

Keith, 36 and his parents Paul and Sarah

Keith is a non-verbal autistic adult with high support needs. Keith loves being outdoors – he will walk for hours in any weather. He likes being in water, swimming, spinning the wheels on toy cars, listening to songs from the eighties on the radio, looking at magazines and he loves eating crisps. Keith communicates through behaviour, actions and sounds. Carers need to know him well to understand what he is trying to communicate. Routine is absolutely vital to Keith. He needs consistent care in a consistent location. During lockdown Keith was diagnosed with depression because his routine changed so much and he couldn't go outside.

Keith lives at home in Milton Keynes with his parents, Paul and Sarah, and his sister, who is diagnosed with Asperger's¹ and works full-time. Neither Paul nor Sarah work anymore - they are both full-time unpaid carers. Previously, Paul was a trained chef and worked in a computer shop. He stopped working when Keith was diagnosed with epilepsy at age 16. "I had to walk away. It wasn't a choice – my family came first." Sarah was a hairdresser.

As well as being autistic, Keith has epilepsy and IBS which contribute to complex needs that require 2:1 support. Despite this, only Sarah can claim Carer's Allowance. Paul does not receive any Carer's Allowance.

It took years of fighting to get suitable support for Keith. Initially they were given one night of respite a fortnight. When Paul and Sarah fought to get him day care, their respite was stopped. At the time, Paul would hide in his daughter's wardrobe to get a five-minute break.

When they received care through their local authority, Paul constantly felt like the council was trying to find reasons to withdraw Keith's support. He felt that staff weren't trained to support Keith, and said they would ignore suggestions from Paul and Sarah about the best ways to support him, which would lead to meltdowns and dangerous situations that could have been avoided. Paul and Sarah are constantly worried, always waiting for the phone to ring. Past incidents include solitary confinement, Keith running out in front of a car in distress, and Keith being dropped off by a taxi service (employed by the council to transport him) alone in the middle of the street.

In 2022, the local authority withdrew Keith's day care support. They gave 2 weeks' notice, and did not issue anything in writing. The reason given was that they could not meet his needs. Paul submitted a Subject Access Request and discovered that the council had a meeting where they had decided Keith lacked mental capacity and would be better off in residential care instead of being transported to the day centre. This meeting was not minuted, and Paul and Sarah had not been informed about it. Paul and Sarah were very concerned about the impact this change would have on Keith's safety and happiness.

After services had been stopped in April, Paul and Sarah eventually found a new day centre for Keith to start going to in October. The withdrawal of support had already had a serious impact on Keith's wellbeing. Paul was told the local authority wouldn't provide transport to the day centre. Paul and Sarah hired legal support and said they would go to a judicial review if transport was not provided. At the last minute, the council agreed to provide transport so Keith could attend the new day centre.

The local authority told Paul that Keith could get more care if they moved to NHS Continuing Healthcare (CHC) funding. A few days after Keith started at the new day centre, the local authority moved him to CHC funding, but Keith's respite care decreased from seven nights a month to just five.

Over time, Paul has become ill. He was diagnosed with Type 2 diabetes, and had two heart attacks during two particularly stressful periods – one while challenging an incorrect care bill via the ombudsman, and the other when they were fighting to get respite care. Paul lost a significant amount of

¹ People who might previously have received this diagnosis now receive an autism diagnosis. Some people who were originally given this diagnosis still use the phrase and some don't. We have used the language people prefer when writing these pen portraits.

weight, to the concern of people around him. He says “There was a day when we were interrogated by council staff – it’s all on tape. I looked so unwell they wanted to call me an ambulance, but I said no – I’m not going anywhere until Keith’s care is sorted out. It was a nightmare. I wouldn’t put my worst enemy through it.” He puts Keith’s care before everything else – he doesn’t have a choice. Paul needs multiple surgeries which he has had to delay because he can’t afford to be out of action for the recovery period. When Keith received local authority care, they had an emergency plan in place for if Paul or Sarah became suddenly ill (for example, if Paul had another heart attack), which was reassuring. Now Keith’s care is CHC-funded, there is no such plan in place, which worries Paul and Sarah. Paul worries that if he is honest about his health problems in his carer’s assessment, it might be used against him as a reason to put Keith into full-time residential care, which Paul believes would be hugely detrimental.

Paul says “Being a carer is stressful enough, but the hardest thing is having to constantly fight for every little bit of support for your family. Because they’re not listening to you.” Paul describes hiring lawyers, challenging decisions via the Local Government Ombudsman five separate times, and providing masses of paperwork to prove their need for support. The mental toll on Paul has been considerable. He says “I’ve felt like a failure. I thought I’d let him down when the services ended. I blamed myself.”

Now, Keith’s care is fully funded through CHC. He goes to a day centre five days a week and gets five nights of respite care each month. This care allows Paul and Sarah to rest, take care of themselves, spend time together and with their daughter, who they also support. Paul also spends time campaigning and sharing his experiences on a voluntary basis, trying to get better support for unpaid carers and disabled people who need care.

Currently, Keith enjoys going to the day centre, and the care is mostly good. Keith runs out of the house to get on the bus that transports him to the centre, he fits in, the staff are trained to meet his needs, and they notify Paul and Sarah of any incidents. Paul describes it as ‘needs-led’. There was a bad accident at the centre where Keith was badly scalded in the shower and staff did not call 999 (which they should have given the severity). Several members of staff lost their jobs. Because Keith was enjoying being there and there weren’t any other suitable care facilities in the area that could meet his needs, Paul and Sarah felt they had no choice but to continue sending Keith to the centre. There haven’t been any similar incidents since.

Paul says in an ideal world, the many barriers to getting care and support and related benefits would be removed. There would be better training and understanding for people with complex needs. Paul would like Keith to get the full support he needs from staff who are trained to meet all his needs. Paul would also like his daughter to get the right support “especially when we’re no longer here. I know Keith will be in full-time residential care, and my daughter will need assisted living.” If they were properly supported now, Paul and Sarah’s first priority would be getting themselves well, including having postponed surgeries, and then they might even be able to start working again. Paul is turning sixty this year. He hopes that one day he and Sarah might be able to go on holiday, and get a good night’s sleep. “I’d like to be able to do the things that sixty-year-olds do: go out, and spend some time with my wife.”

Paul says unpaid caring should be recognised as a job. He also thinks Carer’s Allowance should have different rates that reflect the level of care you provide. “I just want to make a difference. And I don’t think that will happen until the people making the decisions are involving people with lived experience. That’s the key. And not just as a box-ticking exercise. Too often people – who might be going through even worse than I am – just aren’t heard.”