Inflammatory
Neuropathies UK

Living with Inflammatory Neuropathies:

Findings from My Neuro Survey 2024/25

IN this together

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Contents

You can access more reports and findings from the 2024/25 My Neuro Survey via **neural.org**, For more from Inflammatory Neuropathies UK, or more on the conditions we support such as GBS, CIDP, and MMN - please visit our website via **inflammatoryneuropathies.uk**. If you have questions about our findings, please contact **hello@inflammatoryneuropathies.uk**. If you would like to request a larger font document, please also reach out to us via the email above.

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Introduction

My Neuro Survey is the largest patient experience survey for people impacted by neurological conditions in the UK. The latest version of the survey was undertaken between 22nd July and 15th November 2024. The results were released in 2025.

The survey is open to anyone impacted by a neurological condition, whether they are someone directly impacted or someone who supports someone who is directly impacted. The survey is put together and run by the various **Neurological Alliances** across the UK, and supported by specialist health and neurological charities, including **Inflammatory Neuropathies UK**.

The survey collected the views of over 10,000 people, including people impacted by Inflammatory Neuropathies. This report focuses on the responses from three distinct groups of people, those impacted by **Guillain-Barré Syndrome (GBS)**, those impacted by **Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)**, and those impacted by **Peripheral Neuropathies (PN)**, who may come under the remit of **Inflammatory Neuropathies UK**.

Pic: Neural.org.uk - The survey launches in London, backing the 1 in 6 living with a Neurological Condition

This report

We wanted to look at themes and issues that impacted people with **Inflammatory Neuropathies**, and to examine the similarities and differences across different conditions, but also against a comparative group of people living with all neurological conditions (the 'All' group). We wanted to know what was the unique experience of people with **Inflammatory Neuropathies**, as well as where things were comparable across all conditions.

The aim is to present an accessible overview of how **Inflammatory Neuropathies** impact people's lives, what support people receive, and where gaps remain. All from information and data provided by the community itself.

While people impacted by other **Inflammatory Neuropathies** may have taken part, the level of information needed for the analysis in this report was restricted to conditions that achieved a high response rate. As a result, only **GBS** and **CIDP** were considered. We have included **PN** within this report as both a comparative

The role of Inflammatory Neuropathies UK and the Inflammatory Neuropathies Community

As an organisation, **Inflammatory Neuropathies UK** values information and data, so were a vocal advocate for **My Neuro Survey**, committing time and resource to supporting the development and the rolling out of the latest version of the survey. We wanted to ensure that people impacted by Inflammatory Neuropathies were involved with and responded to the survey to not only have their voices heard, but to ensure that we had access to data and information that could help shape the charity's strategic direction and future work.

As a result of this, we were fully committed to sharing the survey with our community, and seeking to make sure that we achieved a good response rate. We made sure that we shared the survey with our community through targeted mail outs, within our newsletter and other communications, and across our social media channels.

It is vital as a person-centred organisation that our membership and community have their voice heard and amplified, and we wanted to ensure that people impacted by Inflammatory Neuropathies were heard within the survey responses.

We were delighted by the response of our incredible community with **186** (3%) of responses linked to **Inflammatory Neuropathies UK** (although we were known as **Guillain-Barré and Associated Inflammatory Neuropathies (GAIN)** at the time).

This meant that we were the **sixth placed organisation** (out of 64) in terms of responses, an incredible achievement for us and our community. This was also a significant improvement on responses to previous surveys.

Our conditions were also well represented with **GBS** being the **23rd most represented**, and **CIDP** the **30th most represented** out of 70 conditions or options that were mentioned in a response to the survey. **Peripheral Neuropathies** was **14th**, but may not be wholly representative of **Inflammatory Neuropathies.**

Who Took Part?

The 2024 survey was the largest undertaken to date. Most responses were from adults, but there were also significant responses from carers. For the first time, children and young people were able to respond.

