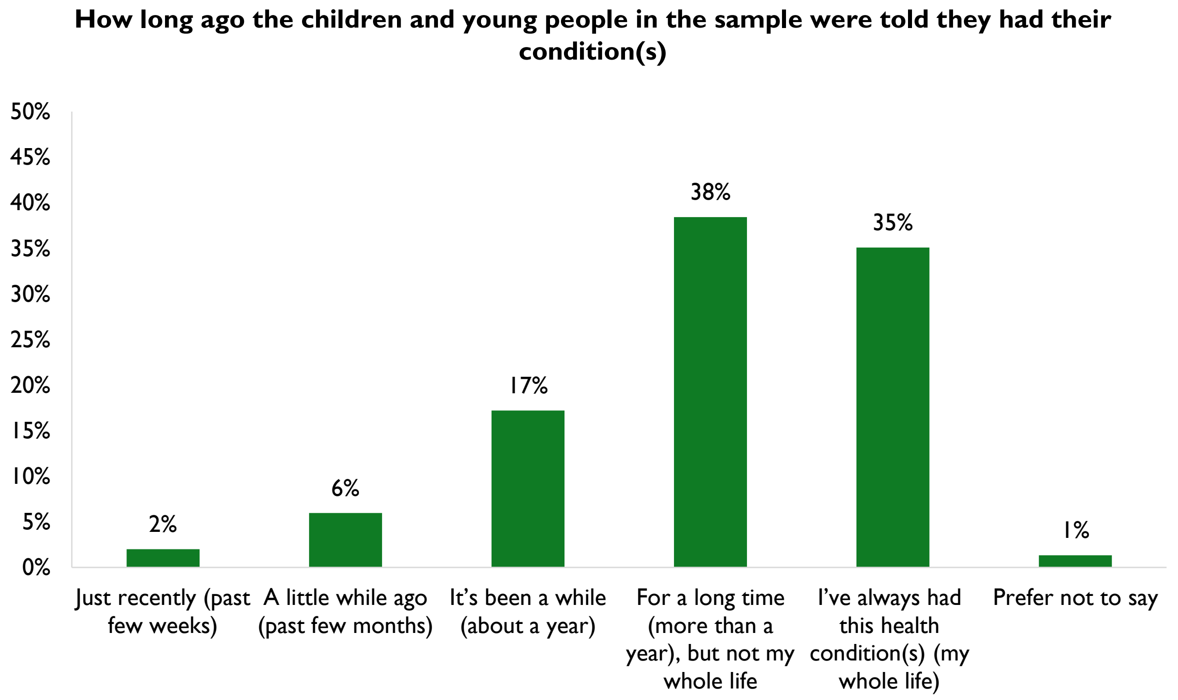

Chart 13: *Child survey Q: 'When were you first told that you had your condition(s)?' Base n=151.*

Impact of their neurological condition(s)

Impact on health

For children, **thinking and learning** was the most commonly reported impact, with **74%** (n=107 / 145) of the children self-reporting that their neurological condition affected them in this way. Over **3 in 5** children reported that their condition impacted their **sleep and energy** (62%, n=90 / 145), **mood** (62%, n=90 / 145), or **movement** (61%, n=88 / 145).

How the children and young people in the sample reported their condition(s) affects them

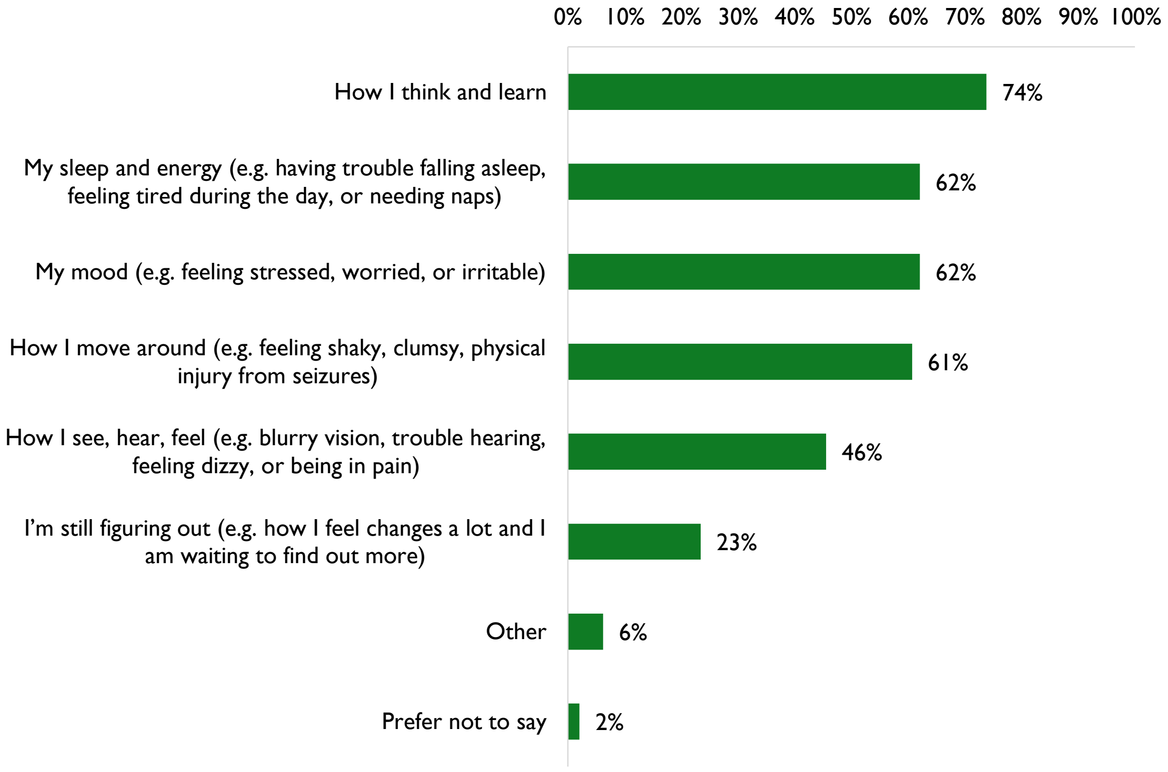

Chart 14: *Child survey Q: 'How does your neurological condition(s) affect you?' Base n=145.*

Older children aged 14-17 were the most likely to report impacts on their thinking and learning than those aged 11-13 and those younger than 7. Specifically:

- 88% (n=56 / 64) of children aged 14-17
- 63% (n=17 / 27) of children aged 11-13
- 76% (n=22 / 29) of children aged 7-10
- 48% (n=11 / 23) of children younger than 7

The impact of neurological conditions on health varied depending on whether children had multiple conditions. Across every health impact asked about, children with multiple conditions more often reported experiencing these impacts compared to those with a single condition.

How the children and young people in the sample reported their condition(s) affects them, by those that have one vs. multiple conditions

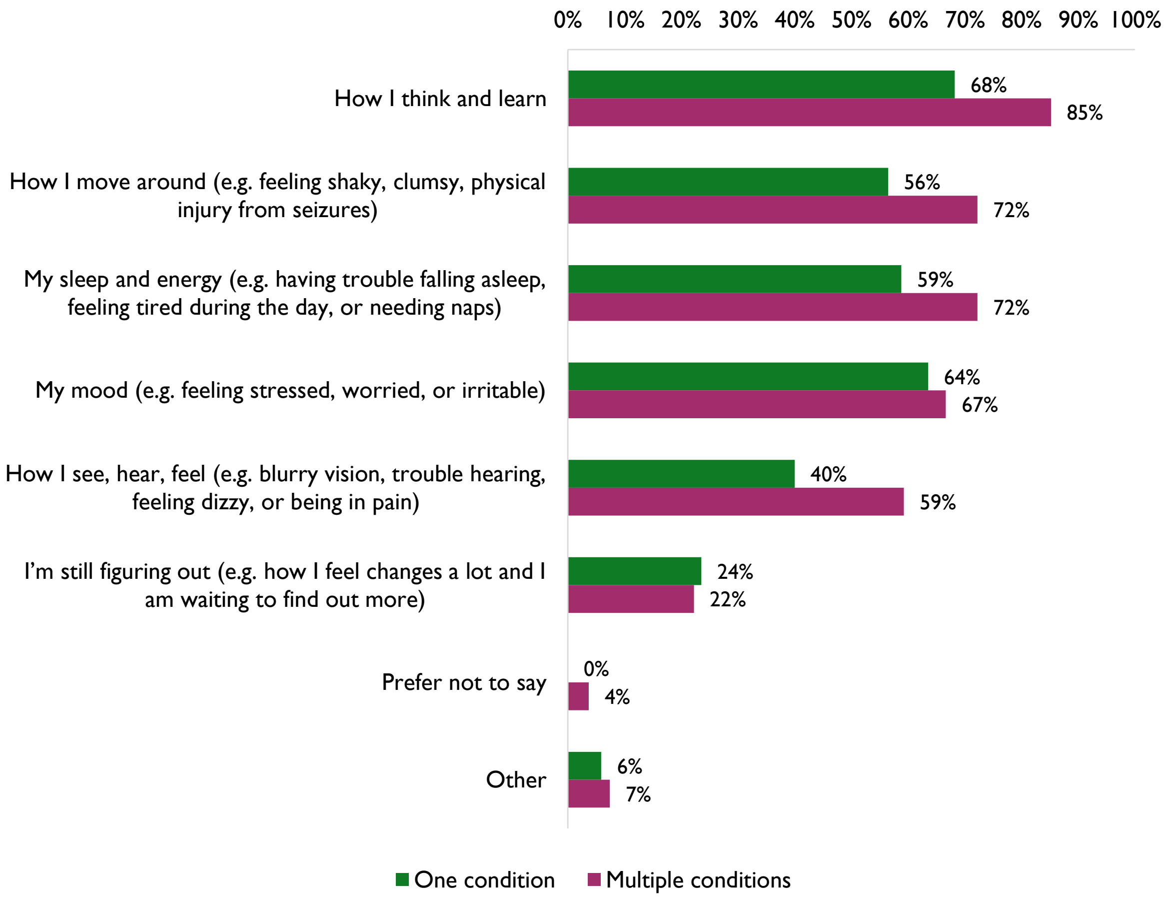

Chart 15: *Child survey Q: 'How does your neurological condition(s) affect you?' by 'What is your neurological condition?', coded to identify those that only have one neurological condition and those that have more than one. Base n=139.*

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

More than half of the children self-reported experiencing negative emotions due to their condition. 56% (n=81 / 145) said they felt frustrated and angry, while 51% (n=74 / 145) felt worried and stressed. Nearly half (48%, n=70 / 145) also reported feeling left out or missing out on things. Additionally, over a third of children felt scared about the future (39%, n=56 / 145) or like they can't keep up (38%, n=55 / 145).

Older, adolescent children were more likely to self-report experiencing these negative emotions. For example:

- 70% (n=45 / 64) of children aged 14-17 reported feeling frustrated and angry, compared to 44% (n=35 / 79) of those aged under 14.
- 67% (n=43 / 64) of children aged 14-17 reported feeling worried and stressed, compared to 39% (n=31 / 79) of those younger.
- 64% (n=41 / 64) of children aged 14-17 self-reported feeling left out or missing out on things, compared to 35% (n=28 / 79) of those under 14.

In contrast, fewer children reported feeling proud of themselves for how they handle their condition (32%, n=46 / 145), feeling mostly okay (20%, n=29 / 145), happy that they are unique (10%, n=15 / 145), or hopeful about the future (7%, n=10 / 145). Younger children were more likely to report these positive feelings. Specifically, 37% (n=29 / 79) of those aged under 14 reported feeling proud of how they handle their condition, compared to 27% (n=17 / 64) of those aged 14-17.

There was a noticeable link between how children felt about their condition and the impacts on their health. For example, 81% (n = 57 / 70) of those who felt left out or like they are on things reported an impact on their mood, compared to 61% (n=28 / 46) of those who felt proud of themselves. This difference was statistically significant.

Experience with healthcare services

A large majority of children (95%, n=141 / 149) reported that they had accessed healthcare services at least once in the past year, reflecting the widespread use of healthcare across this sample.

Most and least commonly used healthcare services

The 5 healthcare services most used by children (as reported by carers) were:

- GP (84%, n=201 / 239)
- Paediatrician (74%, n=175 / 238)
- Neurologist (71%, n=170 / 239)
- Scans (e.g., MRI, CT) (58%, n=135 / 233)
- Physiotherapy (52%, n=125 / 240)

In contrast, the least commonly used services, as reported by carers were:

- Supported living/residential care (0%, n=1 / 232)
- Inpatient Neurorehabilitation (1%, n=2 / 228)
- End of Life Care (2%, n=4 / 230)

Services children have most often been unable to access

For the services that carers were aware of and felt were relevant, the services they reported that children were most often unable to access were:

- Inpatient Neurorehabilitation (84%, n=27 / 32)
- Outpatient Neurorehabilitation (83%, n=29 / 35)
- Day Services (76%, n= 39 / 51)
- Neuropsychiatry (76%, n=44 / 58)

These high percentages of unmet need suggest challenges in accessing specialised neurorehabilitation and psychiatric care for children.

