

Frances Ryan, March 2018

'I could be taken from my home': why disabled people once again fear being 'warehoused'

Frances Ryan

In the 1970s, disabled people were often placed in out-of-town institutions. Then came the independent living revolution. Is the clock turning back?

"In fear for my life," Lucy Watts, 24, tells me from her family bungalow in Benfleet, Essex. Watts has a range of severe health problems – muscle weakness around her lungs; kidney and stomach problems; and dysfunction of the nervous system. Osteoporosis, degenerative disease in her spine and a progressive muscle disease mean she uses a wheelchair. She is hooked up to intravenous drips as we talk. But it isn't Watt's health that is causing her to fear for her life. It is the government's care cuts.

Since 2009, when her condition first deteriorated, Watts has lived comfortably at home with her mum, Kate, and sister, Vicky, with the aid of a complex care package: at first some social care delivered through her local authority, and then a more comprehensive arrangement funded by the NHS's [Continuing Healthcare scheme](#). Over the years, even with a care plan in place, Watts's mum has been left to take up much of the slack, sometimes finishing work at 4pm, coming home, handling IVs and medical care until 11pm, then sleeping on a mattress on the floor next to her daughter's bed.

The jigsaw of support has enabled Watts to make remarkable achievements: being an ambassador for several charities, sitting on medical boards, gaining an MBE in 2016 for services for young people with disabilities. But in 2015, Watts's mum developed a brain tumour. While Kate was in hospital, Watts would be without the care she needed at home.

Watts turned to her clinical commissioning group (CCG), the local NHS body responsible for healthcare provision, in the hope she would be given a full care package to cover her mum's recovery period. Instead, she was given another solution: Watts would be placed in a nursing home. "They told us the only two that would provisionally take me were an elderly nursing home or a learning disability home," she recalls. When she pressed further, she says she was told that once in the home, she would be unable to go out – not even to visit her mum in hospital or to go to her own vital medical appointments.

After Watts threatened to bring legal action, she says the CCG backtracked and agreed a 24-hour care package. Castle Point and Rochford CCG says it is unable to discuss individual cases, but that its priority is to provide "high-quality care packages that are safe, clinically appropriate and meet people's needs", and that "depending on individual situations, different options could be suitable, including support at home and the opportunity to have a personalised health budget". But Watts still feels as if the CCG is "desperate to get me in a home" because her independence is "too costly". "At times, I've been made to feel unworthy of being alive," she says.

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Watts's case is shocking but it is far from rare. As deep cuts to social care and NHS care set in, the Equality and Human Rights Commission (EHRC) [warned last year](#) that disabled people across the country face being "interned" in care homes due to cost-cutting measures. A dozen NHS organisations [are facing legal action](#) over what the EHRC calls "discriminatory" policies around pushing disabled people into residential care. Continuing healthcare of the kind that Watts relies on can be arranged in a care home, nursing home, hospice or a person's own home. But new funding caps, which have already been rolled out in at least 44 CCGs across the UK, mean that many disabled people may now be prevented from living at home with their families despite being well enough to do so. As Watts puts it: "I'd be taken from my home and stripped of my life."

As recently as the 1970s and 80s, disabled people in Britain were routinely put in out-of-town institutions – ["warehoused"](#), as it was known – as a way to reduce the costs of providing support. Over the past 40 years, disabled campaigners have fought for the basic right to independent living. Against longstanding prejudice that treats disabled people as children to be cared for or dehumanises us as objects to be put away, the independent living movement fought for disabled people to be seen as ordinary adults, with the same right to fundamental freedoms as anyone else. But as austerity measures kicked in, this progress has been [increasingly under threat](#).

"These cuts are rolling the right to independent living back years," says Linda Burnip, the co-founder of the campaign group Disabled People Against Cuts. "DPAC is being inundated with cases where disabled people are losing the right to live independently or having care packages slashed."

Jean Almond remembers vividly her brief time in a care home. "It virtually killed me," she says. Almond, 66, has multiple sclerosis and is quadriplegic, and is supported at her home in St Helens by a rotating team of five personal assistants. Her husband, Geoffrey, fills in the gaps, helping her during the four nights a week that her care package doesn't provide an assistant.