There were:

10,342 responses overall

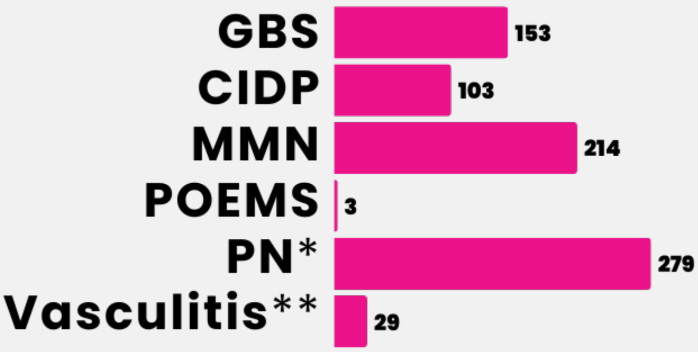
8,691 adults

1,249 carers

402 children & young people

The response from the **Inflammatory Neuropathies** community was amazing, especially since we have one of the smaller cohorts. In terms of comparisons, and due to obtainable data, **we are only utilising data reported back from adults**.

The number of adults from within the **Inflammatory Neuropathies** community (from the total of adults with all neurological conditions of 8,691) was **504.** Broken down by



*Of the PN group, 30 were awaiting diagnosis, 12 had GBS, 11 had Vasculitis, 4 had CIDP, and 3 had MMN
** May not be fully representative of the Inflammatory Neuropathies cohort

Most respondents across all groups were:

Aged 45 or older

White

Living with a spouse or partner

Spread broadly across the UK, mostly in England

The majority of respondents across all groups were **women**, except **CIDP** which showed a more balanced gender split.

Due to available data, we have only been able to look at information around adults impacted by **GBS**, **CIDP**, and **PN**, and have compared this against each other, and against the data for all adults with Neurological Conditions.

Key Themes Across All Three Conditions

By looking at the information reported in the survey, we can identify four key themes for people impacted by **Inflammatory Neuropathies**.

Daily life is significantly Impacted

People commonly reported difficulties with movement, fatigue, pain, and managing everyday activities.

Many feel under-supported by the health system

A number of respondents said they do not feel fully supported and sometimes lack someone to talk to about their condition.

Work and income are heavily impacted

Many say their condition affects their ability to work, and some have stopped working altogether.

People want to take part in research but are rarely invited

Across all groups, interest in taking part in research is high, but only a small number have actually taken part.

How Inflammatory Neuropathies Impact on Daily Life

The survey asked a number of questions about daily living which allowed us to look in depth at responses under a number of themes.

Symptoms and Health

Across **all three** conditions, people experience:

- **Fatigue**
- **Movement problems**
- **Pain**
- **Sleep disturbance**
- **Impact on thinking and memory** *(to varying degrees)*

While there were these shared experiences, there were also a number of key differences:

GBS

- Symptoms vary widely, with the impact of residuals having a large range
- Many report fatigue and movement problems, but the level of impact differs greatly between individuals
- Some people reported memory issues while others didn’t

CIDP

- People reported ongoing fatigue and mobility issues
- The range of fatigue was wider than for other conditions
- The range reported for mood or mental health was large

People impacted by **CIDP** reported more mental health conditions than the other Inflammatory Neuroptahies groups

Peripheral Neuropathies (PN)

- **PN** respondents reported the most severe symptoms overall, especially:
  - Pain
  - Sleep problems
  - Cognitive difficulties
- They also have the highest levels of physical co-existing health conditions.

Compared to all neurological conditions

We wanted to understand how symptoms and health compared between Inflammatory Neuropathies and other neurological conditions.

- Pain and fatigue levels in the **Inflammatory Neuropathy** group—particularly **PN**—are as high or higher than in the wider neurological population
- Mental health problems (such as anxiety or depression) are slightly less common in neuropathies than in the broader neurological community

The Impact on Everyday Activities

The survey also looked at everyday activities, and what it was like living with a condition. People across all groups report that their condition impacted:

Daily tasks
Social life
Hobbies
Staying active
Family relationships
Finances

However, it was also noted for specific conditions that:

- For people impacted by **GBS** there was a more mixed picture. Some experience profound difficulties, while others reported less daily impact

