

WOW Voices

How Disabled People really feel about Welfare Reform

Many disabled people, their friends and families believe that Governments of many colours have deliberately created a hostile environment and made life much more difficult for them.

When we've complained about this the Politicians have told us that we can't prove that's what they've done. No-one cares. Disabled people have no voice.

We have asked Disabled People, their friends and their families to give us their voices so that what they are feeling and experiencing can be recorded.

Society will be able to read what we think it has done to us and because we are human beings, perception is as important as causality.

The 4 of us behind this phase of the WOWpetition campaign know what has been done to disabled people. It hasn't stopped us crying when we read these "voices".

The WOW Campaign 2018

You can still send us your experience by using the form that you find here <https://wowvoices.uk/send-us-your-voices/>

Voices will be published on the website, shared on social media and included in the next version of our ebook

Assessments are all too often wrong and appeal in court over rides the DWP decision and allows the benefit, Appeal can take up to anything 18 months with no benefit denying them their Warm Home payments and other passports benefits. How do I know this, I have been through the system with family and friends.

Assessments are only in place to cut welfare bill but it's costing taxpayer millions and causing claimants distress and hardship! Assessment reports I have been involved in are full of contradictions, opinions and lies! I can only speak for myself but I created a Facebook group about this issue several years ago and I've heard numerous similar stories! Why should sick people have to go to court to get what they are entitled to? What they've contributed to!

Trudy

I have fear of heights so how am I supposed to arrange this trip and cross the bridge, they just don't care about our illnesses and what we suffer, when they changed me over from my lifetime award of DLA to PIP they awarded me a 3 year award and reduced my money by £30 per week, things are going to get worse as they have another 12 billion of welfare cuts coming down the line, I am only living on PIP as they had already denied me ESA, how will I pay for my prescription medicine now, how will I pay for food, how will I pay for heating, Teresa May danced on to the stage at Tory party conference to the Abba music dancing queen is she taking the p***, we are now witnessing the disablecide of British disabled people by the Tory government, Mahatma Gandhi said " the worst kind of violence is poverty" This Tory government and its predecessor are embarked of a regime of violence

a victim of the crimes of the Tory Government

The care agency is contributing to the disabled hell now it seems. Staffing crisis ... 5 months I have only been out the house once, I cannot rely on them to turn up cancelling calls last moment as staff off sick or cannot cover my call. I have resorted to online shopping for everything including food causing a huge increase in my bills due to delivery charges for months.

The food is frequently not what I have wanted or very poor dates. Bread for the next 3 – 4 days with just 2 days date for an eg. Without this there would be no food to rely upon for 2 disabled people. All my health appointments have had to be cancelled. Finally joined an expensive site to source independent carers to pay out my own pocket to attend some essential appointments delayed since February out of sheer frustration adding to my stress and I shall struggle still with my mental health to cope.

Culminated Friday by my being verbally abused and told it was all my own fault and called inflexible by the agency management because I objected to my call dropped yet again last few hrs before they were due leaving no carer for me to unload and put away the essential and already organised online food shop, when asked if they can 'do my call another day'. It also means no shower or hair wash for me now for 2 weeks if then.

They threatened to call the police because this had distressed me badly yet again because I refused them permission to call my GP. I lived the evening out cringing at every passing vehicle in case the police were coming to take me away. 2 days later I am still shaking. Is this how care is supposed to be?

The reason I started [this petition](#) wasn't just about the DWP, it was about people being able to help each other

If we can't travel to friends then how can we help them? If our friends are sick and we have no money, how can we visit them in hospital?

If they need a hand in the home then how can we go visit and help if we have no money to travel?

Its about partaking in local politics and fighting for our rights, because it seems to me no one else wants to help us. Because this issue doesn't bother them. It's about us being able to go out to enjoy things like the rest of society, and yes it is also so we can get to medicals, receive treatments from NHS appointments, fix our mental health.

No one should be stopped from travelling by bus because of finance. Who says the oil beneath our feet and under the sea belongs to only the rich. Time we started sharing earth's resources and the wealthy stopped being greedy.

Maria

I had my PIP assessment at the beginning of the year, the lady assessing me was a physiotherapist, she appeared nice and understanding and I believed everything was going to be fine. She told me she could see I was in pain and there was no need to do a physical assessment.

The shock came with the report, she gave me no points whatsoever, wrote that I appeared fit , walked well and fast and that I REFUSED to do a physical assessment.

She also said that she saw me opening my hand bag and that apparently proved that I can walk and do everything unaided. In her opinion my good eye contact and ability to explain my illness also prove I don't need any support.