Which services are and aren't meeting needs (for those who have accessed them)[11]

For carers of children who have accessed various healthcare services, the following services had the highest proportion of carers reporting that it met the needs of the child they support:

- Neurosurgery (92%, n=48 / 52)
- Specialist nurse (89%, n=85 / 96)
- Scans (e.g., MRI, CT) (86%, n=116 / 135)
- Respiratory services (84%, n=26 / 31)
- Orthotics (84%, n=71 / 85)

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[11] Please note that these lists exclude all services which were used by fewer than 30 respondents, to ensure robust comparisons across services

However, the services that meet the needs of children the least (as reported by carers) were:

- Counselling (39%, n=24 / 61)
- Social worker (51%, n=29 / 57)
- Respite care (58%, n=18 / 31)
- GP (59%, n=118 / 201)

These findings point to areas where there may be opportunities for improvement in service delivery, especially in mental health support and general healthcare.

Reflections on experiences with healthcare services

The reflections on interactions with healthcare professionals varied, with some positive and some less so. Nearly half of the children in the sample (45%, n=66 / 148) self-reported feeling supported and listened to by healthcare professionals. Children aged 13 and below were more likely to report feeling supported, with 53% (n=43 / 81) agreeing with this statement, compared to only 35% (n=23 / 65) of children aged 14-17.

Half of children affected by neurological conditions (50%, n=75 / 149) reported understanding what is happening with their health, that healthcare professionals use words they understand (51%, n=75 / 147), and that they feel comfortable asking their doctor or other healthcare professionals questions (51%, n=76 / 149).

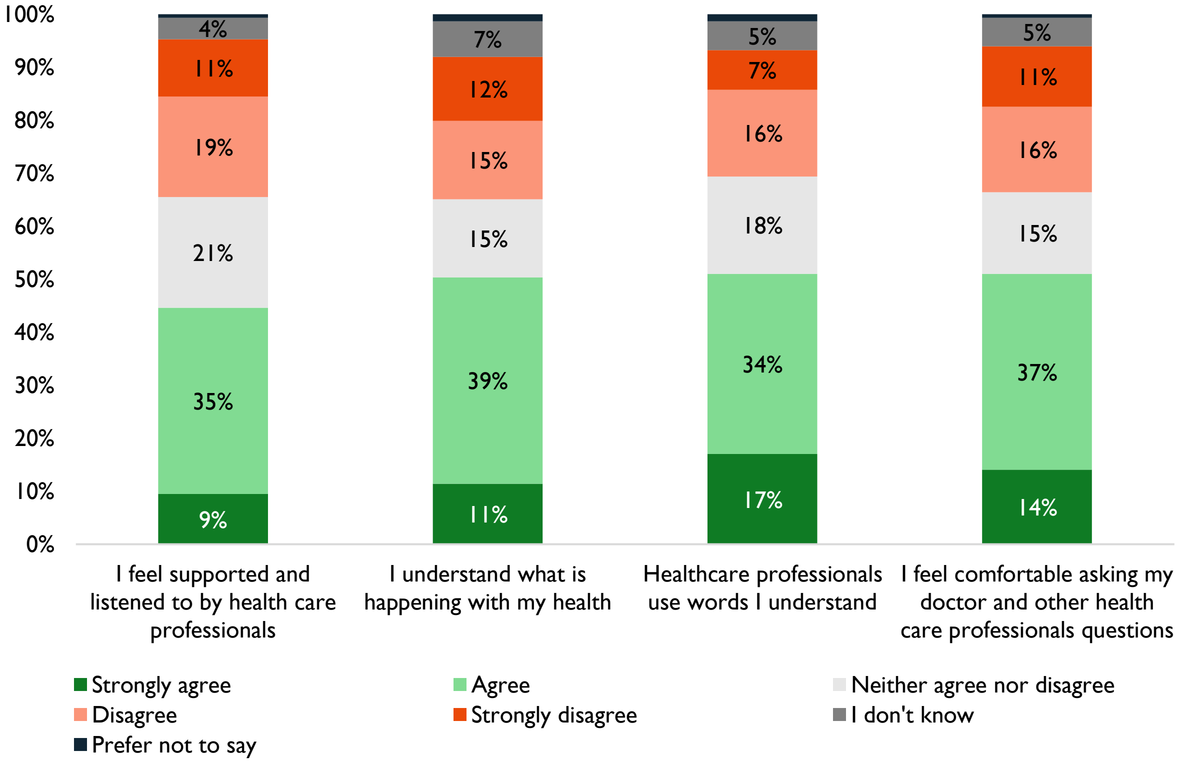
However, children with multiple conditions self-reported greater difficulties in understanding their health and communicating with healthcare professionals. A higher proportion of those with multiple conditions reported the following:

- 33% (n=18 / 54) did not understand what was happening with their health, compared to 19% (n=17 / 88) of those with 1 condition.

- 39% (n=21 / 54) disagreed that healthcare professionals used words they understood, compared to 11% (n=10 / 87) of those with 1 condition.

Over half of the children and young people in the sample (57%, n=84 / 148) self-reported feeling mostly scared or nervous before an appointment. Notably, a higher proportion of girls (61%, n=, n=42 / 69) reported feeling scared or nervous before an appointment compared to boys (53%, n=39 / 74). Additionally, 50% (n=75 / 149) felt they needed more support or information from healthcare professionals.

Interestingly, just under half (46%, n= 30 / 65) of those who felt supported and listened to by healthcare professionals also reported feeling scared or nervous before an appointment. However, of those who reported feeling unsupported, **73%** (n=32 / 44) reported the same feeling.



Proportion of children and young people in the sample that agreed or disagreed with different statements about their experiences with healthcare

Chart 16: *Child survey Q: 'How much do the following statements reflect your experience with going to hospitals, the doctors, and other places related to your neurological condition' Base n=147-149.*

Children and young people affected by neurological conditions shared their experiences of healthcare services. The key challenges highlighted were:

- **Difficulty with appointments and access to professionals**

  "More regular appointments"

  " Actually hold the meetings they say they will hold, do the tests they say they need to do in a timely manner"

- **Difficulty communicating with professionals**

  Tell me that my condition is real and that it's not just "all in my head" or that [I'm] "faking for attention". a big reason [I'm] so insecure about my condition is because of doctors and healthcare professionals that make me feel like [I'm] just being silly and that nothing [I'm] experiencing is actually real.

  "Be more understanding of Fnd. [I've] had doctors act like [it's] all in my head and like [I] can help my symptoms when [I] can not. They need more understanding on fnd and [shouldn't] be so fast to judge"

Carer's reflections

Carers' reflections on whether healthcare services were meeting their children's needs were generally more negative. Only around a third (31%, n=77 / 249) of parents and carers felt their child was happy with their healthcare experiences in the past year.

Carers of children (who felt the services were relevant) reported particularly negative experiences with **mental health services** and **government-provided personal and support services**:

- 45% (n=111 / 249) of carers agreed that medical and healthcare services were meeting their child's needs.
- Only 18% (n=36 / 198) agreed that government-provided support services met their child's needs.
- Even fewer, just 13% (n=20 / 159), agreed that mental health services met their child's needs.

Carers of older children (aged 13-17) were more likely to report dissatisfaction with both **medical/healthcare services** and **government-provided services**, and were generally more unhappy with their experience:

- 52% (n=47 / 90) of carers of children aged 13-17 disagreed that medical and healthcare services met their child's needs, compared to 20% (n=10 / 50) of carers for children aged 0-5, and 29% (n=30 /109) for those caring for children aged 6-12.
- 71% (n=50 / 70) of carers of children aged 13-17 disagreed that government-provided personal and support services met their child's needs, compared to 49% (n=42 / 86) of carers for children aged 6-12, and 45% (19 / 42) for those caring for children aged 0-5.
- 71% (n=50 / 70) of carers of children aged 13-17 disagreed that mental health services met their child's needs, compared to 62% (n=41 / 66) of carers for children aged 6-12.

Experience with support services

1 in 4 children self-reported that they do not receive any support outside of their home, and this figure did not vary significantly by age. Where children did receive support, the most frequently reported source of support for children and young people was through their school. This may reflect the importance of educational settings in providing both academic and emotional support to children affected by neurological conditions. Specifically:

- 38% (n=56 / 147) reported receiving support from their school for schoolwork.
- 24% (n=36 / 147) received support for their happiness and wellbeing at school.
- 16% (n=23 / 147) received support related to their attendance.

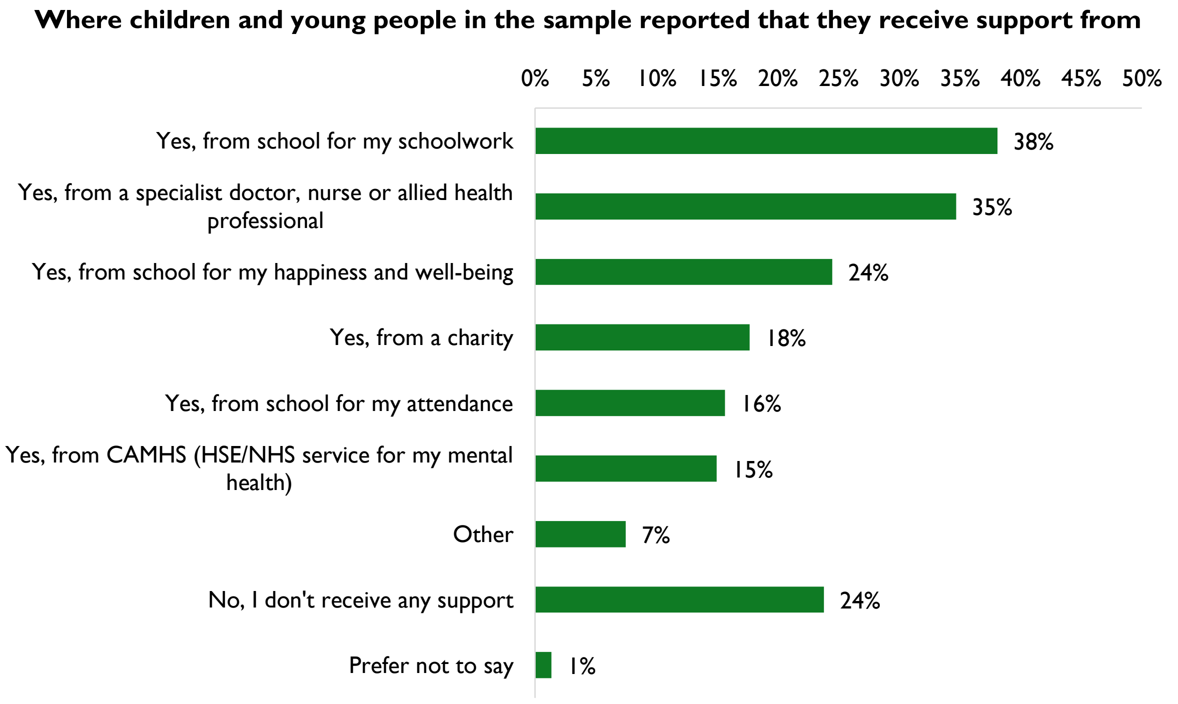


Chart 17: *Child survey Q: 'Do you get support from outside your home?' Base n=147.*

Additionally, 35% (n=51 / 147) of children reported receiving support from a specialist doctor, nurse, or allied health professional, indicating that professional healthcare support remains an important part of managing their condition.

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

About the carers

The survey captured responses from a wide range of carers, reflecting different ages, genders, ethnicities, and locations across the UK.

The majority of carers reached in the sample were female (78%, n=969 / 1241) and over half (59%, n=732 / 1242) were aged 55 or older. This reflects the caregiving role often being undertaken by individuals in mid-life or later. The sample also included a diverse range of carers from across the UK.

78%	Female
21%	Male
0%	Other
0%	Prefer not to say

1%	18-24
5%	25-34
14%	35-44
21%	45-54
25%	55-64
22%	65-74
12%	75+

95%	White
1%	Black or Black British
2%	Asian or Asian British
1%	Mixed or multiple ethnic groups
1%	Other
1%	Don't know / Prefer not to say

73%	England
15%	Scotland
8%	Wales
4%	Northern Ireland

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

The majority of carers were closely related to the individuals they support: 47% (n=590 / 1243) of carers are the spouse or partner of the person they care for, while 37% (n=462 / 1243) are the parent or guardian. A smaller proportion, 9% (n=115 / 1243), are the child of the person they care for. Only 1% (n=10 / 1243) of the sample reported that they were a paid caregiver.