- People with **CIDP** reported an impact on everyday activities which was moderate to high impact, particularly around hobbies, being active, work and studying, and how they feel about life
- **PN** respondents reported the greatest impacts, describing life as regularly or constantly challenging

Work and Employment

Responses within the survey highlighted that work is an area where **Inflammatory Neuropathies** have a major impact on life:

Many respondents say their condition impacted their ability to work or study

Some have had to stop working

Most did not feel discriminated at work

Those who remain in work often need support

Compared with the wider neurological population:

- The impact on work is similarly high
- People with Inflammatory Neuropathies sometimes had higher household incomes than the wider population

Healthcare Experiences

Clearly one of the biggest areas of concern for people with neurological conditions is around their healthcare, and the survey focussed heavily in this area. Again, from the responses there were clear themes as well as differences between conditions.

Access to Care

People commonly see:

- Neurologists
- GPs
- Physiotherapists

People impacted by **GBS**, also reported accessing OTs, and wheelchair services, although these weren't reported as frequently by people impacted by other Inflammatory Neuropathies.

However, compared with people across all neurological conditions, those with neuropathies are less likely to access:

- Pain specialists
- Neuropsychologists
- Social workers

This is notable because symptoms often include severe pain and sleep problems, which would benefit from specialist support.

Feeling supported

The survey asked questions around feeling supported, and receiving information.

- Many people with **GBS** and **PN** said they do not always feel supported by the health system
- **CIDP** respondents are slightly more positive but still report mixed experiences
- Most people were supported by families and friends

When receiving information, most people reported that this had come from their Neurologist. People with a **PN** also reported that they had received information from a GP, but this was notably not a response from other groups. Some people said they received no information at diagnosis.

Some people had found information from charities or from their own research.

Research Participation

People with rare conditions are often asked to take part in clinical research, and the **My Neuro Survey** asked about this.

- Most respondents across all groups said they would take part in clinical research
- However, very few had actually taken part in any clinical research

This seems to highlight a clear gap between what people want and what is available.

Comparing different experiences of Inflammatory Neuropathies

We were really interested in seeing what the **My Neuro Survey** results showed in terms of people's experiences of different **Inflammatory Neuropathies.** As we had enough data and information around **GBS**, **CIDP**, and **Peripheral Neuropathies**, we were able to look at these three conditions, and how the impacts compared and contrasted. We were then able to draw out a number of themes and assumptions based on the data and other information.

GBS

- **GBS** is often very severe at onset, and recovery varies person to person, meaning that we see a wide range of impacts across respondents
- People may feel unsupported once they leave hospital
- Symptoms and impacts range from low to very high depending on recovery progress, severity of the condition, and treatment

CIDP

- Experiences are steadier ,but still impactful. We see more similarities within the overall experience and patient journey as a result
- People understand their condition fairly well, but still face daily challenges
- The progressive nature of the condition, and the impact on certain elements of life (work and study, mobility, social interaction, relationships) really shines through

Peripheral Neuropathies (PN)

- People reported the highest levels of:

Pain

Sleep disturbance

Cognitive issues

Impact on work and relationships

- Least likely to feel supported by the health system
- Reported as the most burdensome of the three conditions

Comparing Neuropathies to All Neurological Conditions

One of the things that we really wanted to explore, was with regard to similarities and differences in the experiences of people impacted by **Inflammatory Neuropathies** and people with all Neurological Conditions. We wanted to know if things were the same, but more importantly what was different about living with the impact of **GBS**, **CIDP**, or a **Peripheral Neuropathy**.