When her husband went to a week-long conference in 2005 and she needed replacement care, Almond hoped that staying in a care home would be a decent solution. But, at just 53, she was told her only option was a nursing home for the elderly. Once there, she underwent an ordeal she can't forget. Staff gave her the wrong medication – doubling some doses and skipping others – leaving her "out of it" and bleeding on the floor. She says she was given a suppository without her consent because all the residents had one – "They called it 'bowel-opening day'" – while no one was given help to shower all week. The home has since been investigated and several staff members dismissed.

While good residential care does exist, there are also repeated reports of abuse, most infamously with the [Winterbourne scandal](#) in 2012 – last week a survey by University College London found that abuse is taking place in 99% of care homes due to chronic underfunding.

More than a decade after Almond's stay, with care cuts hitting the news, she and her husband are "worried to death" over her care package. Geoffrey is now 70 – "Age is creeping on," he says – and Almond is anxious that as her needs increase with age, and her husband's ability

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to physically support her decreases, she will be forced out of her own home. “I live in fear of being returned to a care home,” she says. “I’ve still got all my faculties ... and it’s worse like that, isn’t it? I’d rather die.”

Fear seems to go hand in hand with care packages in this climate. I spoke to several people who had been told they would have to move to a care home, while disability organisations told me of people who were afraid to speak out in case their CCG or local council punished them by cutting their care hours. Dan Burden of the Spinal Injuries Association says the organisation is now hearing of people with spinal cord injuries “being threatened with institutions” rather than receiving care at home with their families. “People are scared to go on the record, worried that the situation will get worse for them if they speak out.”

The same cost-cutting that has CCGs pushing some disabled people into residential care is also severely reducing the care packages that for years have enabled others to live at home. On paper, these disabled people are still afforded independent living but in reality the care is becoming so threadbare that it is barely meeting their most basic needs. Lorraine Howard, 47, has recently been told her care package will be gutted. For 24 years, Howard, who has the severe muscle condition spinal muscular atrophy type 2 and uses a wheelchair, had a 24/7 care package funded largely by the Independent Living Fund (ILF) – a standalone pot of money that supported 18,000 severely disabled people. But in 2015, the coalition government abolished the fund and transferred responsibility to cash-strapped local councils.

Howard’s life has until now been a well-oiled machine. She has a team of four personal assistants, one of whom has been with her for 12 years – “They know exactly how to care for me ... we’re like a little family” – and this has enabled her not only to stay well but to make a home in Coventry with her husband, Howard, and raise a daughter, Kiah.

But [like other former ILF users across the country](#), in February 2017 Howard was reassessed for her care package by her local council. Two weeks later, she received a phone call informing her that it was “cutting her care considerably”: she would lose her night care completely and be left with three and a half hours a day to go to the toilet, wash, eat and drink. She would get one shower a week, and 10 hours out of the house. “How can someone who has needed 24-hour care all their life go to almost nothing?” she asks. “My care needs haven’t suddenly got better just because the government needs to save money.”

This type of gutted care package is worryingly common. More than a million disabled people are now living without the care they need, [according to the charity Leonard Cheshire Disability](#), with reports of people with serious health conditions [waiting 14 hours to go to the toilet](#) or left to sleep in their clothes. Campaigners fear that cut care packages such as Howard’s represent a “drip, drip” assault on independent living, where councils or CCGs do not technically force disabled people out of their homes but reduce at-home support to such a degree that they have no choice but to accept a place in a care home.

Howard has appealed against the decision and her care package is now being reviewed by a panel at the council. “A panel that has never met me,” she adds. Coventry city council says Howard’s care package is still going through an assessment process and it will “manage any subsequent transition arrangements as professionally and sympathetically as we can”. In the

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meantime, Howard tells me her social worker has asked her if she would consider sleeping in a hospital bed (so big it would be in a separate room) to save on night care, and even wearing adult nappies despite the fact she isn't incontinent. "It's humiliating," she says. "I am an adult woman with a husband."

The prospect of losing her 24/7 care has led Howard to have suicidal thoughts and she has seen her GP for depression. "I'm normally a very happy, confident, outgoing person. This government is slowly killing me."

In Benfleet, Watts's mum is recovering well but Watts is still battling over her care package. As things stand, she says, it feels like it's her life "but on someone else's terms". Despite her optimism, Watts admits she is still worried about the future. "They could so easily place me in a nursing home," she says. "I'm very scared, frightened. Petrified even."

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<https://www.theguardian.com/society/2018/mar/27/disabled-people-independent-living-care-homes>

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