“I shouldn’t have to spend my time fighting for support”

**Lorraine Cox**, 39, from Derrylin in Enniskillen, was diagnosed with [motor neurone disease (MND)](https://www.nhs.uk/conditions/motor-neurone-disease/) last summer. She applied for [Personal Independence Payments](https://www.mariecurie.org.uk/help/support/benefits-entitlements/living-with-terminal-illness/personal-independence-payment) to help with the impact of the disease on her day-to-day life and, to her shock, was declined.

“From the moment I started the application process, I felt like I wasn’t being taken seriously. Just because I don’t look ill – I still wear make-up and dress well every day, but that doesn’t mean that I’m less entitled.

“People don’t realise the impact MND can have on your life, it’s the little everyday things that become a struggle.”

“I first started noticing something wasn’t right about 14 months ago. I went to the doctor, and then for an MRI scan, and was diagnosed pretty quickly after that.

“It came as a shock – you never think it’s going to happen to you.

“Now, I’ve completely lost the feeling in my left hand. I can’t make my own bed, my children help me get dressed, I have a cleaner, I can’t cook the way I used to. My balance is off and I can now feel my foot starting to go too.”

## Angry and disheartened

As part of her PIP application, Lorraine had a face-to-face consultation with a Disability Assessor. It was after this that she was told her application had been declined.

“I felt so angry when I was assessed as not fitting the criteria, it’s very disheartening and I just don’t understand why it has to be so difficult.

“Work is very important to me as it gives me some independence and allows me to focus on something else. It’s a bit of escapism from my condition.

“But I want to reduce my hours next year so I can spend more time with my kids. As I don’t have long, I want to spend quality time making memories.

“Looking ahead is the hardest part. I’ve started to have nightmares about my kids, a sense of loss or them being taken away from me. They have a wonderful father, but it’s not the same as having a mummy.”

## A matter of principle

“My kids have been so amazing, they are so adaptable. They’ve put things in perspective for me, it’s put fire in my belly and encourages me to fight for what I know is right.

“I’m a very determined person and I’m not going to give up. It has become a matter of principle even above the money. I shouldn’t have to spend my time fighting for support, it’s exhausting.

“Situations like these really make you realise what’s important in life and I’m very lucky that I have a good support network around me.”

## Speaking out

“I felt I had to speak out about my situation as I don’t want others to have to face the same struggles at such a difficult time.

“The process needs to change and that’s why I think [Marie Curie's campaign to change the 6-month rule](https://www.mariecurie.org.uk/policy/campaigns/scrapsixmonths) is so important.

“I’m hoping that in the future, things are made much easier for people and they can spend time with the people they love most, instead of fighting against an unfair system.”

## Why was Lorraine declined?

Lorraine was unable to apply for PIP under the fast-track Special Rules for Terminal Illness because she doesn’t have a medical prognosis of six months or less to live.

Marie Curie has been campaigning to remove this restrictive criteria, to make it easier for people with terminal illnesses to access the support they need, when they need it.

Lorraine challenged the decision to refuse her claim, and after an eight-month battle, has been awarded the basic rate of the daily living component of PIP, although she hasn’t been granted the mobility payments – a decision she is appealing.

*Source:* [*https://www.mariecurie.org.uk/blog/the-struggle-to-get-benefits/221392*](https://www.mariecurie.org.uk/blog/the-struggle-to-get-benefits/221392)