Similarities

Things that were noted as similarities in the experiences of people impacted by **Inflammatory Neuropathies** and all Neurological Conditions included:

- High levels of fatigue, pain and movement difficulties
- The significant impact on work and daily life
- The reliance on informal support (family, friends)
- A high interest in research participation
- People in the All group and people with **CIDP** were more likely to have someone to talk to than people with **GBS** or a **Peripheral Neuropathy**
- Similar age groups
- Predominantly white ethnicity

Differences

The differences between the experiences of people impacted by **Inflammatory Neuropathies** and all Neurological Conditions included:

- People impacted by **Inflammatory Neuropathies** reported less access to specialist services such as pain management and neuropsychology
- People impacted by **Inflammatory Neuropathies** reported higher household income, but still experienced financial strain
- The range of impact across different variables was less for all Neurological Conditions than for people with **Inflammatory Neuropathies**
- Responders were more likely to be female for the All group rather than the **Inflammatory Neuropathies** group who had a more equal gender balance
- People with a **Peripheral Neuropathy** reported higher symptom severity than the All group
- The All group reported higher levels of mental health conditions
- People in the All group were more likely to have more pre-arranged appointments
- People with an **Inflammatory Neuropathy** were less likely to get information on their condition through their own research

Key Issues Highlighted

After looking at and analysing the data from **My Neuro Survey**, and comparing and contrasting information across conditions and cohorts, we were able to highlight a number of key issues.

Information at diagnosis is inconsistent

A meaningful number of respondents received no information, and access to information varied considerably. Most people received information from their Neurologist

Lack of coordinated, ongoing support

Many people feel that they were left to manage on their own, particularly after diagnosis or hospital discharge

Specialist services can be difficult to access

Pain, psychological and social care services are not always available to everyone, particularly those with an **Inflammatory Neuropathy**

Research opportunities are lacking

Despite high enthusiasm for research, clinical trial access is low

Peripheral Neuropathy appears to be under served

PN respondents consistently report:

- Higher symptom severity
- Less support
- Greater impact on work and life

Lessons for Inflammatory Neuropathies UK

With these key issues in mind, we think that there are a number of lessons for **Inflammatory Neuropathies UK** and actions that we can take as a result.

Improved information

From the responses, we can see that people are not getting the information that they need, either at the point of diagnoses, or along their patient journey. We can also see that people aren't getting their information from charities, and that includes us.

We need to improve our information offer, ensuring that it is accessible and available to everyone. We need to ensure that more people are able to access information directly from us, and that it is available when they need it. We need to ensure that clinicians (particularly Neurologists) are informing people they see about us, and that they have access to information from **Inflammatory Neuropathies UK** they can pass on.

Actions:

1. **Review** and improve our information offer in coproduction with our community
2. **Look** at the forms and variety of information available, and **improve** the delivery routes – online, and in hospital and community settings
3. **Build** on our clinician offer and ensure information is available to hand and promoted

Look into co-ordination

People highlighted that co-ordination is an issue, and that finding the way to the right place on your journey can be difficult.

We need to look at what people need and want, and ensure that we can support the development of a more co-ordinated approach, either directly or indirectly.

Actions:

1. **Work** with our community to better understand this issue through surveys, research, and listening
2. **Look** into the potential for a remote co-ordination service
3. **Examine** opportunities to link into existing models such as Social Prescribing to **improve** opportunities for people

Better post diagnosis/discharge support

From the **My Neuro Survey** responses, we can see that there are significant issues around post diagnosis or post discharge support. This is reflected in our own research and discussions, where people tell us that they often feel left to fend for themselves as their journey progresses.

We need to better understand the impact of this issue on people, in terms of physical health, mental and emotional health, and social wellbeing.

Actions:

1. **Undertake** research on the scale of this issue, the impacts, and potential ways forward
2. **Look** at the current pathways for people and **map** out improvements, and service models that may help

3. **Build** a new best practice pathway that can be used to navigate the system

Improved access to services

Our analysis of the **My Neuro Survey** responses showed that people impacted by an Inflammatory Neuropathy are less likely to access specialist services than other people with Neurological Conditions. This could be because of a lack of information, a lack of opportunities, a lack of services, or other variables.

We need to understand the issues, and look at ways of ensuring that our community is able to access services fairly and equitably.

Actions:

1. **Map** out the services and opportunities that should be available
1. **Develop** shared information that demonstrates what people should receive with information on how to access it
2. **Link** work into the 10-year plan, changes to NHS service specifications, and ensure that we **advocate** on behalf of the community with decision makers in order to reduce health inequalities

Help people to feel more supported

One of the key issues that was drawn from the findings was that people did not feel supported. While we feel that this is probably across the system as a whole, we also need to bear some responsibility as we offer a support function for people impacted by **Inflammatory Neuropathies**.