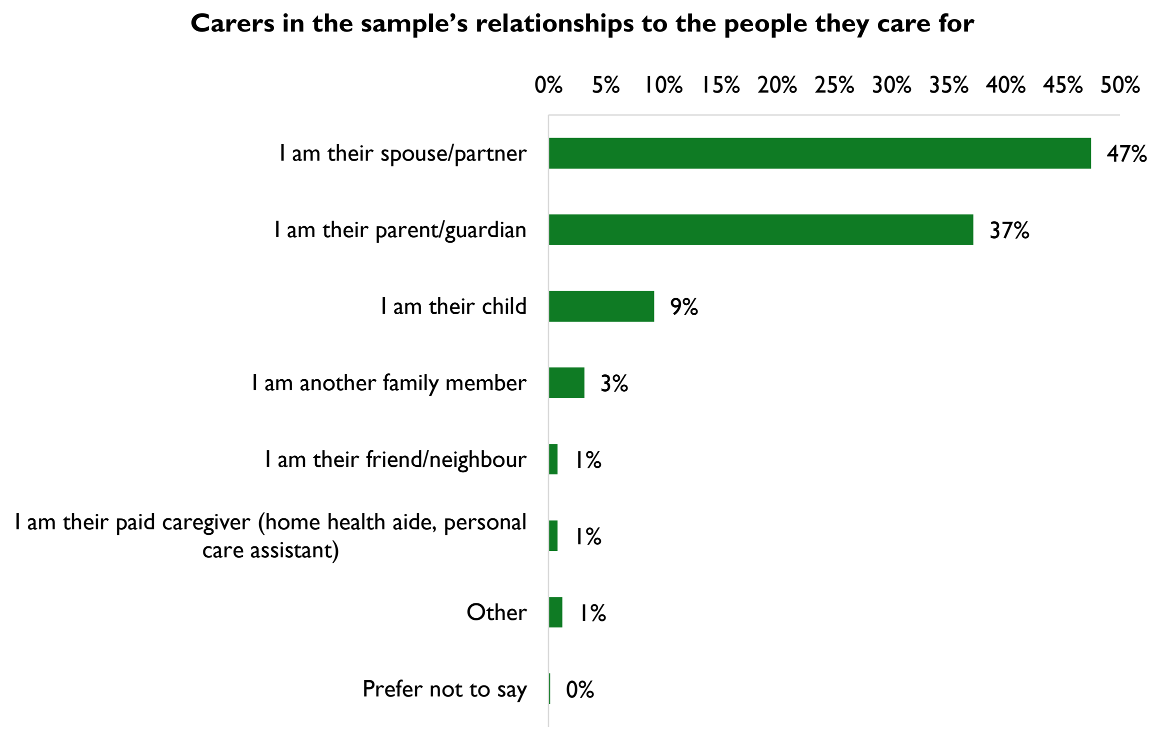


Chart 18: *Carer survey Q: 'What is your relationship to the person you care for?' Base n=1243.*

Level of caring responsibility

A large proportion of carers in the sample (73%, n=910 / 1244) reported being the primary caregiver for the person they support. Additionally, 19% (n=233 / 1244) of carers share the main caregiving responsibilities with someone else, while 8% (n=94 / 1244) assist with caregiving but are not the primary caregiver. Additionally, 15% (n=192 / 1245) of carers reported caring for more than one person.

Caring hours and long-term commitment

Over half of carers (52%, n=651 / 1246) reported spending 50 hours or more each week caring for the individual they support. Additionally, almost a third (29%, n=355 / 1245) have been providing care for more than 10 years, showing the long-term nature of the role.

Intensity of care

The time spent on caregiving is further reflected in the level of dependency of the person being cared for. 95% (n=1188 / 1244) of carers reported that the person they care for relies on them to some degree for daily activities, with 48% (n=591 / 1244) stating that the person they care for requires assistance with most or all daily activities, highlighting the significant level of dependence.

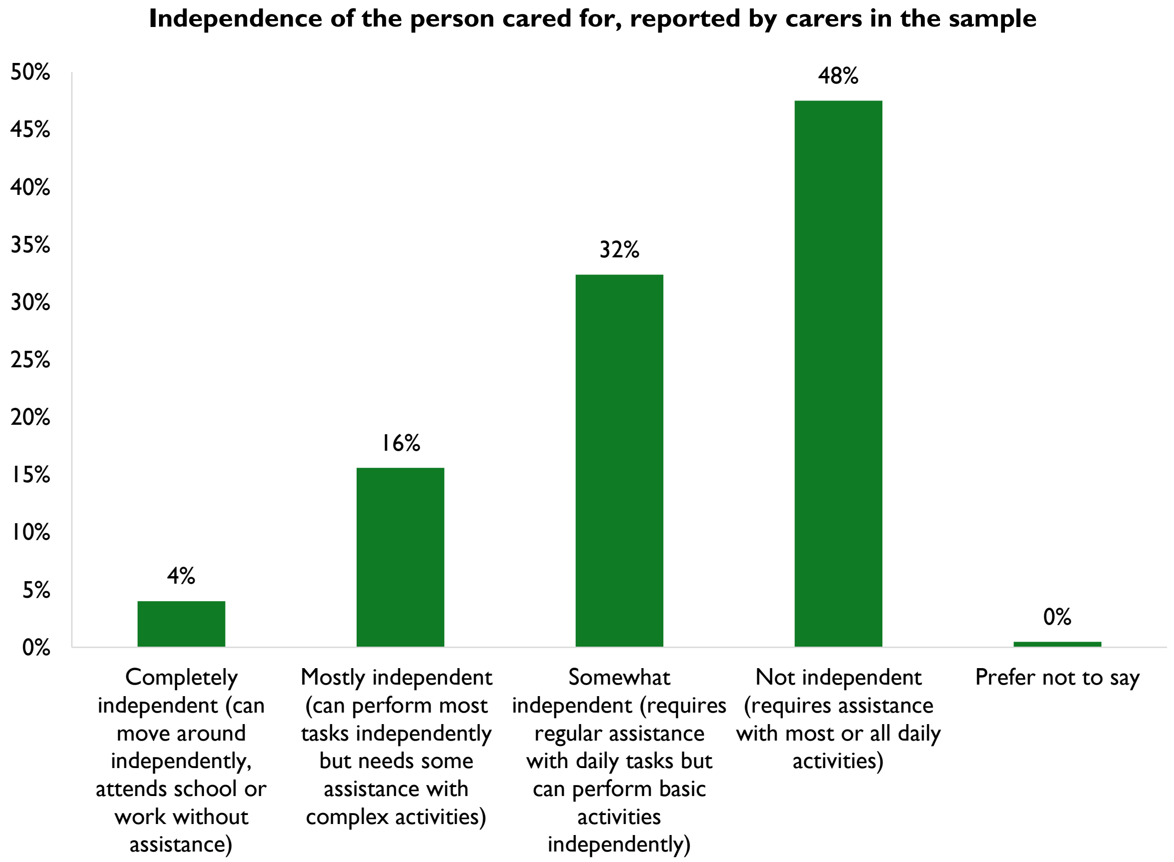


Chart 19: *Carer survey Q: 'How independent would you say the person you care for is in their daily activities without your assistance?' Base n=1244.*

Carer's experiences

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

The majority of carers reported feeling capable of meeting the day-to-day needs of the person they care for, with 78% (n=965 / 1241) stating they could meet these needs, and 69% (n=861 /1241) reporting that they were able to meet the person's health and wellbeing needs.

- Carers of children were more likely to feel confident in their ability to meet their needs. 90% (n=226 / 251) of carers of children reported being able to meet day-to-day needs, and 82% (n=204 / 250) said they could meet health and wellbeing needs. In comparison, 73% (n=629 / 859) and 66% (n=564 / 860) of carers of adults reported the same, respectively.
- However, carers with long-term health conditions of their own were less likely to report being able to meet the day-to-day needs of the person they cared for. 72% (n=485 / 673) of carers with their own long-term health conditions agreed they could meet these needs, compared to 84% (n=423 / 503) of those without a health condition.

Managing their own health and wellbeing

Despite their ability to support others, carers often struggled with their own needs. Only 51% (n=627 / 1241) of carers felt they could manage their own health and wellbeing, and 22% (n=268 / 1223) reported that they suffer from a mental health condition.

This issue was also reflected in how carers experienced their day-to-day lives. 84% (n=1043 / 1243) of carers reported finding day-to-day life challenging at least some of the time, with 16% (n=197 / 1243) of carers indicating that every day felt challenging. Carers supporting more than 1 person were more likely to report finding every day challenging, with 22% (n=41 / 190) feeling this way compared to 15% (n=152 / 1043) of those supporting just 1 person.

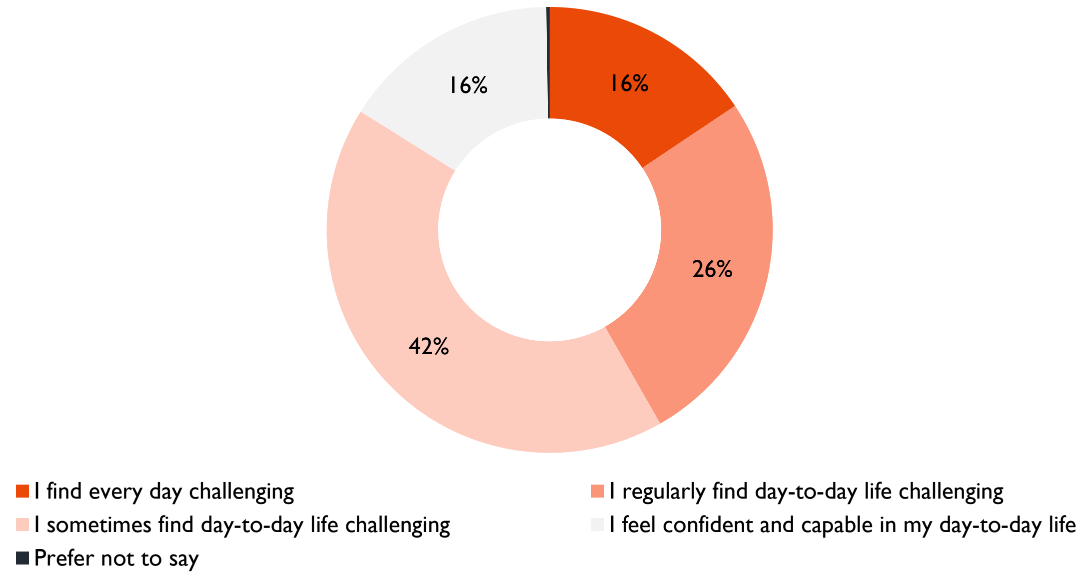

Proportion of carers in the sample that reported finding their day-to-day life challenging

Chart 20: *Carer survey Q: 'How do you feel most of the time about your own life?' Base n=1243.*

Carers who supported individuals with more independence were more likely to report feeling confident and capable in their day-to-day life. 28% (n=68 / 244) of carers supporting someone with complete or partial independence felt confident, compared to only 13% (n=128 / 992) of those caring for individuals who were less independent.

Conditions and their impact on carers' confidence[12]

Carers of individuals with Dystonia (23%, n=9 / 39), Alzheimer's Disease (23%, n=7 / 31), and Huntington's Disease (23%, n=7 / 31) were most likely to report feeling confident and capable in their day-to-day lives.

Conversely, carers of individuals with Functional Neurological Disorder (FND) (5%, n=5 / 92), Migraine (8%, n=4 / 49), and Acquired Brain Injury (8%, n=5 / 60) were least likely to report feeling confident and capable.

Impact of caring on work and financial stability

Carers frequently reported that their responsibilities had a significant impact on their work and financial stability. Nearly half (49%, n=601 / 1233) of carers reported having to cut back on other expenses due to the cost of caring, while 48% (n=599 / 1236) had to reduce work hours or leave their jobs entirely. Around 6 in 10 carers felt unable to advance in their careers or pursue educational opportunities (59% – n=724 / 1233; and 62% – n=766 / 1236 respectively).

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[12] Please note that only conditions for which 30 or more carers responded to this question were included in this breakdown

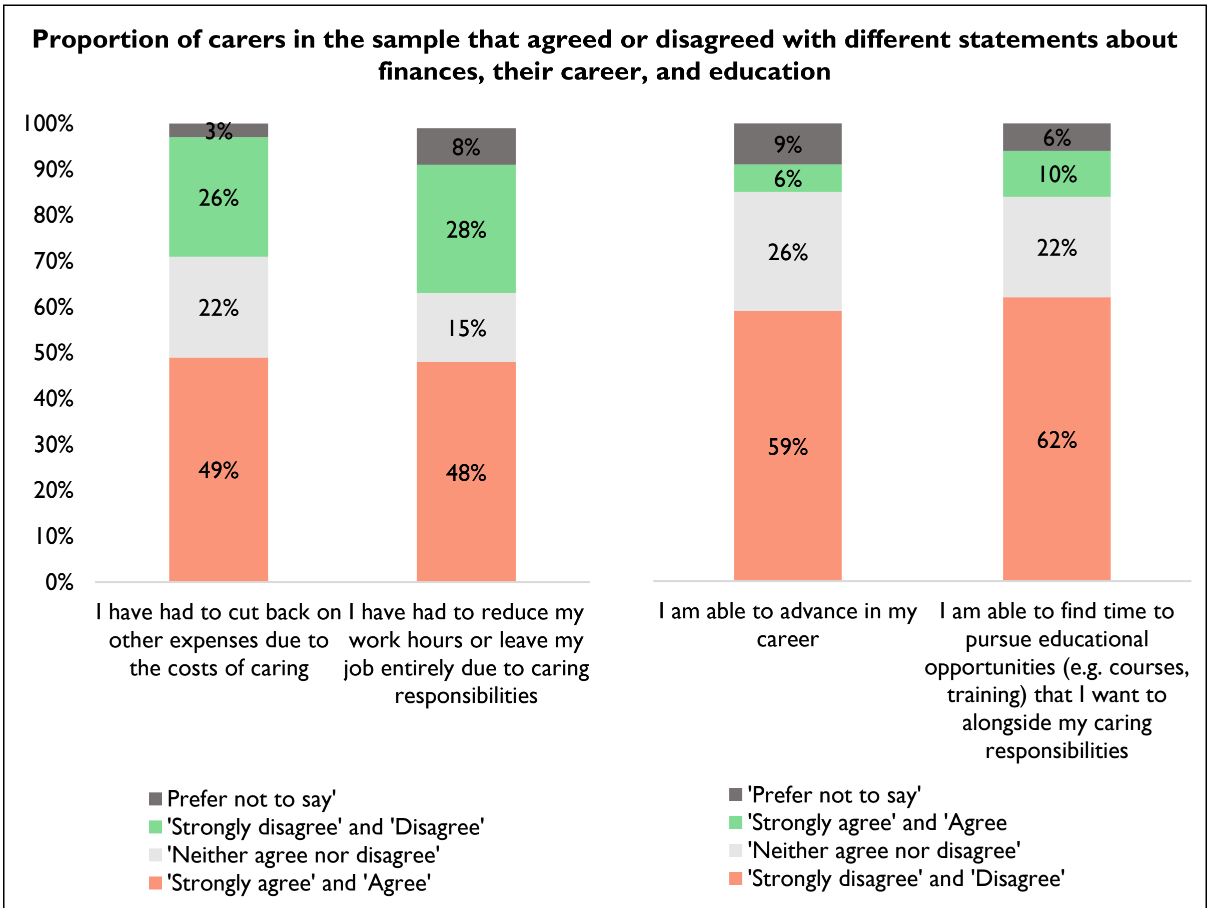
Proportion of carers in the sample that agreed or disagreed with different statements about finances, their career, and education

Chart 21: *Carer survey Q: 'To what extent do you agree with the following statements?' Base n=1,233-1,236.*

Carers of children and young people were particularly affected, with 68% (n=171 / 251) reporting having to cut back on expenses and 74% (n=186 / 251) needing to reduce their work hours or leave their jobs.