The mandatory reconsideration was another joke as they copied and pasted her answers in all the boxes. The result would be funny, if not so tragic. My good eye contact apparently makes me able to deal with anything from incontinence to social anxiety and preparing meals.

My husband works so we are not starving but we would need the extra money because my disability has extra expenses.

Claire

No understanding of m.e whatsoever. I may as well have been talking to a child. I lost count of the times I had to say there is no average day as things vary and change so quickly. I felt like she was simply ticking boxes and there was no degree of variation allowed for answers and she did little to try to understand that or even pretend to understand. Having been kept waiting for almost 2 hours, i had to request somewhere dark and quiet as the waiting room was too bright+loud. This was ignored in the report. The questions were irrelevant to m.e. The “physical examination” consisted of asking me to raise my arms and legs. I did it and said i was in pain whilst doing it and the report said i did it without problem. I refused to crouch during the exam but the report said i did it without problem. When trying to explain my symptoms and daily struggles it was like talking to a brick wall.

She didnt write down what i said but just ticked the boxes so the extra info was ignored. There is no room for variation or individual problems. The report came back full of mistakes but when i complained that the lady had made up that i crouched/did certain things i was told simply that she is an independent assessor with no need to make it up so why would she lie. My stress, depression and anxiety levels are through the roof. I didn't know at the time of the assessment but i was pregnant, i have had to go through mandatory reconsideration and multiple meetings with various job centre staff all whilst pregnant, disabled & in a lot of pain. My tribunal was just after my son was born and I was so ill afterwards that I couldn't look after him for days.

My family had to come and help, changing their plans/taking time off work and looking after him as well as me. I have since been told that my tribunal waiting time has pushed me over the time allowed to have ESA so i don't qualify now anyway. Belfast office also said that as i have 'chosen not to work' my husband should be supporting me, not the benefits system. I'm not entitled to anything else because i am married. My husband is on a very low wage yet we are constantly told we are entitled to nothing else. Had i known that ESA would cause such stress in my life and affect me on a daily basis i would have not even bothered. Its too much. I cry every time i think about having to go through the process only to be told i cant get anything anyway.

Katy

I originally went for the assessment 11 months ago. The waiting and the uncertainty has been a huge stress, having to go through details again and again, as if they they don't believe me and want to catch me out. The biggest worry though has been feeling like I could be being watched or judged. There are stories in the news about assessors secretly filming claimants to catch them out and I think that's disgusting. It causes such high anxiety for me that I often don't like to be out on my own. Or even out at all.

My partner had an indefinite DLA award due to several chronic conditions some of which he has had since childhood. Last spring he was transferred to PIP and was assessed by a young physiotherapist employed by ATOS.

It is very hard to manage several medical conditions at the same time because not only you have to deal with the symptoms and the side effects of the medications but also how different drugs regimes interact with one another and how at times certain therapies have to be stopped because they make another condition worse. And how at times some conditions will have to be left untreated because it would be too dangerous to do anything.

In the claim form he explained in detail how this makes daily life hard and complicated and he included medical evidence from three consultants.

The result was zero points for everything. The assessor did not even try to understand the problem preferring to focus on manual dexterity and eye contact which are both completely irrelevant in this case. She did not take into account the constant pain, fatigue, dizziness and other physical symptoms. And the amount of energy and time required every day to ensure that all conditions are kept under control. Most of the questions were standard and irrelevant.

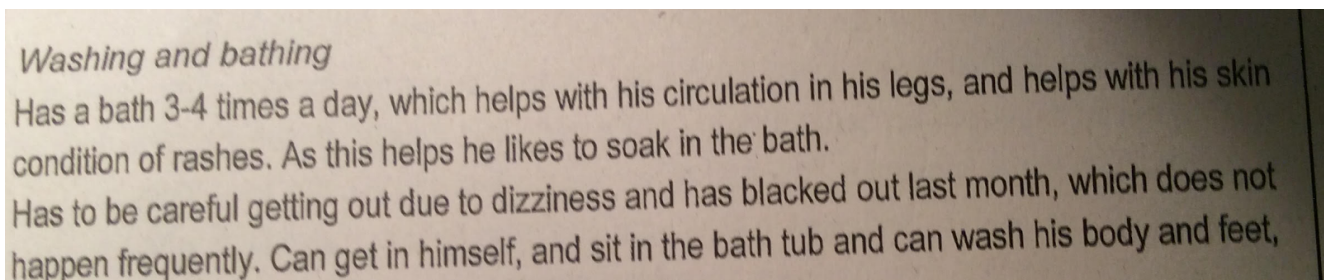
The report was also shoddy, she did not list all his medical conditions, forgetting two, including one which causes significant problems. She did not list all the symptoms or side effects. Not all medical evidence provided was listed in the report, with two letters completely ignored.

