

My Neuro Survey 2024

Key findings



Thank you for taking part in My Neuro Survey 2024



Over **10,000 people** took part in the survey.

This included adults, children and young people.

Some people shared their own experiences of having a neurological condition.

Others told us what it is like to care for someone with one.



By sharing your story, you have helped us understand what life is really like.

We will use what you told us to help make sure that care and support are better in the future.

Thank you for helping us make a difference.

What adults told us about living with a neurological condition



Many adults have lived with their condition for a long time.

More than half of the people who answered the survey have had a condition for **more than 5 years**.



Some people waited **a long time for a diagnosis**.

More than 1 in 5 people said it took over 5 years to find out what condition they had.

Some people said they were **not given helpful information** when they were told their diagnosis.

What adults told us about living with a neurological condition



Neurological conditions **affect people in different ways.**

Most people said they felt **fatigue.**

Other common problems included:

- Pain
- Poor sleep
- Memory problems
- Low mood or feeling down
- Problems moving or walking



Many people said it was **hard to do everyday things**, like:

- Being active
- Meeting up with friends
- Enjoying hobbies or free time

What adults told us about living with a neurological condition



Nearly half of the adults said they had **problems with work.**

Some people had to **stop working** because of their condition.



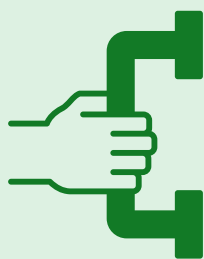
Lots of people found it **hard to get the healthcare they needed.**

Some of the most difficult services to access were:

- Neuropsychiatry (support for the brain and mental health)
- Pain management
- Mental health services

Only **1 in 3 adults** said that the care they received met their needs.

What adults told us about living with a neurological condition



Some people said they got support with:

- Special equipment
- Changes to their home



But others:

- Did not know what help they could get
- Found it hard to afford the support they needed

About **1 in 5 adults** said they were **getting no support at all.**

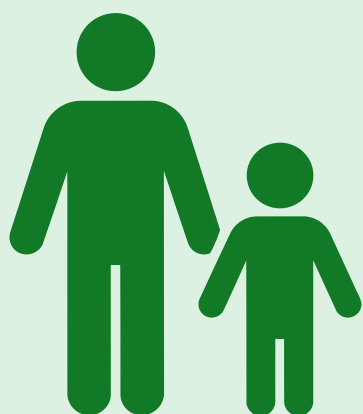
What children and young people told us about living with a neurological condition



Children and young people with neurological conditions told us **how** their conditions affect them.

They can make:

- Learning harder
- Mood go up and down
- Energy levels low
- It harder to join in with others



Younger children were more likely to say they felt **proud** of how they manage their condition.

Older children and teenagers were more likely to say they:

- Felt left out
- Felt frustrated
- Were worried about the future

What children and young people told us about living with a neurological condition



More than half of children said they feel **nervous or scared** before medical appointments.



Some children also said:

- They **don't understand what is happening** during appointments
- They find it **hard to ask questions**

Many carers said it is **hard to get the care their child needs**, especially:

- Mental health support
- Government-funded services

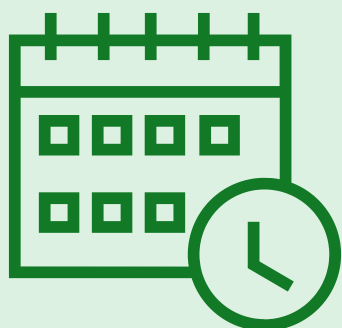
Carers of **older children and teenagers** were more likely to say that **services were not meeting their child's needs**, compared to carers of younger children.

What people told us about caring for someone with a neurological condition



Family members, friends, and paid carers of people with neurological conditions shared their experiences.

Most carers in the survey were family members.



Many carers were providing **50 hours or more** of care every week.

Over half of them said they had been caring for **more than 5 years**.

Many were also dealing with their **own health conditions** at the same time.

What people told us about caring for someone with a neurological condition



Most carers said they could meet the daily needs of the person they care for.

But **fewer carers said they could look after their own health and wellbeing.**



Many carers said they felt:

- Emotionally tired
- Stressed about money
- Not supported in their role

Nearly 6 in 10 carers said they had to **work less or leave their job** because of caring.



Some carers said they **could not get:**

- Respite care (a break from caring)
- Mental health support

Mental health



Many adults and children in the survey said they experienced **mood or mental health problems** linked to their condition(s).

This included:

- Low mood
- Stress
- Anxiety



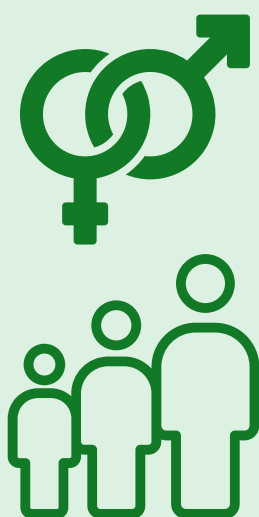
Many people said it was **hard to get help** for their mental health.

Even when people did get support, many said it **did not give them the help they needed**.

Finances



More than 1 in 3 adults said they **struggled with the cost** of managing their condition.



Some groups were **more likely to say they had money problems.**

This included:

- Women
- Younger adults
- People from minority ethnic backgrounds



Some people said:

- They **could not get the benefits they needed**
- They had to pay for care or support themselves

Involvement in decision-making



The survey asked people if they felt involved in decisions about their care.

About **half of adults** said:

- They felt **involved in decisions**
- They understood their condition and the treatment choices they had



The answers from children and young people were more mixed.

Only about 1 in 3 children and young people said they felt involved in decisions about their care.

Thank you and next steps



Thank you again for taking part in My Neuro Survey.

Your stories are powerful.

They are already helping to make changes.



The Neurological Alliances will use the survey results to:

- Help leaders and decision-makers **understand what life is like** for people like you
- Talk to politicians, NHS leaders, healthcare staff, and local services

We want to make care, support and services better.

We will keep campaigning to make sure:

- Your voices are heard
- Action is taken