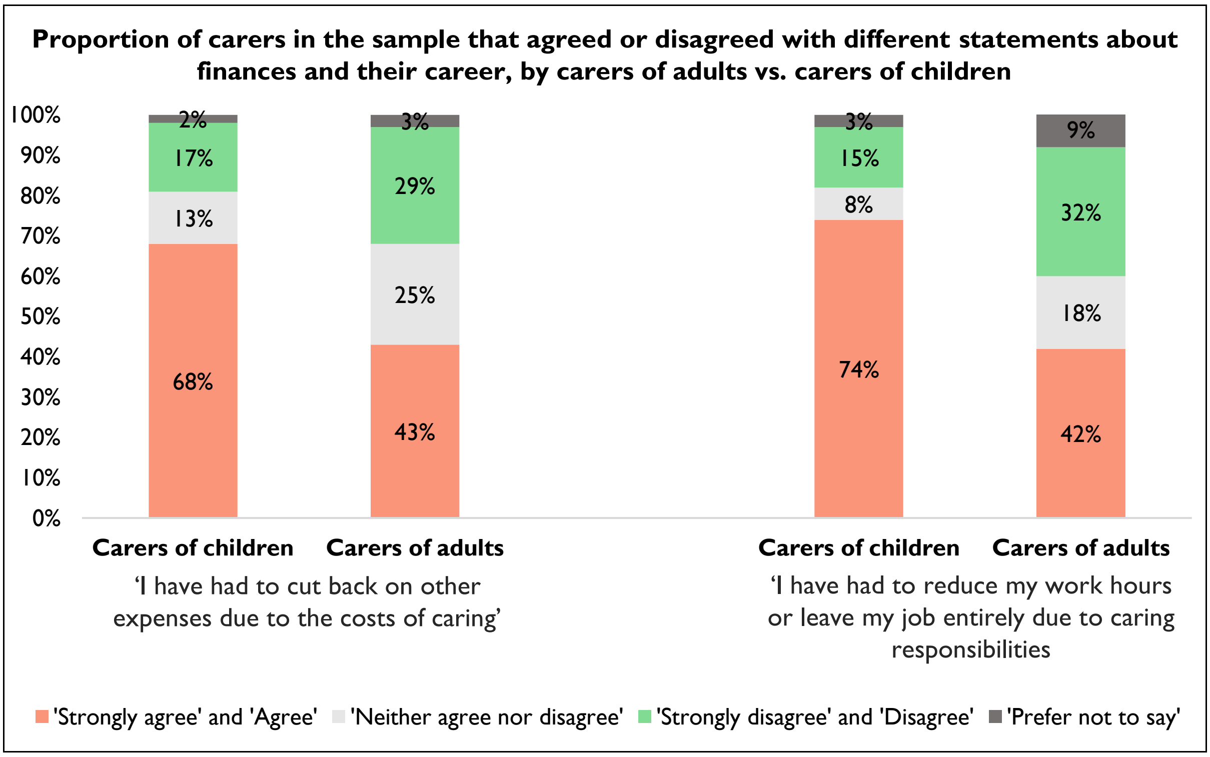
Proportion of carers in the sample that agreed or disagreed with different statements about finances and their career, by carers of adults vs. carers of children

Chart 22: *Carer survey Q: 'To what extent do you agree with the following statements?' by 'How old is the person you care for?' Base n=251-855.*

Carers of individuals with Spina Bifida (85%, n=34 / 40), Fibromyalgia (81%, n=26 / 32), and Autism (75%, n=101 / 135) were the most likely to report reducing their work hours[13].

Over half of women (53%, n=508 / 963) reported reducing their work hours or leaving their jobs, compared to 32% (n=83 / 262) of men.

Barriers to effective caregiving

Carers of adults

Carers of adults most often reported that a lack of access to healthcare professionals affected their caregiving experience, with 85% (n=726 / 856) of carers indicating this was an issue to some degree (a little, somewhat, quite a lot, or very much). This was followed by their own health condition(s), with 80% (n=682 / 857) of carers reporting that their own health conditions impacted their caregiving experience. Additionally, 75% (n=641 / 857) of carers felt that a lack of knowledge or training in caring for the specific condition of the person they care for was a barrier.

Proportion of carers for adults in the sample that indicated an impact of different factors on their experience providing care

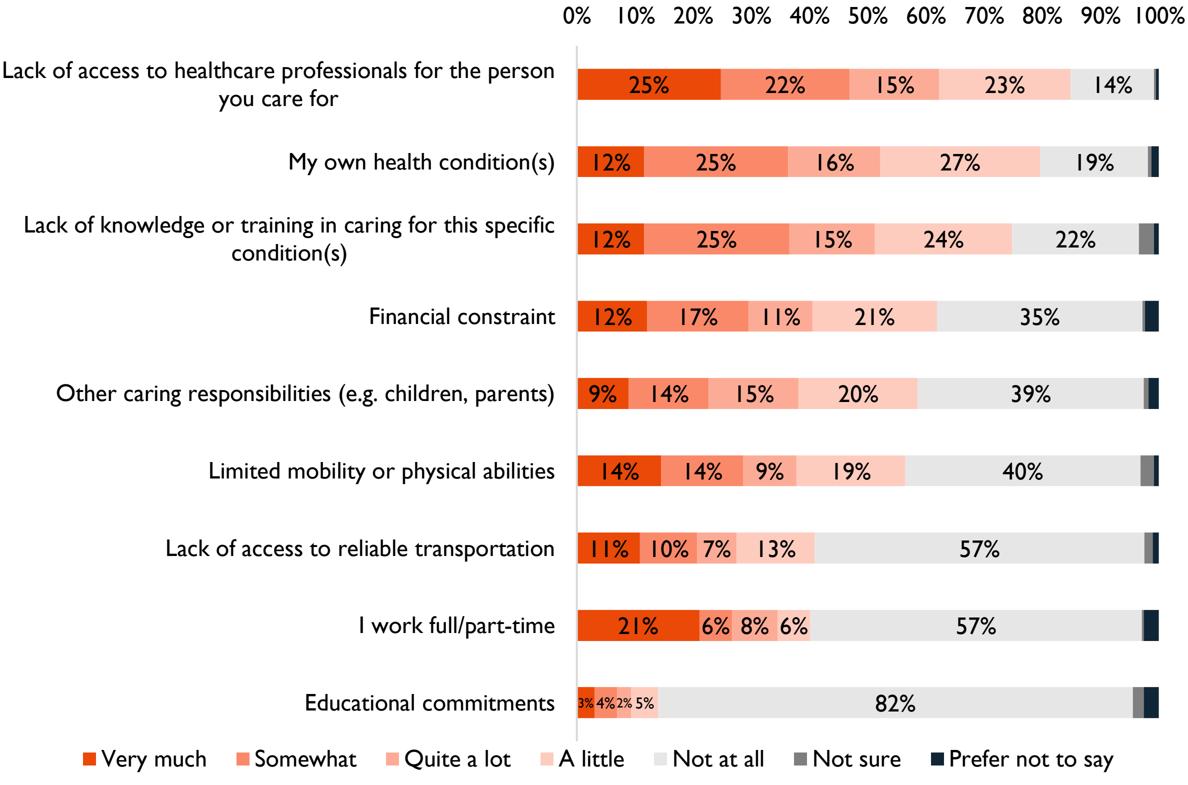

Chart 23: *Carer survey Q: 'How much do the following affect your experience providing care?' by 'How old is the person you care for?' coded into carers of adults. Base n=853-857.*

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[13] Please note that this only includes conditions for which 30 or more responses were received

Carers for adults with the following conditions reported the highest[14] proportions of lack of access to healthcare professionals as a barrier:

- Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS): 100% (n=57 / 57)
- Functional Neurological Disorder (FND): 98% (n=50 / 51)
- Stroke / Tia: 94% (n=30 / 32)

Similarly, the highest proportions of carers reporting a lack of knowledge or training to care for the person they support were for those caring for individuals with:

- Functional Neurological Disorder (FND): 88% (n=45 / 51)
- Corticobasal Degeneration (CBD): 86% (n=51 / 59)
- Progressive Supranuclear Palsy (PSP): 86% (n=146 / 170)

Carers of children

Carers of children most often reported that other caring responsibilities affect their experience providing care, with 88% (n=220 / 250) of carers of children indicating this was a challenge to some extent (a little, somewhat, quite a lot, or very much).

Proportion of carers for children in the sample that indicated an impact of different factors on their experience providing care

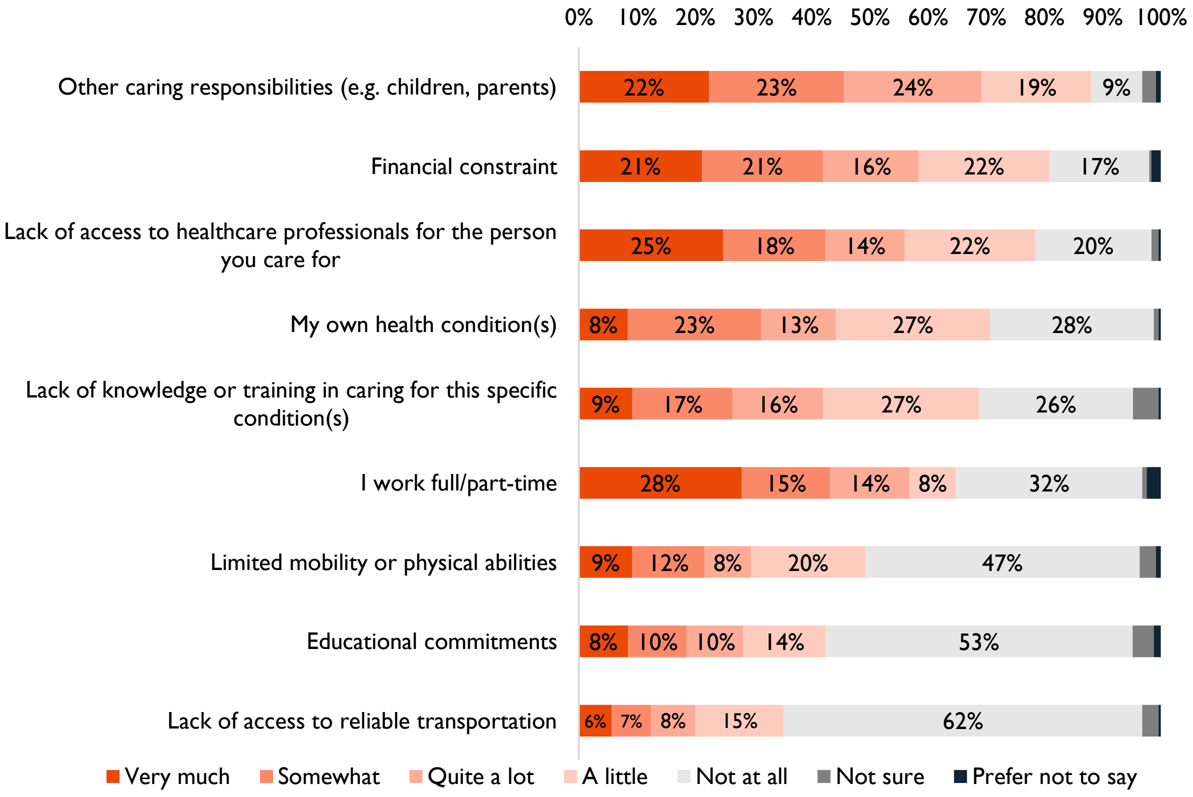

Chart 24: *Carer survey Q: 'How much do the following affect your experience providing care?' by 'How old is the person you care for?' coded into carers of children. Base n=246-250.*

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[14] Please note this excludes conditions for which fewer than 30 responses were given to this question

Financial constraints were the second most common challenge reported by carers of children, with 81% (n=202 / 250) reporting this factor impacting their caregiving experience. Additionally, 78% (n=196 / 250) of carers of children reported that lack of access to healthcare professionals for the person they cared for was a barrier. Working full-/part-time was reported as a barrier for 65% (n=162 / 250) of carers of children, with almost half (43%, n=70 / 162) of this group reporting that it affects their experience caring 'very much'.

Carers of those affected by neurological conditions shared their experiences with caring. The key challenges highlighted were:

- **Lack of condition specific knowledge and understanding**

  "All other places approached say that she is too young, too complex or both... if government - top to bottom - was able to better recognise that unpaid carers provide the bulk of care... care providers [wouldn't] end up treating people as commodities or objects."