Both the claim form and the medical evidence stated that two of his medical conditions are not well controlled and one is only managed conservatively because of the impact any intervention would have on other conditions. The assessor wrote in the report that all his conditions are well controlled with medication and there are not problems in managing them. The fact that his disabilities have extra costs and require constant support was not even taken into consideration.

In many instances she wrote exactly the opposite of what was in the claim form and was said at the assessment. He stated that he no longer reads books as he does not have the concentration to do so because of fatigue and pain. She wrote that he regularly reads.

He stated that he tries to go out once a day in the morning, which is the best time of the day for him, but often has difficulty managing even this, she wrote that he goes for walks three times a day.

He stated that he tries to have about 2 long baths a week because they are good for his circulation but that it is becoming increasingly difficult to organise them. And she wrote this.



Washing and bathing
Has a bath 3-4 times a day, which helps with his circulation in his legs, and helps with his skin condition of rashes. As this helps he likes to soak in the bath.
Has to be careful getting out due to dizziness and has blacked out last month, which does not happen frequently. Can get in himself, and sit in the bath tub and can wash his body and feet,

For his Mandatory Reconsideration two of his consultants wrote new very detailed letters, spelling out that given the precarious state of his health removing any support “could lead to increased complications, hospitalisation and risk of mortality”.

It was also pointed out to them the poor quality of the report on which the decision to award 0 points was based.

The decision maker for MR replied that while doctors can make diagnoses they can't assess how these affect people's lives while the assessors are properly trained to understand the impact of a disability on people. And they stand with zero points for everything.

My question is how they can do this when they don't even ask the correct questions, neglect evidence, focus on irrelevant issues and record facts inaccurately? I also do not believe they can understand decades of complex health issues and the cumulative effect they have had on someone's mental and physical health in 30 minutes!

I know for a fact this is not an isolated case, there are lots of similar experiences. Some are luckier because they are supported by family and friends. Some are on their own and besides the impact of the loss of financial support and the access to other services people would get with PIP, it is extremely hard to be betrayed and let down by those institutions which are supposed to help.

Laura

My son was assessed for PIP at the beginning of this year. Despite it being after the court ruling (regarding mobility, taking a journey and mental health) the assessor took away his mobility award. It was a big issue as my son is seriously affected. Government said they would review everyone, they have not contacted my son at all to do a review. We are too scared to contact them about this as my son would be in serious trouble if he lost the care element of his PIP. My son keeps coming in and out of work and has been homeless many times he relies on this benefit to work and support him when out of work. I was diagnosed with Autism after becoming ill.

I lived in a secure council house for 30 years in which i could support my son with somewhere to stay if he became homeless. I was forced to move out due to the room tax, i had no money to move and ended up at a really terrible place. I was then forced to move due to anti social tenants who the housing association were evicting and was moved to a property in absolute disrepair. This was a housing association that was doing this but were like private landlords, they even put me on a rolling monthly tenancy.

This Christmas the DLA i was awarded will be re assessed for PIP and Universal credit has just come into this area this September. I already know i will be under assessed in which i will then be forced onto universal credit – it saves DWP paying for transition. I will be at risk of being evicted (as i have had to complain about the disrepair to the ombudsman – who is no authority at all at the moment). My health has become much worse, I have been forced to move twice and the threat to my home and cuts to benefits and facing assessments is really made me ill.

I am constantly fighting suicidal thoughts and have become much worse. I still have to do so much to support my son, there is absolutely no safety net for him. What is so sinister is the government have incited discrimination between those on benefits and those who are working. Its so appalling that some people become filled with hatred towards those of us who are on benefits, not only is there a threat to becoming homeless and having no money to survive but you also have negative behaviours towards you from others because you are on benefits. What do the government want – for all of us to crawl under a stone and die?

I read up dates everyday on any news about them stopping universal credit- presently it is severely affecting my mental health, its been constantly building since universal credit came out as you feel under constant threat. Starving and being homeless is terrifying when you are disabled and ill. I pray every day this nightmare will stop. Everyone must know that the government are completely breaching human rights in housing and benefits, they are also doing everything to damage the younger generation – they stopped their benefits and they are encouraging zero hour contracts to turn them into slaves. This is a very serious dark night of the soul for humanity. God help us all.

Gemma

My daughter took me there, she is my carer. I did not use my wheelchair and walked with two crutches instead. Lots of stupid and irrelevant questions, really tiring, it took me a week to recover from it. I scored 0 points for everything. They wrote I went there on my own, could walk normally at normal pace (!!!!), that I could touch the top of my head and my nose and could hold my passport.