We need to look at our core support offer and ensure that it links into more general community services, and that we are able to reach and engage with more people.

Actions:

1. **Review** our core support offer in coproduction with our community
2. **Look** at reach and engagement with the wider inflammatory Neuropathies community, understand the lack of engagement, and **improve** how we link in with people
3. **Identify** ways of improving overall support, and linking our models with wider support models

Getting involved in research

Lots of people impacted by **Inflammatory Neuropathies** want to be involved with research and clinical trials. However, only a small proportion actually are. This is potentially due to the lack of research and clinical advancement, but in the current period of growth in our sector this is a worrying trend.

We need to understand why people's enthusiasm for involvement is not turning into actual involvement.

Actions:

1. **Understand** the current picture in terms of research and clinical trials, and develop an opportunities map
2. **Build** closer relationships with pharmaceutical companies and clinical researchers to link research with our community
3. **Improve** our own system for capturing interest in research and informing people of opportunities

Better reach and engagement

We have identified that our biggest issue is reach and engagement with people impacted by **Inflammatory Neuropathies**. The responses to the **My Neuro Survey** has emphasised that while we reach and work with a dedicated cohort of people, we don't reach everyone, not by a long way.

We need to improve our reach and engagement so that we better serve the community that we are entrusted to support.

Actions:

1. **Improve** our internal data systems so that we better understand our own cohorts
2. **Work** with others to better understand prevalence and demographics of the **Inflammatory Neuropathies** community
3. **Improve** on the numbers of people we reach and support

Different approaches for different conditions

The **My Neuro Survey** demonstrated clear issues between **Inflammatory Neuropathies** and other Neurological conditions, but also different issues across different Inflammatory Neuropathies. What was clear was that not all **Inflammatory Neuropathies** were the same.

We need to ensure that we have different approaches for different conditions, and that we don't neglect some conditions in favour of larger or more vocal cohorts. This includes looking at the conditions that cross cohorts and boundaries, or don't have dedicated support such as **Peripheral Neuropathies**.

Actions:

1. **Map** our current approaches by condition, and identify gaps and opportunities
2. **Develop** dedicated information and services for different conditions
3. **Focus** on some of our smaller conditions, and **identify** approaches that cut across conditions (including those outside of our core workstreams)

Conclusion

My Neuro Survey 2024/25 shows that people with **Inflammatory Neuropathies** experience significant challenges in their health, daily life, employment, and access to care. While many themes mirror those seen in the wider neurological population, several issues stand out:

- People often feel unsupported and under-informed
- Services and opportunities that could improve quality of life are not consistently offered
- There is a strong appetite for research involvement that is not currently being met
- Better coordination is needed

These findings underline the need for better information, more coordinated care, improved access to specialist support, and greater opportunities to participate in research, as laid out in this report.'

These findings demonstrate that there is a lot to do for people impacted by **Inflammatory Neuropathies**, and many improvements that could impact on people's lives. This includes significant learning and improvement opportunities for **Inflammatory Neuropathies UK**.

While the charity has demonstrated that we do work well with our community, and can generate action, we can also see from responses and analysis that there is much more we can do for people impacted by **Inflammatory Neuropathies**.

Inflammatory Neuropathies UK is dedicated to making improvements and acting on findings directly. We will ensure that we act on what people have told us, and have been fed into the report, with an aim of ensuring positive change is in place and benefiting our community by the time of the next **My Neuro Survey**.

IN this together

Inflammatory Neuropathies UK are **IN this together** to support:

Guillain-Barré Syndrome
CIDP MMN
and other Inflammatory Neuropathies

We provide:

Information and Advice **Peer Support**
Personal Grants **Emotional Support**
Access to Online and Local Groups
Condition Booklets **Fact Sheets**

And we:

Raise Awareness **Commission and Fund Research**
Advocate and Campaign

IN touch

We love to talk, if you have questions, comments, or queries, reach out to us:

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