  "I have been surprised by how little opportunity has been offered to me to understand and be trained in safe ways of lifting, transferring and moving my wife, who has limited mobility because of her neurological condition."

- **Emotional and practical strain on carers**

  "I worry if my husband's condition gets worse and I am unable to cope. The huge costs of care worry me."

  "We have had a respite break... but my child needed to come too... I am exhausted... My child's condition is classed as rare... we get no support from the NHS."

  "We pay for a private 30 min carer to help get him up otherwise I have to cope... council social services carer visits offered were so hopeless..."

- **Struggles with home care and adaptations**

  "I had to drag him on the seat of his Walker to the stairlift to get him to bed... I am in my eighties and found it really difficult... Different teams would be arranged... then suddenly discharge him from their care."

  "Getting good advice for adapting the house was scarce... if only one could see into the future."

Support for carers

Carers frequently reported issues accessing the support services they felt were relevant to them. Notably, 67% (n=613 / 912) of carers were unable to access mental health and wellbeing support for themselves, and 67% (n=462 / 691) also reported being unable to access respite care. Additionally, 57% (n=309 / 543) reported challenges accessing transport services.

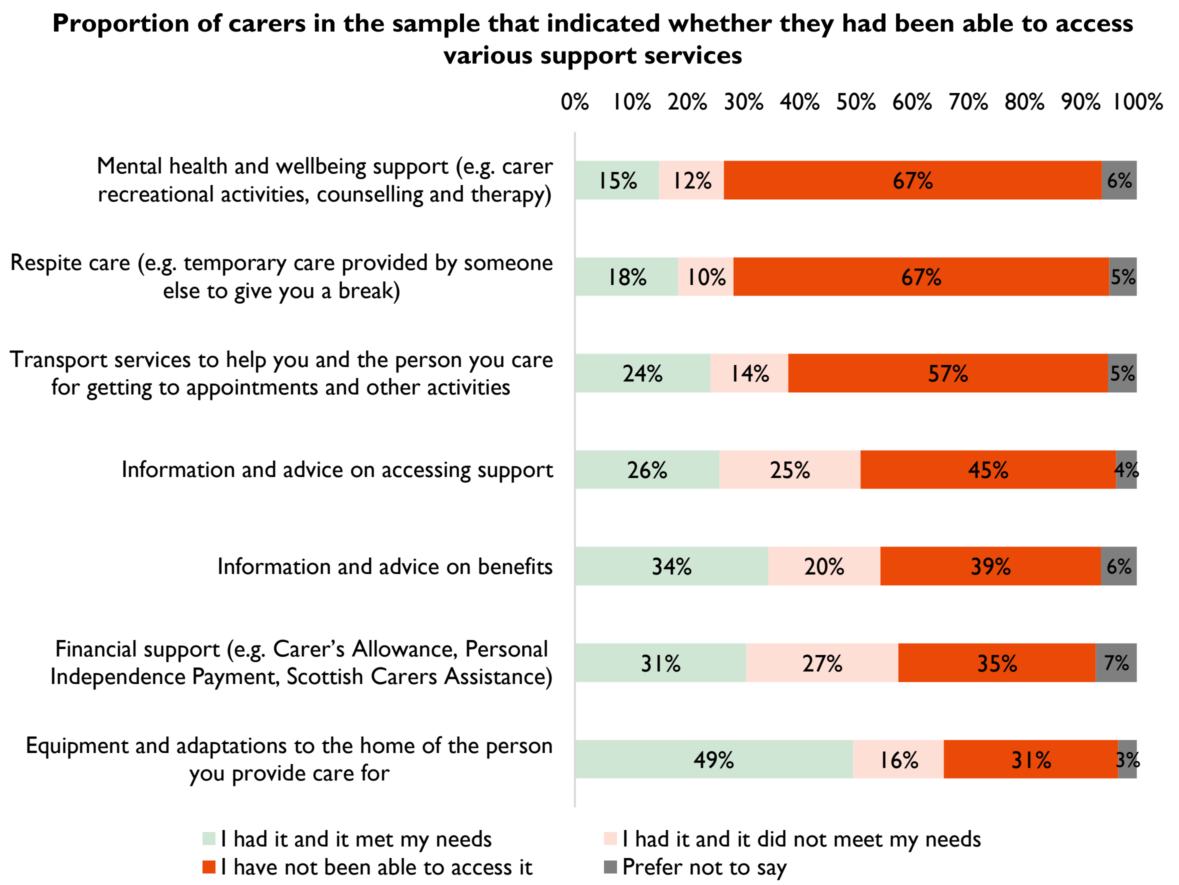

Chart 25: *Carer survey Q: 'In the past 12 months, have you used any of the following types of support for your caring responsibilities?' coded to exclude those that indicated a service was 'not relevant'. Base n=543-1,033.*

Those who had been unable to access respite care or mental health support were more likely to report finding day-to-day life challenging. 21% (n=126 / 612) of those who couldn't access mental health support found every day challenging, with 25% (n=116 / 461) of those who couldn't access respite care reporting this. This was notably higher than the 16% (n=194 / 1243) of the overall sample who felt that every day was challenging.

Only 24% (n=293 / 1239) of carers felt supported in their caregiving role, with half of the sample (50% (n=621 / 1239) reporting they did not feel supported.

Of the services that carers were able to access, the most effective was equipment and adaptations for the person they cared for, with 75% (n=435 / 577) agreeing that it met their needs. However, many carers felt that financial support (47%, n=218 / 464) and information and advice on accessing support (49%, n=259 / 525) did not meet their needs.

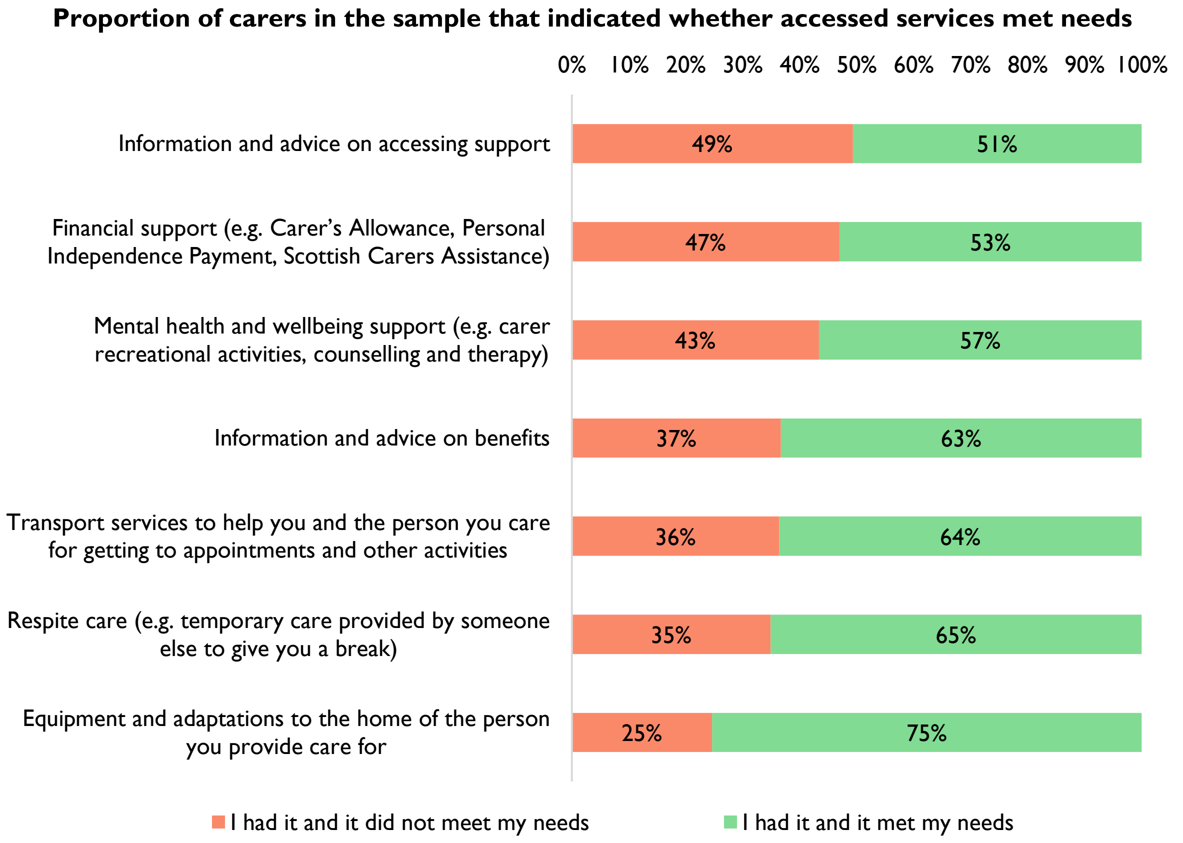

Chart 26: *Carer survey Q: 'In the past 12 months, have you used any of the following types of support for your caring responsibilities?' coded to include only those that indicated they had accessed a service. Base n=195-577.*

Carers who felt that mental health support met their needs were more likely to report feeling confident and capable in their day-to-day lives (20%, n=27 / 135) compared to just 9% (n=9 / 105) of those whose mental health support did not meet their needs.

Carers of those affected by neurological conditions shared their experiences with support services. The key challenges highlighted were:

- **Respite care is unavailable and hard to access**

  "It has been over 2 and a half years and we have had no respite. It has had massive effect on mine and there quality of life. Good respite provision for people with very complex health and learning disabilities does not exist in our area and anywhere further away has no space or prospect of space. As a parent and carer respite allows everyone to have a break and recharge and be able to care as they would want for people they love."

  "There is not an adequate respite solution in Scotland that has space for my son or his twin... Since moving to Scotland in April 2022... still waiting with no adequate solution."

- **Financial barriers to respite or day centre support**

  "I would love to be able to stop the isolation in which she lives, but I cannot cover the cost of a day centre for approximately £100 a day."

Chapter 4: Mental health

Prevalence of mental health across the sample

Diagnosed mental health conditions were common among adults affected by neurological conditions, with just over 1 in 3 adults affected by neurological conditions (36%, n=2857 / 7834) self-reporting this.

Beyond this, many more described an impact on their mood and mental health in connection with their neurological condition. In total, 84% (n=7174 / 8530) of adult respondents, including both those self-reporting and carers answering on behalf of an individual, said their condition affected their mood and mental health to some extent – whether a *little, somewhat, quite a lot,* or *very much*. Out of the 15 types of health impacts asked about, mood and mental health was the fourth most commonly experienced by the sample.[15]

Extent to which the adult respondents indicated their neurological condition(s) impact their mood and mental health

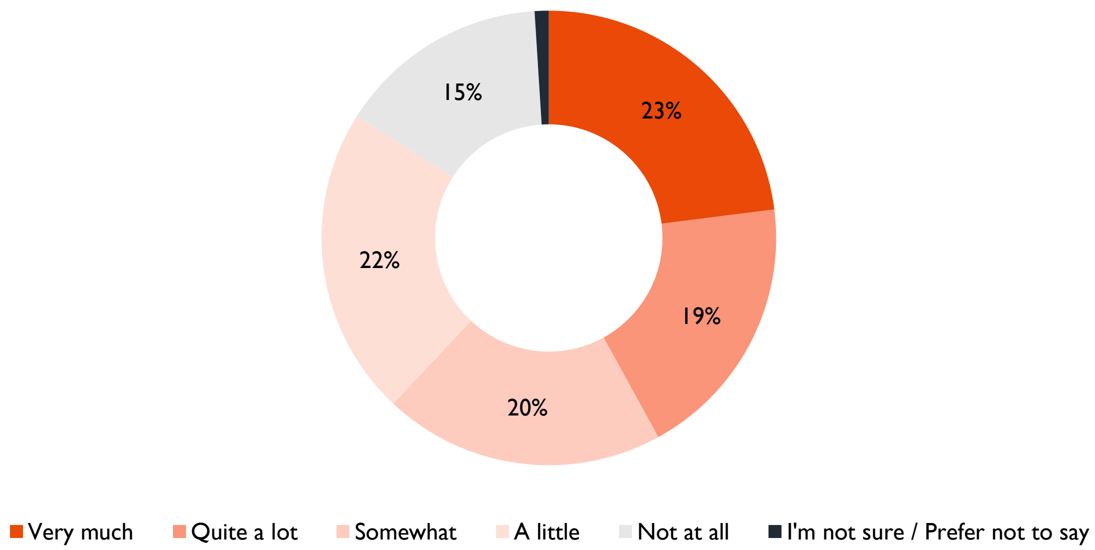

Chart 27: *Adult survey Q: 'Which, if any, of the following ways does your neurological condition(s) impact your health? Mood and mental health issues (e.g. anxiety, irritability, social withdrawal, psychosis, impulsive behaviour)' Base n=8,530.*

Certain groups of adults affected by neurological conditions were more likely to report that their mood and mental health were 'very much' affected by their condition. This was particularly common among:

- Those who reported also living with a mental health condition (45%, n=1273 / 2842) compared to those without one (9%, n=443 / 4833)
    - *Note: This data is based solely on adults answering for themselves, as carers were not asked if the person they support had a diagnosed mental health condition*
- Those aged 18-44 (36%, n=727 / 2020) compared to those aged 45 and over (19%, n= 1244 / 6489)
- Women (25%, n=1440 / 5815) compared to men (19%, n=487 / 2595)

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[15] This is based on the proportion that selected their neurological condition impacted their mood and mental health 'a little', 'somewhat', 'quite a lot', or 'very much'

- Respondents in lower income households – those earning under £35,000 **-** (27%, n=975 / 3625) compared to those earning more (18%, n=460 / 2608)
    - *Note: This data is based solely on adults answering for themselves, as carers were not asked the annual household income of the person they support*

While impacts on mental health were present across many conditions, certain groups of adult respondents, (*including those answering for themselves and carers responding on behalf of an individual),* were more likely to say their condition very much affected their mood and mental health. These included those living with:

- Autism (52%, n=134 / 258)
- Cluster Headache (47%, n=58 / 123)
- Chronic Headache (45%, n=127 / 281)
- Functional Neurological Disorder (45%, n=350 / 781)
- Restless Legs Syndrome (44%, n=127 / 288)

Overall, the findings suggest the significant emotional and psychological effects that many adult respondents associated with their neurological condition – particularly among those already living with a mental health condition or facing other compounding pressures.

