

Priya greets me with a smile and asks whether I would like tea. "Thanks. White, no sugar," I reply. Books are piled on the bed in her student room, so I take the only chair.

Priya's kind offer has posed her a set of challenges of which I am unaware. How do you make tea? Is it made with boiling water? Will she remember to add milk? She returns after 20 minutes with a perfect cup of tea. She is sorry I had to wait so long, but at least she is not cooking me a meal, she says. That can take hours.

She has no mental illness and no visible physical disability. But the encephalitis she contracted at 15 made her blind for six months and has left her struggling with the simplest tasks and prone to seizures that can strike with a few seconds' notice.

Her defiance of her condition, and the devotion of her family, earned her a place at the London School of Economics (LSE). She wants to find work championing the cause of fellow sufferers.

Yet the doctor who assessed her for disability living allowance (DLA) insisted she could find no evidence to support her claim, and it was rejected. It had taken the family months to learn about DLA because none of the social workers had mentioned it during her time in hospital. They learned eventually of their benefit entitlement through support groups they contacted.

The family was determined to appeal against the decision – both Priya's mother and sister had given up work to nurse her. Many months later, after more distress, more form-filling and more assessments, the original decision was reversed.

Priya's experience is far from unique.

Headway, the brain injury association, and the Association



A new study highlights the difficulties people with brain injuries have in claiming disability living allowance, writes volunteer Sarah Hurn

INJURY TO BENEFITS

for Spina Bifida and Hydrocephalus (Asbah), which campaigns for sufferers of spina bifida and hydrocephalus, has carried out research into people with brain injury who were claiming DLA. It found that one in four initial claims were rejected. But three-quarters of those rejected appealed and 71 per cent were successful. The two charities were so disturbed by the findings that they held a meeting with the Department for Work and Pensions (DWP) about the problems.

DLA is an important benefit for people with brain injury but the survey found a lack of awareness among sufferers and professionals. Respondents said they had difficulty with claiming. "The forms are a nightmare" and "I couldn't fill it out on my own...it was very confusing" were some of the comments. Even professionals asked to fill out the forms were often at a loss as to how to complete the application. Headway estimates that 80 per cent of its members have problems with the disability assessment process.

Typical disabilities for people with brain injuries include short-term memory loss, comprehension difficulties and an inability to solve problems and organise simple daily tasks. These are not mental illnesses, but the current DLA application process recognises only mental illness and overt physical disabilities. Assessing doctors often fail to spot the "hidden" disabilities faced by brain injury survivors, whose lives are nevertheless blighted by their condition.

Headway and Asbah are trying to raise awareness of the problems: they want professionals to encourage brain injury victims to apply for disability allowance, and they want the government to provide those professionals with the necessary information.

The survey also recommended that DLA claiming processes should be simplified and that people with brain injury need to be made more aware of their eligibility for DLA.

The two charities are also calling for principal carers to be present at the DLA assessment, and for the forms to include sections for those with cognitive difficulties.

Maira Henderson, principal medical officer at the DWP, has been keen to meet the charities and evaluate the survey. The DWP has recently piloted a new DLA claim pack and is trying to improve the brain injury training given to assessment doctors. Henderson asked to hear of any specific examples of examining doctors who lacked understanding of "hidden" disabilities.

Priya has just finished her second year at the LSE but, unlike her fellow students, has three more years to go. The college has awarded her a two-year extension. The tutors realise how bright she is, but also appreciate her struggle with everyday tasks.

It is an attitude she hopes will be reflected in future DLA assessments. CC

Sarah Hurn is a volunteer for Headway
REFERENCES
 'Claiming DLA: A Battlefield or a Minefield?' is available from Headway
 0115 924 0800 or Asbah 01733 555988