

'I was a citizen, now I'm nothing': disabled readers on life under austerity

Lying on the floor for hours awaiting help, unable to afford both incontinence pants and food ... This is the reality of disability cuts for Stephen, Alex and Elli

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Tuesday 30 May 2017 06.51 EDT

When Theresa May was challenged by a disabled voter over cuts to her disability benefits and social care last month, it shone a light on the way Conservative policies post-2010 have disproportionately targeted disabled people. Recent years have seen the introduction of many cuts and changes - from the rollout of "fit to work" tests to the abolition of disability living allowance - as well as a lack of action on existing inequalities, such as inaccessible housing. It all amounts to an unprecedented assault on disabled people's rights and living standards in Britain.

In a series of interviews over several months, the Guardian has followed three disabled readers - Stephen, Alex, and Elli - as they experience the reality of life since austerity.

Stephen's story: I'm managing to work in pain, but for how long?

"I want the minister in charge to come here and tell me how I'm meant to live. I've worked since I was 15. I pay my taxes. Why do I then have my benefit taken away?" Stephen, 52, asks from his front room in Maidstone with his wife, Elaine, next to him.

A car accident in his 30s left Stephen with osteoarthritis of the spine, memory problems and a degenerative disc in his back. There's rarely an hour of the day his legs or his feet aren't racked with pain, and he moves uneasily around the house, holding on to the wall with one hand to pull one leg along. Elaine's ill herself - she has fibromyalgia, a degenerative spinal disorder, and knee problems - but it's since the austerity cuts came in that, in Stephen's words: "Our life's just got worse."

Elaine had to give up work as a hotel caterer in 2014 but doesn't get any income support. The government put a time limit on how long disabled people can have some out-of-work sickness benefits, so after six months of receiving employment and support allowance, Elaine's benefit was stopped - despite the fact her disability hadn't got better. Packets of medications and pain relief sit in a small basket on the sofa table. Stephen used to get free prescriptions, but when NHS cuts kicked in three years ago, this went too.

The couple's only income is Stephen's job as a warehouse manager at Morrisons. Because the pain in his legs means he can't use the bus, he relies on a Motability car - a government scheme that lets disabled people swap mobility benefits for the lease of a car, wheelchair, or scooter - to get there. But after being tested for the new personal independence payments (PIP), he was rejected

for the mobility part of the benefit this spring and - like more than 50,000 other disabled people since 2013 - he's been told he must return his vehicle.

The couple have had a temporary reprieve - the Motability charity has extended the lease for a few months - but Stephen will need to return the car in September. Elaine's already had her own benefit cut in the transfer to PIP - that's £300 a month gone - but Stephen's rejection could mean his entire wage could go too. "If I lose the car, I can't get to work. £30,000 a year," he says. "Who's going to pay that?"

The Department of Work and Pensions (DWP) states that "more people are on the Motability scheme now than before PIP was introduced, and under PIP 26% of people get the highest level of support compared to 15% under DLA", and that anyone can appeal if they wish. Two days ago, Stephen contacted me: the DWP turned down his first appeal to keep his car. "I work despite the pain," he says. "[And now] they've kicked me aside."

Alex's story: I was treated worse than a farm animal

"It's not just the cuts. It's how disabled people are being treated within that," says Alex, from Islington, north London. "You're treated worse than an animal going to the slaughterhouse."

The 44-year-old has multiple severe conditions - a spinal and head injury, degenerative hands and feet, chronic fatigue, double incontinence, and mental health problems - and is unable to walk. For the past four years, Alex has been living in a cramped top-floor flat.

Because the flat is too small for a hoist to let a carer help Alex move safely, Alex is forced to crawl to get from one room to the next: slowly pulling along the carpet, legs dragged on one side. To be able to leave the flat, Alex balances on crutches to get down two flights of stairs. It's a visible strain: Alex's feet twist with each step and breaths are short. Outside, at the bottom of another seven concrete steps sits Alex's wheelchair, chained up on the street. With no lift, Alex can't get it into the flat.