Adults' experience with mental health services

Despite a high number of adults (and carers on their behalf) reporting that their neurological condition impacts their mood and mental health, many adults affected by neurological conditions indicated a lack of adequate support when it came to their mental health needs. Fewer than half of adults affected by neurological conditions (44%, n=3409 / 7758) agreed with the statement 'I have someone to talk to about my mental health and well-being', while over a third (37%, n=2865 / 7758) disagreed with this.

1 in 4 adults (25%, n=1900 / 7738) reported that they did not feel comfortable raising or discussing their mental health with a healthcare professional.

Among those who considered mental health services relevant to them (or the person they care for), nearly half (48%, n=2653 / 5519) disagreed with the statement: '*[My / Their] care from mental health services meets my needs*'. This perception varied across different groups:

- 56% of adults (or their carers) with multiple neurological conditions disagreed, compared to 43% of those with just 1 condition.
- 60% of adults (or their carers) who were still awaiting a diagnosis disagreed – substantially higher than the sample average.
- 58% of adults with a diagnosed mental health condition disagreed, compared to 40% of those without a diagnosis (but who still said mental health services were applicable to them).

A link also emerged between unmet need and broader struggles with daily life. Among adult respondents who selected *'I find every day challenging'* or *'I regularly find day-to-day life challenging*', 57% (n=1855 / 3251) disagreed that their care from mental health services meet needs. This contrasts with 28% (n=447 / 1604) of those who selected *'I feel confident in my day-to-day life'* or *'I sometimes find day-to-day life challenging.'*

Additionally, mental health services were less likely to be seen as having improved in the past year, with only 14% (n=716 / 5046) of those who felt they were relevant agreeing they had improved – this was lower than the 17% (n=817 / 4852) who felt personal and support services had improved, and the 24% (n=1936 / 8140) who reported this for medical and healthcare services.

Adult respondents shared their experiences with mental health. The key challenges highlighted were:

• **Mental health services reported as inaccessible or inadequate**	Long waits, dismissive experiences, and misaligned care approaches – especially with psychological services for physical conditions. *"Only because of my complex mental health condition am I receiving mental health support but it is not about my neurological disorders."* *"I had CBT... which was wholly inappropriate... it was always a discussion about what I should find the extra energy to do for myself... I was told there was nothing else and I was discharged."* *Mental health care doesn't exist and there is no help at all for my very recent ADHD diagnosis.*
• **Emotional toll of living with neurological condition(s)**	Respondents described anxiety, depression, and distress linked directly to their condition and experiences with care. *"I would like to be less anxious about my condition as it is a very visible disease"* *"The stress of being treated like a work shy scammer when you've worked all your life has a massive impact on your self worth and general mood!"*
• **Unsupported navigating Trauma / PTSD**	Respondents described unaddressed trauma, often worsened by how they were treated by healthcare professionals. *"There was no offer of someone to talk to about that experience and therapy to process the trauma."* *"The majority of ME patients also suffer from PTSD (myself included) as a direct result of how medical professionals have treated us..."*

Adults' experiences with counselling

Among adults (and carers reporting on their behalf) who considered counselling relevant, 46% (n=1932 / 4202) reported that they had not been able to access it, and of those who had accessed it, 43% (n=750 / 1746) said that it did not meet their needs (or the needs of the person they support). These findings point to significant barriers around both the accessibility and effectiveness of counselling for many respondents.

Proportion of adult respondents (or their carers) that indicated they had accessed counselling, and whether it had met needs

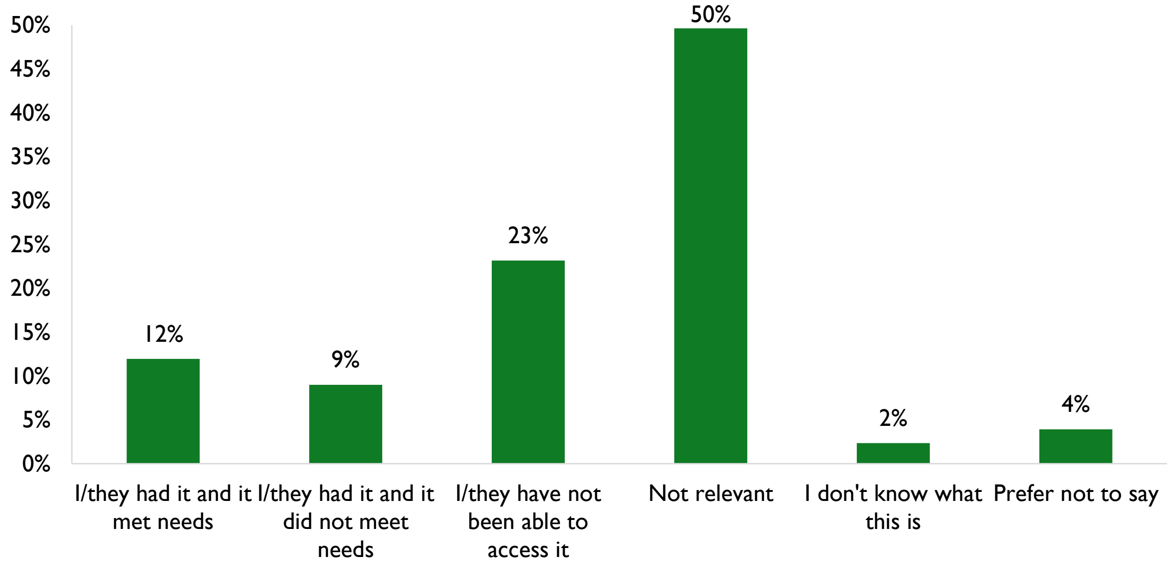

***Chart 28:** Adult survey Q: 'In the last 12 months, have you used any of the following services for your neurological condition(s)?' Base n=8,344.*

However, while many reported challenges with mental health, half (50%, n=4142 / 8344) of the sample, including both adults and carers answering on behalf of individuals, said that counselling services were not relevant to them.

When broken down by condition[16], the 5 conditions with the highest proportion of adult respondents (who knew what counselling was and felt it was relevant to them) reporting that they had *not been able to access counselling* were:

- Myasthenia (60%, n=21 / 35)
- Brain Aneurism (58%, n=19 / 33)
- Progressive Supranuclear Palsy (PSP) (56%, n=65 / 116)
- Guillain-Barré Syndrome (56%, n=34 / 61)
- Cluster Headache (56%, n=49 / 88)

For those who had accessed counselling but said it *had not met their needs* (or met the needs of the person they support), respondents with the following conditions most often reported this:

- Autism (63%, n=61 / 97)
- Chronic Headache (59%, n=47 / 80)
- Carpal Tunnel Syndrome (53%, n=28 / 53)
- Migraine (52%, n=122 / 233)
- Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) (52%, n=217 / 421)

These experiences appeared to be linked to how much adults and carers felt that their neurological condition (or the neurological condition of the person they support) affected their mental health. Among those who said counselling had not met their needs (or the needs of the individual they support), 46% (n=345 / 750) reported

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[16] Please note that conditions were only included in these breakdowns where base sizes were above 30, ensuring the data was robust enough for analysis

that their condition 'very much' impacted their mood and mental health. This was much higher than the overall sample, where only 23% (n=1975 / 8530) felt the same way.

Additionally, adults who reported that counselling had not met their needs were also more likely to have a self-reported mental health condition. 60% (n=452 / 750) of this group reported having a mental health condition, compared to 33% (n=2857 / 8691) of the overall sample.

This group also reported greater impacts on their day-to-day life. Among those who felt counselling hadn't met their needs:

- 72% (n=538 / 750) said their condition had a high impact on their daily life, compared to 46% (n=3991 / 8633) of the total sample.
- 85% (n=562 / 1180) said they *'find every day challenging'* or *'regularly find day-to-day life challenging,'* compared to 57% (n=4466 / 7776) of the overall sample.

Mood and mental health issues in the children's sample

Mood and mental health difficulties were commonly reported among children affected by neurological conditions. Over 6 in 10 (62%, n=90 / 145) of children indicated that their neurological condition affected their mood.

Proportion of child respondents that indicated their neurological condition(s) affects them in various ways

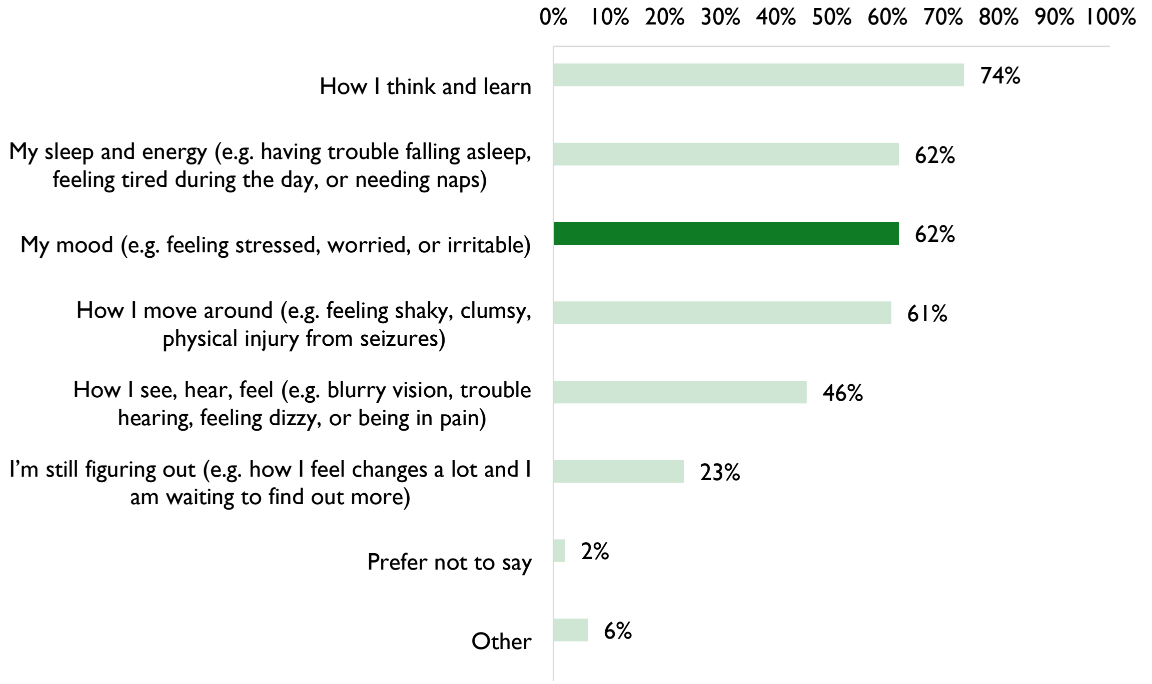

Chart 29: *Child survey Q: 'How does your neurological condition(s) affect you?' Base n=145.*

When looking specifically at carers responding on behalf of children, 8 in 10 (80%, n=198 / 249) reported that the child they care for experienced some degree of impact on their mood or mental health. This includes any response from *'a little'* to *'very much'* when asked the extent to which their neurological condition(s) impact their mood and mental health.

There were no notable differences between children with 1 neurological condition and those with multiple conditions in terms of the likelihood of experiencing mood or mental health-related impacts.

Children’s experiences with mental health services and counselling

In this sample, 15% (n=22 / 147) of children reported receiving support from Child and Adolescent Mental Health Services (CAMHS). This is notably higher than national figures: in England, for example, during 2022–23, 8% of the child and young person population were referred to CAMHS, and only 32% of those referred went on to receive support. This equates to approximately 2.5% of the child and young person population nationally receiving CAMHS support.

Access was higher among certain groups within the sample. Among children aged 14–17, 28% (n=18 / 64) reported receiving CAMHS support. Children who said their neurological condition impacted their mood were also more likely to have received support – 20% (n=18 / 90) of this group had accessed CAMHS.

Despite this level of access, carers frequently reported that mental health support – including counselling – was not meeting children’s needs. Just 13% (n=20 / 159) of carers agreed that the care received from mental health services received meets their needs. Among children who had accessed counselling, only 39% (n=24 / 61) of carers said that the service had met the needs of the child they support, while 61% (n=37 / 61) said it had not.

Chapter 5: Involvement in decision-making

Adults’ reflections on their role in decision-making

In general, adults affected by neurological conditions reported agreed that they are involved with decision-making. Half of the adults affected by neurological conditions in our sample (50%, n=3875 / 7751) agreed with the statement: ‘*I feel involved in decisions about my treatment, care, and support plan.*’ Additionally, 61% (n=4745 / 7754) of adults reported understanding their condition(s) and the available treatment options.

