

NEUROLOGICAL HEALTH

Healthwatch Lincolnshire wanted to understand individuals' experiences of health and care services that support people in Lincolnshire navigating a neurological conditions including multiple sclerosis (MS), epilepsy, fibromyalgia and chronic fatigue syndrome (CFS).

WE HEARD FROM

375
people

CONDITIONS

Respondents experiences related to the following conditions:

MS
ME/CFS
Fibromyalgia
Epilepsy
Brain Injury
Migraines
Functional Neurological Disorder (FND)
and more....

DIAGNOSIS

1. Patients not being listened to - symptoms being dismissed
2. A lack of understanding of conditions both in terms of knowledge and empathy
3. Patients would present to their GP practice multiple times over months and years
4. Not getting a timely diagnosis resulted in some having to give up their jobs

As a result of these issues, some sought a private diagnosis



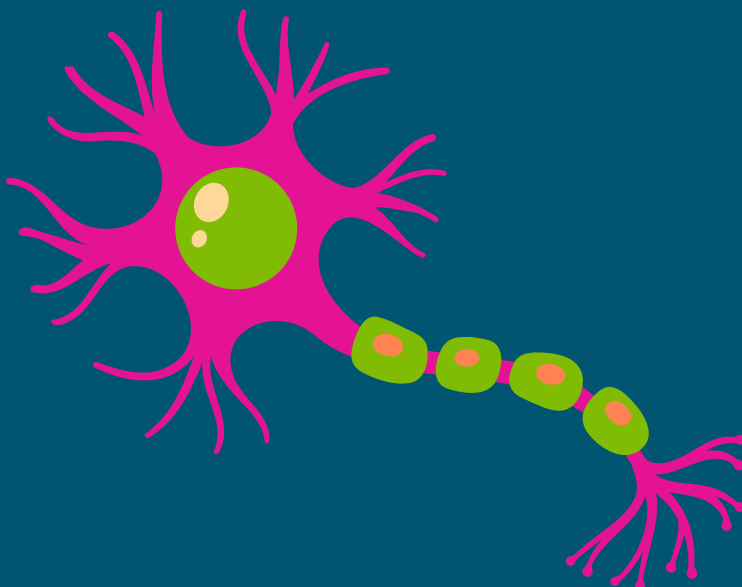
MEDICATION

71%

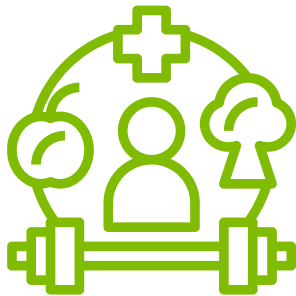


had struggled to get medication that worked for them.

This included issues with side effects, dosages and supply.



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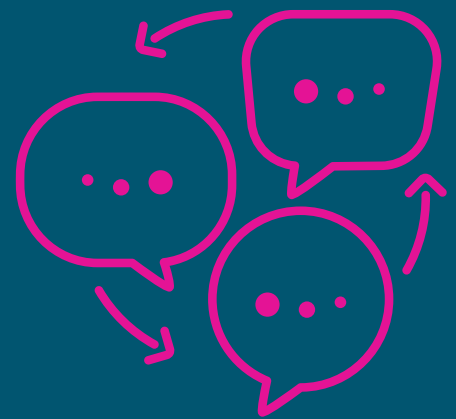


TREATMENT AND MANAGEMENT

Symptoms were mainly managed via medication. Signposting to support and referrals to other services appeared to be inconsistent. Service users also appeared to be unaware of what support is available and what could be beneficial. There was also a call for more holistic support recognising that everyone is different.

WHAT WORKS WELL?

While generally those who accessed specialist care, including MS nurses and consultants, praised its quality, not everyone was able to access such care.



WHAT COULD BE IMPROVED?

1. Listen to patients and show understanding
2. Increase healthcare professionals' knowledge of neurological conditions
3. Establish local specialist neurological centres, hubs, or clinics
4. Improve access to pain clinics and better pain management strategies
5. Provide clear information for patients on diagnosis, prognosis, and management
6. Offer holistic support, recognising that individuals are affected in different ways
7. Reduce waiting times for specialist support and offer interim support while patients wait



Thank you to everyone who shared their experiences.