Our problem is now that not only I lost my DLA and will have to cut down on everything but my daughter lost her carer's allowance and has been told she has to look for a job now. She gave up her job because I was too ill and the unpredictability of my condition meant she had to run home from work so many times because I had fallen or did not answer the phone after a seizure. Her employer was not very understanding and it was very difficult for her. Doctors had told me I needed supervision anyway.

I have MS, osteoporosis and epilepsy. I have very bad days when I need help to go to the loo, can't dress myself or even make myself a cup of tea I now wake up at night worrying that I will end up in bed with incontinence pads all day long.

Stella

DLA told me now that it had gone passed 6 months " well you haven't died, so the high rate doesn't apply" yes the exact words after arguing that the stress of chasing up and the fact my doctor's can not provide an actual death notice but did support a terminal diagnosis and although we are all hoping my trial drug helps it's not a guarantee.

I stayed on low rate and appealed again. I started a trial drug that same year and committed to 3 years treatment, that led to what we now know as the mother drug to immunotherapy. Yes I am still very much alive 8 years on and have had return of cancer in other areas twice more to which more operations have taken its toll on my body and mind.

I finally received high rate the year DLA went over to PIP and then lost high rate because the assessor said "you read books, my home was well kept and I could hold a conversation with eye contact". I read books because I was a professional in psychotherapy and it is still my passion, I'm a good communicator because I am a therapist and my home is tidy because I have been brought up learning a clean home is a tidy mind.

The fact that I am seriously operated on with limited use of my left side upper back and arm or that I suffer huge anxiety with new people was irrelevant as was considering my current return of cancer which had gone from terminal to stage 3 to stage 4 in 8 years, this was not accounted for and left me devastated. In the 8 years of diagnosis I lost my mortgaged home due to financial difficulty, became homeless which took 4 years to be homed, was now an unemployed therapist (a therapist whose depressed can not work).

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Living Proof

I was born in 1957 – we are called ‘Baby Boomers’ which is an insult to our parents. We do not decide when we are born but 1950’s women have worked all their lives for the UK to thrive.

I was born into a family of 6 children & being the eldest was a second ‘mum’ to all my siblings. I had a happy childhood even though I had to take care of my brothers & sister & had a Saturday job (from 13 years old) as well as going to school. When I left school on the Friday in July 1972 I started work the following Monday. I left home & got married in October 1976 – I signed the NI1/CF9 form, which was the form to sign if you were paying full National Insurance contributions & wanted a pension in your own right at 60 (This form is available to view)

I carried on with my life working, looking after my home & husband, bringing up & nurturing 3 children. Even when they were small I found work in supermarkets, cleaning wherever was needed any job I could do even if it was menial – I worked when my husband had finished his work for the day.

So not only was I looking after young children, keeping my house in order & making sure my husband had a good meal when he came home I then went out to work. It was what we done, so no problem I did it. When my children started full time education I could work for slightly longer... then we did not have maternity leave, nursery places, I had no family around so had to look after my children myself.

I gradually increased my working time as my children grew & then was back working full time. Always paying my full NI contributions. I had a life but always in my mind I was retiring at 60.... In 2015 I was made redundant, but I had no worries as myself & my husband had little savings & he was still working so we could afford it with no problem. I then sent off for my State Pension forecast from DWP.

You could have knocked me over with a feather when the forecast was that instead of me retiring in 2017 – I was now retiring in 2023!!

I could not believe it that I now have a retirement age of 66.. after all these years of doing what is right, not being a burden on the state, paying for everything myself through working my whole life.

I am now 61 going on 62 – I have not been able to find another job.... even though I have sent many applications off, even for Apprenticeships, as our MP from the Department of Work & Pensions; Guy Opperman stated we of the age over 60 should apply: I have & I can imagine what the conversation is when they are read by the company who want a young 16/17/18 year old to train & not a 60+ woman.

So now I have no income as my husband is obliged to look after me (as per DWP)... so now we hardly see each other as he has to take on more work to earn more for us to live. Our savings have gone to 0, our bills are going ever higher & we do not have any spare money for anything we had planned to do in our retirement. My husband will have to stay at work for an extra 3 years to be able for us to live.

Our government call this Equality! we are pensioners living hand to mouth – exact words we are living in Poverty & our human rights have most definitely been abused. Our Government have admitted that 1950's women did not get any notice of the pension age rise in 1995. The next 2 rises were in 2011 & 2015. If you go through life knowing you are going to retire at 60 & they stated the pension rise would start in 2020... why would you think any different.

