**Meeting with disabled members of The Unfair Debt group**

23/11/2021

Two disabled women, one of Jewish nationality over the age of 65 and one British Asian of working age. Both are on low incomes, are home-owners and in debt.

“I have MS, theumatoid arthtritis, heart problems, COPD, I only have one kidney, I have tumerous cancer, Hepatitis from a blood transfusion, cellutlitis, a melanoma and edema. I need social care support , having fallen over a number of times, but Newham Council won’t provide it because I own my own home where I lived with my husband. I worked all my life – around 38 ½ years - paying tax at the 40% tax-rate, I made thousands of pounds of savings but it all went on adaptations to the house when my husband fell ill – more than £55,000 in total. He had diabetes, heart problems, edema, COPD and pancreatic cancer. I also took out loans to make more adaptations and those had interest on them and so now I am thousands of pounds in debt. Newham Council say I have to pay for my own social care support but I can’t afford it. They say if I sign my house over to them so they get it when I die then I can have social care support from them now. I won’t do that. But it means I can’t have an operation I needed. I have had 8 mini-strokes and a heart attack and I need an operation. But I wouldn’t be able to manage when I came out so I can’t have it.”

[NB – note-taker queried whether this is legal and whether social care is means-tested solely on income and not assets – agreed to refer the question to Inclusion London disability justice project]

“The Council also takes so long to respond to requests for support. Our GP asked for a social worker and equipment and incontinence pads. That was in the February. We heard nothing. We finally heard back from Newham social services in March – a few weeks after my husband had died.”

“I am very lucky I got my PIP. I am a member of a Facebook group for PIP claimants and when I read all these stories from people who are bed bound being asked to go to assessment centres, I realise how lucky I am. Several people in this group have been bed bound for years and the DWP hounds them to go to assessment centres.”

“I think it is more different for people with hidden impairments. I have osteo-arthritis, my upper body is restricted, I’m hypertensive I have high blood pressure. I’m obese because I can’t exercise because of the pain and I need better pain management. When I try to exercise my blood pressure shoots up. I also have incontinence issues. But people at work don’t see all these. I am expected to do a lot of over-time. I get bullied at work and go home really upset. It brings my blood pressure up and had to have stress leave. There is no sympathy for me as a disabled person. I get laughed at more. And this you have to understand is in the NHS. I work for the NHS. I get mocked for always having something wrong with me and being off sick and management don’t understand. I have a colleague with Crohns disease and she was told she was not allowed to use the toilet except on official breaks. She made a complaint and the same manager who had bullied and ignored me was moved to another department. If management aren’t sympathetic to disabled staff then how can we expect them to be sympathetic to disabled patients. At work one day a woman called in asking to speak to a mid-wife but I could tell there was something else wrong. Often people will ask for one thing when it is something else they really need support with. I was helpful on the phone and agreed to go and find a mid-wife for her to speak to. As I came from the phone my manager started asking me, “ooh you’re being very friendly, is that a friend of yours or something?” As if I was doing something wrong. But I ignored her and found a mid-wife for her to speak to. It turned out the woman was not only pregnant, she was also homeless and suicidal. I am so pleased I ignored my manager.”

“I think things are definitely getting worse. When I had a work station assessment at work this time round, I had a massive battle to get the equipment I need. They argued that because I only work at this job one day a week I can hot desk. I challenged the outcome of the assessment and was ignored. So I referred myself to Occupational Health and they bought me a chair and a footstool and the equipment I needed.”

“I have always worked. When I was single I had a one bedroom flat from the Council which I bought and when I got married my husband moved in and we had three children. Then after our third child my health really deteriorated. I had an OT assessment and adaptations were fitted. But now the flat isn’t suitable and it is making my health worse. We desperately needed to move so I looked into different options. If I sell it I won’t get enough to buy anywhere else in London. You can get housing benefit while your home is on the market but only up to a maximum of six months. So I thought to rent out my flat and rent somewhere else for us to live. For private renting we would need a big deposit that we just don’t have. I did find somewhere with two bedrooms where the landlord wasn’t worried about a deposit, just that we pay him on time. I had been to the Council’s OneStopShop and they said I would be able to get Housing Benefit. So after we moved I applied. 7 or 8 months later I was told I wasn’t entitled to anything because I own the one bedroom flat. They had given me the wrong advice. On top of that, the tenants didn’t pay during the pandemic so I ended up being without any rent from that flat for a whole year.”

“I am too ill and tired and exhausted to be able to join in with protests against all these things that are wrong even though I want to.”

“My husband has had a lot of problems with his earnings and Carers’ Allowance. He used to take over time when he could but the way the payments would come in would sometimes make it look like he had earned more than £115 week and then the benefit would get stopped until he could prove it. The difficulties this all caused would mean he can’t risk doing over-time now.”

“I find keeping going so exhausting that I make mistakes and forget things and then end up in debt. For example I had a hospital appointment that my husband drove me to and I forgot to sort the Congestion Charge out so we got a fine that we can’t pay and the bailiffs came round last week. They were so hostile to my husband the way they treated him. I have three jobs – I had four at one point. I don’t only have Credit Card debt but I am also in debt to my family. I am a Community Engagement Office in one of my jobs and when it comes to supporting other people I can do it but when it comes to my own life I feel so exhausted and I forget things.”

“It is appalling the way we are treated when we have paid taxes all our life and then get told we are too expensive. When Jeremy Hunt was Health Secretary I went to Parliament and I told him I was not moving from St Stephen’s until he sorted the injections I need which I was not being allowed because I was over 65. I was told it was too expensive to give to people over the age of 65. I stayed there three hours and Jeremy Hunt did sort it out for me.”

“In my work as a Community Engagement Officer I worked with elderly and disabled people over the lockdown who would usually go to day centres so they weren’t isolated but many could not use or have access to the technology. So much is online now, for example the GPs. Having to prove again and again that you are disabled is such hard work, always having to collect the evidence and GPs charging for the evidence. I have to do my Blue Badge again but I keep forgetting. And with everything it’s up to you chase up each person – chase up this one and chase up that one. Especially with hidden impairments you have to prove again and again. I have lost hope.”

“My friend’s husband was found fit for work even though he had a heart problem. So he went back to work and about an hour after arriving he collapsed and died. That was about 2018.”

“They say that if you become a carer, you’ll end up needing care yourself. I didn’t believe it. I used to do all the administration and management of my Mum’s direct payments, all the paperwork. It was so much work, such hard work. As her carer I found out about all sorts of things you could get as a carer, for example pampering services. There doesn’t seem to be the same for disable people.”