Proportion of adult respondents that agreed or disagreed with different statements about their role in decision-making

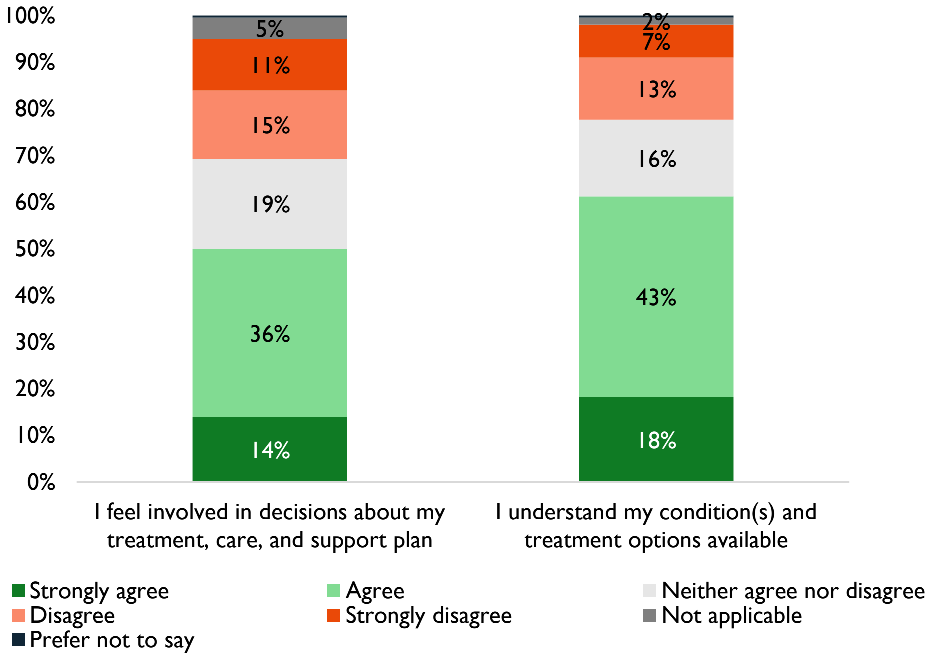

Chart 30: *Adult survey Q: ‘How does your neurological condition(s) affect you?’ Base n=145.*

Certain groups were more likely to feel involved in decisions about their treatment, care, and support plan:

- **Men** were more likely to agree (60% (n=1288 / 2154) compared to women (46%, n=2546 / 5483)
- Adults with **higher annual household incomes** were also more likely to feel involved, with 55% (n=1443 / 2622) of those earning over £35,000 agreeing, compared to 46% (n=1666 / 3655) of those earning under £35,000
- **Adults living with a spouse** (53%, n=2547 / 4784) were more likely to feel involved than those living alone (45%, n=839 / 1811)), with friends or housemates (37%, n=34 / 91), or with parents or other relatives (48%, n=368 / 774)

Additionally, those who felt involved in their healthcare decisions were notably more satisfied with their healthcare experiences**.** Among those who agreed they reported that they felt involved, 58% (n=2221 / 3858) reported being ‘happy’ or ‘very happy’ with their healthcare in the last 12 months, compared to just 7% (n=135 / 1989) of those who disagreed that they felt involved.

Adult respondents shared their experiences decision-making. Some of the key themes highlighted were:

- **Decisions made without their input** *"I have been waiting for over a year for a decision to be made about whether I am eligible to have a drug for my MS, a team of doctors needs to meet up but nothing seems to happen!"*
- **Poor communication delaying decisions** *"When [I] was diagnosed [I] was told to google my condition as they [didn't] know much about it."*

  "I have been forgotten about in the system many of times... zero communication throughout and I had no point of contact [I] was literally abandoned with my own overactive mind thinking all the worst things.

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

Carers of adults affected by neurological conditions often report being closely involved in the decision-making process regarding the care and treatment of the person they support. A majority (59%, n=726 / 1241) said they were '*fully involved in all decision-making*', while 28% (n=348 / 1241) noted they had significant involvement, with the person they care for making the final choice in most decisions. Only a small portion (10%, n=129 / 1241) felt that their role in decision-making was more limited, with some decisions being made by the person they care for or other professionals. A very small group (3%, n=36 / 1241) reported not being involved in any decisions about the adult they care for.

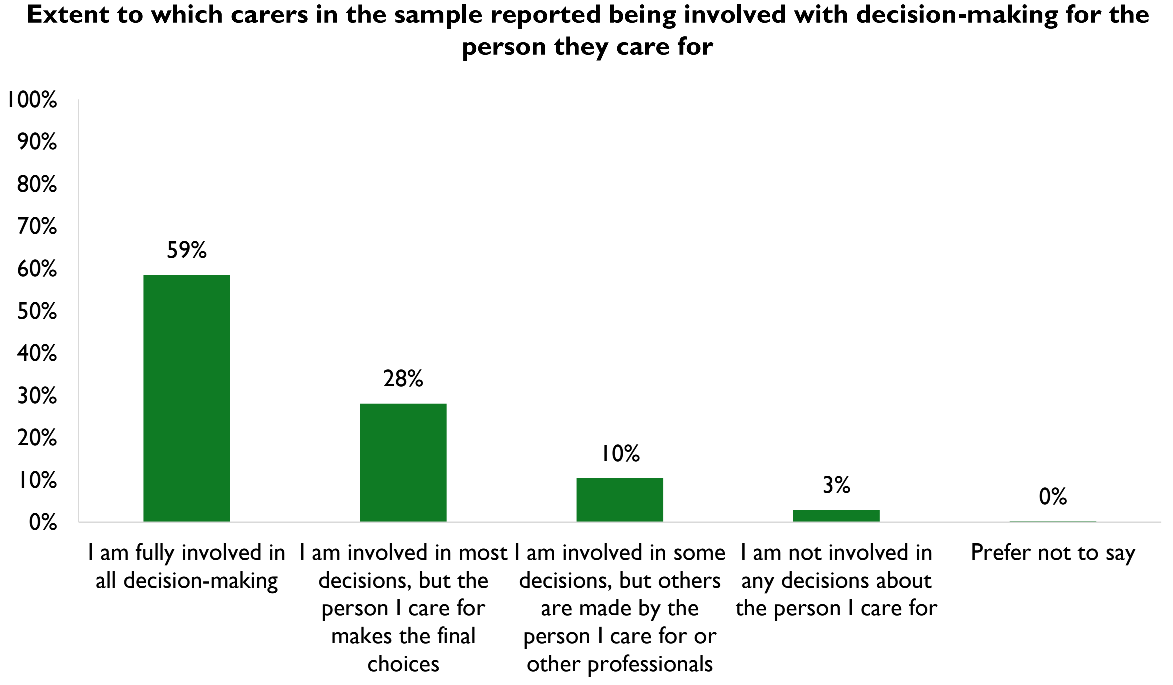

Chart 31: *Carer survey Q: 'How involved are you in making decisions for the person you care for?' Base n=1241.*

It is important to note that these findings may reflect the fact that carers were answering on behalf of the individuals they support. As a result, the level of involvement appeared to be higher when reported by carers, compared to adults self-reporting on their own involvement.

The level of involvement varied by age of the person being cared for. Carers of older adults (aged 65 and over) were more likely to report being fully involved in decision-making. Among this group, 64% (n=311 / 483) of carers said they were fully involved, compared to just 35% (n=58 / 166) of those caring for someone aged 18-34.

Children's sense of involvement in decisions about their health

The responses from children and young people about their involvement in decisions regarding their health was fairly split. Over a third (35%, n=52 / 149) of children and young people agreed that they 'don't always feel involved in decisions' about their health. This proportion was similar to the number of children who disagreed with this statement (34%, n=51 / 149), indicating that children are just as likely to feel involved as they are to feel not involved.

Proportion of children and young people in the sample that agreed or disagreed that they don't feel involved in decisions about their health

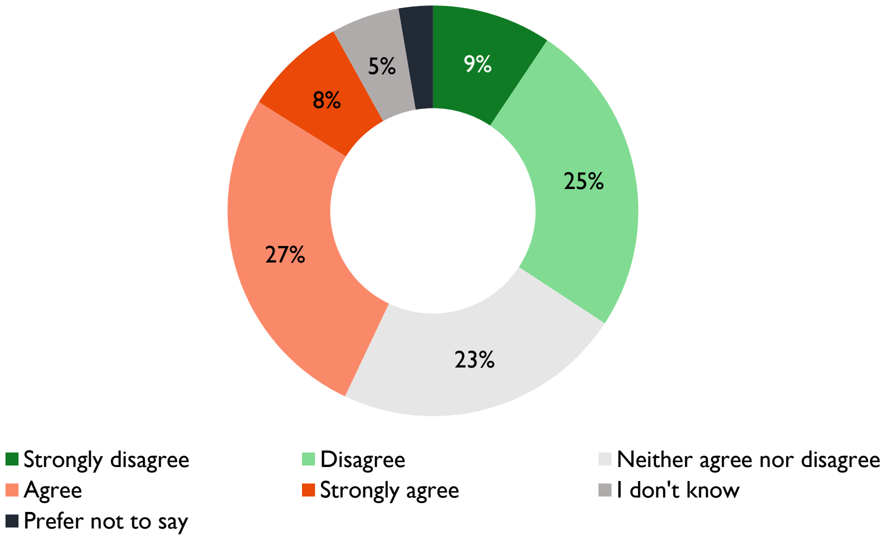

Chart 32: *Child survey Q: 'How much do the following statements reflect your experience with going to hospitals, the doctors, and other places related to your neurological condition? I don't always feel involved in decisions about my health' Base n=149.*

This trend was consistent across children of different ages, suggesting that feelings of involvement in health decisions were not strongly influenced by age within the sample.

Carers' role in health decisions for the children they support

Most carers of children affected by neurological conditions reported being closely involved in decisions about the health and care of the child they support. A large majority (81%, n=203 / 250) of carers said they were '*fully involved in all decision-making*', while 12% (n=29 / 250) reported that they were '*involved in most decisions*', but that the person they care for makes the final choices. Only 6% (n=14 / 250) said they were only involved with some decisions, with others being made by the child they care for or other professionals, and 2% (n=4 / 250) reported not being involved in any decisions about the child they care for.

This high level of involvement was particularly common among carers of younger children. Of those caring for children under 12, 89% (n=143 / 160) said they were fully involved in decision-making, comparted to 67% (n=60 / 90) of carers looking after children aged 13–17.

Chapter 6: Financial support

Experiences with finances

A large portion of adults affected by neurological conditions (and carers on their behalf) reported that their condition(s) 'very much' impact their ability (or the ability of the person they support) to manage financially. 1 in 5 (20%, n=1764 / 8621) adults or carers selected 'very much' when asked to indicate the extent to which their neurological condition affects their ability to manage financially. However, this was the least commonly reported impact out of the 8 day-to-day functioning issues asked about; a third (33%, n=2839 / 8621) of adults and carers on their behalf reported that their condition(s) did not impact their financial management at all. Excluding these respondents (as well as those that were not sure or preferred not to say), the portion of those indicating an effect 'very much' was around a third.

Extent to which the adult respondents indicated their neurological condition(s) affects their ability to manage financially

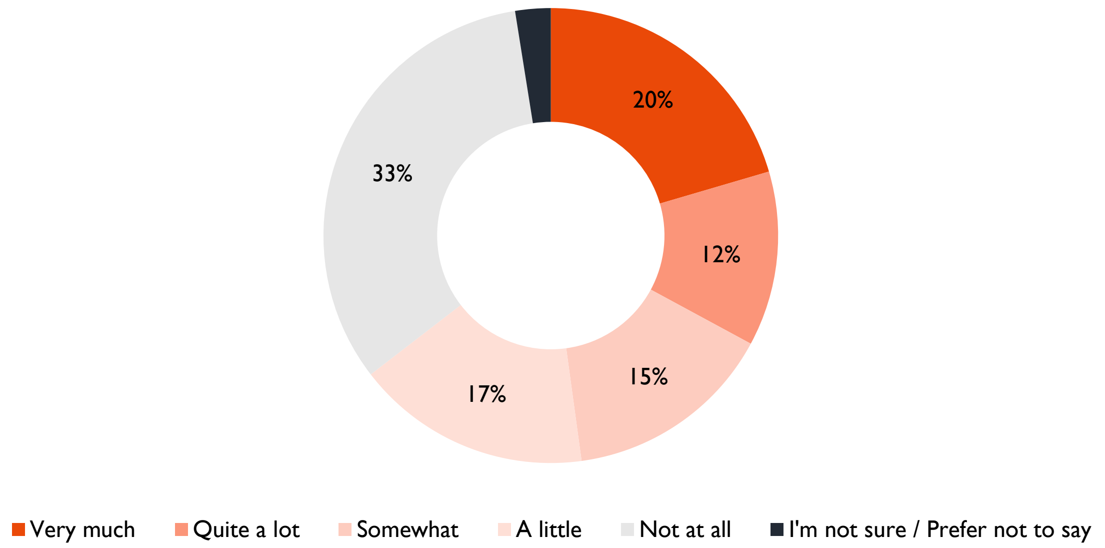

Chart 33: *Adult survey Q: 'How does your neurological condition(s) affect your ability to do the following? Manage financially (e.g. paying bills, being able to afford day-to-day expenses)' Base n=8,621.*

The impact of neurological conditions on financial management was more commonly reported by younger respondents and those living in supported accommodation, as reported by adults affected by neurological conditions and their carers. Among those under 35, 29% (n=269 / 919) selected 'very much', compared to 19% (n=1490 / 7676) of those aged 35 or above. Similarly, those living in supported accommodation also reported a higher level of impact.

When asked about the affordability of additional costs associated with their condition(s), 38% (n=2972 / 7759) of adults affected by neurological conditions disagreed that they could afford these extra costs.

