

Frances Ryan, May 2018

Now disabled people face a kind of internment. Just ask Edith

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Give up her job or go into a care home: that's the choice this 30-year-old was given. And she's by no means alone.

In 24 hours' time, Edith will no longer be able to get out of bed. The 30-year-old has multiple sclerosis, and relies on council-funded care assistants to help her live in her two-bed adapted flat in Hitchin, Hertfordshire.

For 18 months, she has managed with only a couple of visits a day: one at 7am, to enable her to get up for work as a chartered accountant, and another at 8.30pm to help her get out of her wheelchair and back into bed. After years of saving hard for her first home and moving out of her parents', it was meant to be the start of Edith's life. But in February her care agency struck a blow: owing to staff shortages in her area, they would be ceasing their contract, and giving social services 90 days' notice. Three months later, and barely a day until her carers leave, the council hasn't found her a replacement.

Edith is terrified. "Carers helping me out of bed every morning are the fundamental life support which everything else in my life depends on," she says. "And now it feels like the rug is being pulled out from beneath me."

Hertfordshire county council (HCC) says the care agency delivering Edith's support served notice because it doesn't have anyone else in need of support in that area, but that they're continuing to look for other care agencies before the notice period ends. HCC adds that some new care slots have already been offered, but ask Edith what the times were and it's little wonder she turned them down: a 9.30am wake up and 6.45pm night call. That would mean getting up half an hour after she's meant to start work and being back in bed 15 minutes after she typically gets home. Forget going for a drink with friends: she'd be in bed for 14 hours every day. "My housebound 90 year-old grandpa wouldn't accept that," she says.

Edith repeatedly tells me her social worker is doing her best, but in a social care climate of underfunding and staff shortages, she may as well be trying to squeeze blood from a stone. As Edith puts it: "There just aren't enough carers. The system doesn't work."

As vast budget cuts see people with disabilities and older people lose their support to eat, wash, and leave the house, the care sector is "in crisis" because of [severe staff shortages](#). [Low pay, zero-hours contracts and poor conditions](#) means staff are leaving while councils and care homes struggle to hire and retain qualified carers. The drive for [outsourcing public services](#) in recent years, championed by Conservative and New Labour governments alike, only exacerbates this. To get a picture of the scale of the staffing shortage, on anyone day, there

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are [90,000 vacancies for social care jobs](#) in England, according to research by Skills for Care in 2017.

This will only worsen after Brexit as the care sector faces a future without the contribution of its [largely European migrant workforce](#). With no carers found, Edith's social worker has come up with increasingly desperate solutions, including asking Edith's boss to alter her working day around her care call hours. "This isn't shift work. I'm an accountant," she says. Edith tells me she cried as soon as she heard the latest plan: putting her into a care home. If no agency can be found in time, she has been told she'll have to leave her own flat and move into an unnamed residential institution. "I feel like I'm being threatened into accepting a care package which will strip me of my life and just leave me surviving," she says.

Edith is far from alone in this. [I reported in March](#) how disabled people are increasingly being threatened with being "interned" in care homes owing to unprecedented underfunding in the system. I'm increasingly hearing from campaigners and charities that they're assisting disabled people who are being encouraged by authorities to go into an institution as a "solution" to their poor care packages, despite being in their own home for years.

Suggest that a non-disabled person live like this and there would rightly be outrage. And yet, someone like Edith, with her whole life ahead of her, is expected to waste her days in bed or a care home. It's reminiscent of attitudes to disability that were said to have died out before Edith and I were even born: that people with disabilities are "not normal", and as such don't need a career, social life or family.

Friday evening is the last time Edith's carers are scheduled to help her. As time runs out, she has been ringing around care agencies herself, but with no luck. She has even written to her MP for help. The stress would be tough for anyone, but with Edith's MS, it's brutal – she's increasingly fatigued and weak, and pain has developed down her right arm. In her worst moments, she says, she thinks perhaps quitting work, cancelling all plans, and lying in a care home might be preferable to this fight. As we finish talking, I ask her what she'll do on Saturday morning if her carers don't come. "My social workers said we'll have to start looking for care homes."

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<https://www.theguardian.com/commentisfree/2018/may/10/disabled-people-internment-care>

- Frances Ryan is a Guardian columnist