I first spoke to Alex in January, and it's clear over the months that the flat is making Alex's health deteriorate. At one point when we speak, Alex has been bed-bound with a hemiplegic migraine for 11 days - essentially, hit with stroke symptoms that lead the body to go in and out of consciousness. By the end of April, Alex is completely bed-bound. "I can't crawl or go down the stairs at all now," Alex emails - but every couple of weeks they risk falling down the stairs with a personal assistant to go to therapy appointments "because my mental health has deteriorated" too. (Alex has asked to be referred to as "they".)

Alex has fought for months for safe housing from the housing association - even to get on the council's higher medical band - but there are limited accessible properties in the area, and the only options the council offered were out of borough and too far from Alex's doctors. In March, Alex was given some hope, after accepting a ground-floor wheelchair-accessible flat in Islington, but it needs extensive adjustments, and three months later, Alex is still stuck in the current flat.

Islington council's corporate director of housing and adult social services says specialist adaptations and equipment are being installed in the new property and this work is being carried out as fast as possible. They add: "Like London, Islington has a severe housing shortage, and finding suitable, ground-floor, wheelchair-accessible accommodation, in the location requested, has been challenging."

Talk with Alex and what's striking is not only the direness of the living conditions, but the fact it's come at a time when, as Alex puts it, every area of life has also been "infected by cuts" against disabled people. Social care cuts mean Alex is alone in the flat for the equivalent of four-and-a-half-days each week. To afford the wheelchair that sits outside, Alex had to sell possessions from the pavement - "My TV, my landline phone, plates, mugs, my second-hand laptop, clothes, everything" - as the NHS waiting list was three years. (Islington council says a powered wheelchair, which would be suitable for the new property, will be provided as soon as the move is complete.) The fridge is filled with large bottles of milk; since the government cut the medications and equipment available on prescriptions, Alex buys incontinence pants instead of food.

"Only dementia patients get pull-ups now, and then only two a day," says Alex, who can't afford the £80 a month required to buy them every day. "So I'm left in soiled pull-ups causing sores and infections."

Elli's story: I've gone from being a citizen, to nothing

"If I can't get out of bed, I have to shout to get the pizza man to deliver to my bedroom," says Elli, 39, in her bungalow outside Norwich.

Elli has hypermobility Ehlers-Danlos syndrome (EDS), anxiety, and chronic fatigue and pain, and leans on crutches as she makes her way from one room to the next. Her social care package used to help her with day-to-day tasks - dressing, preparing meals, household chores - and enabled her to found and direct a local arts organisation. But in late 2016, Elli had her care cut from 44 hours a week to 22. "They halved it overnight," she says. "It took three 30-minute meetings with a social worker."

Elli laughs at times as we talk - making jokes about not being able to get up once she's sat down - but it's clear that what's happening is taking its toll. She now has no care hours at all to support her for anything her council defines as "social" - including going swimming as physiotherapy - nor anything "medical", such as someone going to the hospital with her. Elli's condition means she falls regularly, but with long gaps without a personal assistant, she's now regularly left to lay on the floor for five hours with dislocated joints because she has no one to help her up. "I've stopped going out now really because if I fall, I won't be able to get up myself," she says.

In March, Elli emails to tell me she's had more support cut. Her Access to Work funding - which pays for a part-time support assistant - has been cut by 100%: £13,000 a year to nothing. "That's not really a cut at all, is it?" she says.

A DWP spokesperson tells me "real terms funding of the Access to Work scheme has increased", but with hers stopped, when her health is at its worse, Elli's bed is now not only her dinner table but her office too: a laptop on the quilt and a pile of paperwork.

In recent years, she's become familiar with fighting for disability support - she tells me she dislocated her wrist filling in the long application forms for PIP - but as she stares at the window from her bed, she sums up the reality for an increasing number of disabled people: "They've taken me from a citizen to nothing, hidden behind a door."

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