Women were more likely to disagree with this statement – 42% (n=2286 / 5489) of women, compared to 29% (n=629 / 2156) of men. Additionally, respondents from Black, Asian, and Minority Ethnic backgrounds were more likely to report financial difficulty, with 51% (n=148 / 290) of respondents from these ethnic groups disagreeing they could afford additional treatment costs, compared to 38% (n=2781 / 7370) of white respondents.

Adult respondents shared their experiences with finances. The key challenges highlighted were:

• **Financial strain due to condition**	*"I just work to keep a roof over my head. I have zero quality of life. I am in constant pain, I'm in a lot of debt, working is very difficult and my life is thoroughly depressing."* *"I'm getting tired. Struggling with depression and social isolation... I need to stay in employment so would like to be considered as a priority patient."*
• **Loss of income or inability to work**	*"I gave up my self-employed job due to my condition... I stress all the time that I will lose my benefits and be made to work."*
• **Financial pressure on family or carers**	*"My husband gave up work 10 years ago to care for me and our children... we live only on benefits."* *"Without the support of my husband... and a private physiotherapy centre which costs around £240.00 per month I would definitely not be doing as well as I am."*

Financial support

Around half (45%, n=3469 / 7766) of adults affected by neurological conditions reported receiving financial support, and a higher proportion of carers (63%, n=697 / 1110) indicated that the adult they care for receives financial support.

Among those who self-reported receiving financial support, a higher proportion also self-reported that their neurological condition impacted their ability to manage financially. 77% (n=2683 / 3462) of adults receiving financial support said their condition impacted their financial management to some degree, with 24% (n=826 / 3462) reporting that it impacted them ‘very much’. This contrasts with 62% (n=4854 / 7770) of the total sample of adults responding on their own behalf who said their condition impacted their financial management at least to some degree, with only 17% (n=1322 / 7770) selecting ‘very much’.

Extent to which adult respondents receiving financial support indicated their neurological condition(s) affects their ability to manage financially

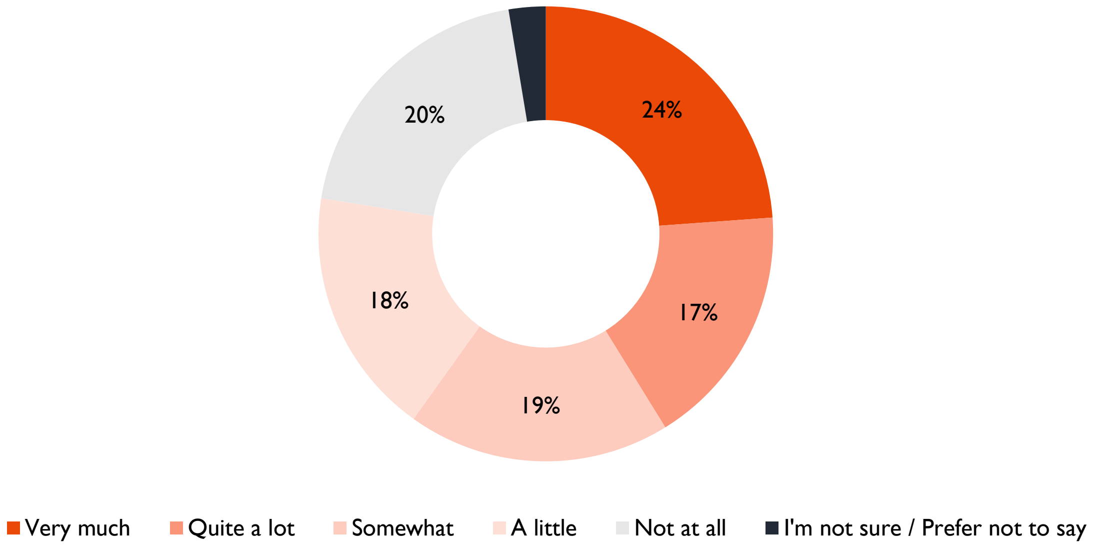

Chart 34: *Adult survey Q: ‘How does your neurological condition(s) affect your ability to do the following? Manage financially (e.g. paying bills, being able to afford day-to-day expenses)’ by only those who indicated they receive financial support in Q: ‘Which of the following types of support do you receive?’ Base n=3,462.*

Those with lower incomes were more likely to self-report receiving financial support. 61% (n=1186 / 1945) of adults with an annual household income of less than £20,000 received financial support, compared to 45% (n=3463 / 7742) of the total sample.

Certain conditions were more commonly associated with receiving financial support. The 5 conditions where the highest proportions of adults self-reported receiving financial support were:

- Spina Bifida (76%, n=119 / 156)
- Motor Neurone Disease (MND) (76%, n=28 / 37)
- Fibromyalgia (69%, n=538 / 779)
- Muscular Dystrophy (69%, n=24 / 35)
- Carpal Tunnel Syndrome (67%, n=111 / 165)

Chapter 7: Children's transition to adults' care

The transition process is often challenging and understanding how young people experience this shift is essential for improving support and information provided during this time. This chapter examines the experiences of children with neurological conditions aged 14-17 transitioning to adult care, exploring whether they feel prepared, have received adequate information, and the challenges they face during this process.

The transition from children's to adult care appears to be a significant challenge for many young people. Among those aged 14 to 17 in the sample, over 3 in 4 (76%, n=50 / 66) self-reported that they had *not received any information* about moving to adult care. Of this group, nearly a third (30%, n=15 / 50) expressed a desire to know more about the process. For the 14- to 17-year-olds who did indicate that they had received some information, 10 out of 14 respondents said they needed *more information*.

Whether children aged 14- to 17- years old in the sample have received any information about the transition to adult's care, and whether they would like to know more

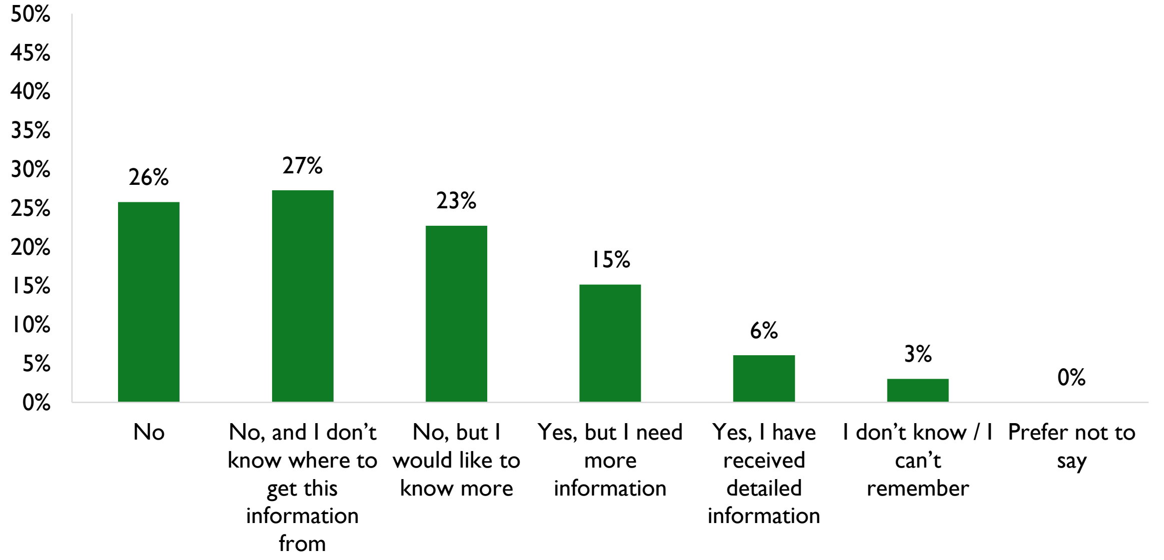

Chart 35: *Child survey Q: 'Have you received any information about moving from children's care to adult care?' coded to only include those respondents who are aged 14-17. Base n=66.*

Additionally, of those aged 14-17 only 8% (n=5 / 64) reported that they had a named worker that was supporting them from moving from children's to adult services.

Chapter 8: Access and confidence to participate in research

Access to clinical trials plays a crucial role in advancing the understanding of prevention, treatment, and support for neurological conditions. Participation in research not only drives improvements in medical treatments but is also considered a good marker of good care where patients are offered such opportunities to engage. To assess interest and participation in research, both adults and children affected by neurological conditions were asked about their willingness to participate in studies related to their condition, as well as their past involvement in research.

Adults' access and confidence to participate in research

The majority of adults affected by neurological conditions expressed interest in participating in research related to their conditions. 70% (n=5447 / 7765) of adult respondents self-reported they were interested in taking part in research about their neurological conditions. However, despite this interest, only around 1 in 4 (27%, n=2130 / 7767) adults have already participated in research.

Overall, 67% (n=3216 / 4836) of adults who reported they had not yet participated in research felt they would be interested in doing so in the future.

Whether adult respondents would be interested in taking part in research studies about their condition(s)

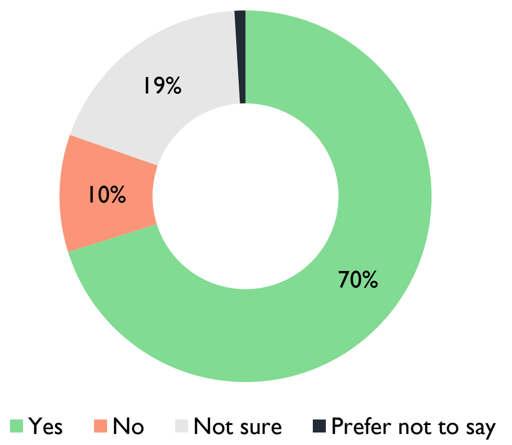

Chart 36: *Adult survey Q: 'Would you be interested in taking part in research studies about your condition(s) to help others with neurological condition(s)?' Base n=7,765.*

Children's access and confidence to participate in research

For children affected by neurological conditions, the level of interest in participating in research is also relatively high. Half of the children (51%, n=77 / 150) said they were interested in taking part in research about their condition. However, 81% (n=121 / 150) of children have not yet taken part in research, and only 1 in 8 (13%, n=20 / 150) have already participated.

Overall, there seems to be a significant gap in participation, with many children expressing an interest in research but not yet having the opportunity to engage in it.

Whether children and young people in the sample would be interested in taking part in research studies about their condition(s)

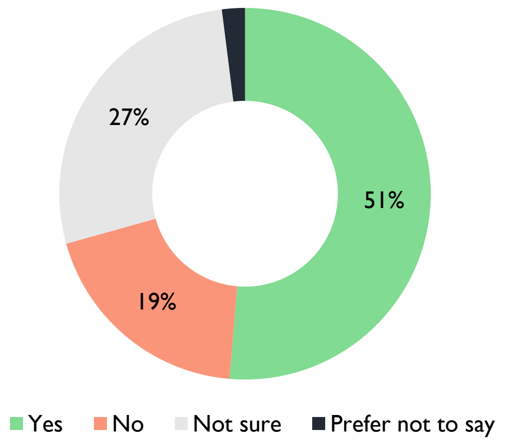

Chart 37: *Child survey Q: 'Would you be interested in taking part in research studies about your condition(s) to help others with neurological condition(s)?' Base n=150.*

Conclusion

An estimated 1 in 6 people in the UK live with a neurological condition. This report aims to provide a comprehensive picture of the experiences of people affected by neurological conditions across the UK, drawing on the experiences of over 10,000 individuals, including adults, children, and carers. The richness of responses, provided by those who took the time to complete the survey, reveals significant challenges in accessing various services and managing the effects of these conditions on people's lives.

Adults affected by neurological conditions reported frequently facing long and difficult journeys to diagnosis, with over 1 in 5 waiting more than 5 years. Even after receiving a diagnosis, many encounter limited access to essential healthcare services such as neuropsychiatry, neurorehabilitation, and pain management. Only 1 in 3 adults reported that services they accessed met their needs. The lack of coordinated, consistent care leaves many feeling unsupported. Continuity of care is rare, and many patients feel they are left to navigate complex conditions with little guidance or follow-up.

The impact on daily life is profound. The majority of adults report significant challenges with fatigue, mobility, mental health, and participation in work or social activities. Nearly half have stopped working due to their condition, and many report financial hardship and difficulty affording treatment-related costs. These challenges are compounded by poor access to financial support and inadequate information on available services. Mental health support is critically lacking – despite high levels of distress and psychological need, many people either cannot access counselling or find it fails to meet their needs.

Children and young people also face substantial challenges. Many report difficulties with learning, mood, and social engagement, and a large number feel scared or nervous about healthcare appointments. Carers of children describe frustration with delayed or inappropriate support, especially around mental health and government-provided services. Older children are more likely to experience negative emotions and less likely to feel supported or understood by professionals.

Carers themselves are under significant pressure. Most are providing extensive, long-term care – often over 50 hours a week – while managing their own health and financial strain. Nearly half have had to reduce their working hours or leave employment altogether. Access to respite care, mental health support, and financial assistance is limited, leaving many carers feeling overwhelmed and unsupported.

Across all groups – adults, children, and carers – there is a consistent theme: there are areas where the existing health and social care system is not meeting the needs of people affected by neurological conditions. The data reveals challenges accessing services and support to manage the effects neurological conditions can have on people's lives. Yet there are also clear opportunities. The scale and depth of the survey findings provide the evidence needed to drive meaningful change. The findings shows that there are areas where existing health and social care services are failing to meet the needs of people with neurological conditions. This must change. The survey results also highlight opportunities to improve the workforce, services and implement best practices, all of which must be prioritised.