We did not have the pleasure years ago to join a company pensions scheme... we were relying on our state pension for our old age. My cousin who at 65 retired March 2017 & he died in August 2017 (1 year ago) he had started work at 14 paid in all his life & had 5 months pension.

Where does all this money go? His wife has an extra £6 a month... makes you laugh. I hope that you can see that our Government has not been fair to it's over 60's – they are waiting for us to die so they do not have to pay us our pensions that we have already paid for. State Pension is not a Benefit, we have paid into it all our working life & we would like some justice.

Jackie L

The whole thing was a big shock and affected my mental health badly. I've had to change my future life plans as I won't have the money for independence anymore. When we arrived at 8am on a Sunday morning, the receptionist had to call her to get out of bed so we knew straight away that she wasn't going to be in a good mood.

I feel like she looked down on me, she directed a lot of questions towards my mother and not me. Waiting for her to arrive felt like an eternity but we weren't in with her for long. She skipped a lot of questions saying they wouldn't affect me. I wonder if I had not invested in a walking aid to help me get about and had just stayed home all the time, would my PIP not have been revoked? That should NOT be the case for anyone.

I have lost my freedom. I used the money for taxis as I can't walk to the bus stop even with a walking aid and that gets expensive. Now I have to rely on other people giving me a lift everywhere or paying for my taxis. I needed this Personal Independence Payment for my personal independence and now that's gone.

Sarah

The housing situation, leaving people like me trapped in an unsuitable house that isn't accessible for my wheelchair, and I sleep on a sofa in a knock-through living room that leads to the kitchen and bathroom. Due to my lack of privacy I had to be discharged from the Bladder & Incontinence service as I just couldn't self-catheterise when I needed to.

The fear of going through appeals again when our area is moved to Universal Credit is palpable and I genuinely don't know if I will be able to cope with it. I need a family-sized disabled access home as my 3 youngest, aged 23, 22 and 20 cannot afford to move out though they are saving for deposits (I mean renting, not buying, deposits). I have a fairly large area I'm willing to live in but there are no houses (I still need to be able to retain my GP, and she is flexible about the catchment area, as she is the only 1 medical professional who knows my complex needs and diagnoses)

The cuts to social care mean that we are not allowed a social worker who is retained for our over-reaching and changing needs, having to reapply for assessment with each diagnosis and with each further fall in my health. I have been waiting for 22 months for my new assessment. The whole system is shattered and we are left wading through the shards. It feels, genuinely, like they want us to die, either by our own hands or with our illnesses. Housing, the DWP and Social Care all interweave and are all killing us.

This is just a brief overview. I haven't even included my illnesses, which include: Ehlers Danlos Syndrome; Fibromyalgia; Meniere's Disease; Raynauds Disease; Arthritis in every joint; Severe Anaemia; Lordosis of the spine; Degenerative Disc Disease & Lumbar Arthritis; 2 Hernias and a partial bowel prolapse...

Kim

Got the first letter in February. Mid-September and I'm still waiting for the result of my Mandatory Reconsideration, nearly eleven weeks after asking for it. It's supposed to be done in six. Months of stress with the badly designed form and humiliating, exhausting face-to-face assessment and all the extended waiting. It's made me very anxious and depressed, and even if they pay me for now, I'll still have to do it all over again in three years' time. There's no security with it., just a future of dread. She wasn't particularly friendly and told me off for trying to talk to her as we had to "stick to the form". It was 40 pages long. She had enough info already. I don't think she got the concept of an M.E. "crash" and how I literally can't do anything during a bad one. She glossed over some other health issues too.

The report I got back was complete garbage, with paragraphs repeated where it had been copied and pasted, but I suspect that was more the DWP decision maker's fault than hers. Too long at about 90 minutes. Frustrating, humiliating, repetitive, pointless, demoralising and exhausting. I was also asked a variant of "Why haven't you killed yourself yet?" Must say, I'm wondering that myself right now. No points for mental health issues. None whatsoever. M.E. in all its glorious manifestations not taken into account for care or mobility.

They're obsessed with "aids" and "appliances" and not much else counts. Something I said was completely twisted to imply its opposite. Tone of report: "You say this on the form but we didn't see you actually die in the assessment so we don't believe you and we know best". Very condescending. Grammar crap as well. They awarded me some money but I asked for an MR because the report was so inaccurate. Waiting to hear result. Nerves shredded. Not sleeping. Supremely stressed. All symptoms including physical pain much worse since this began seven months ago.

Miranda

I am a stroke survivor and on the 6th of September I was forced to attend a Work Capability Assessment. This experience has been a huge eyeopener in regards to the blatant deliberate cruelty perpetrated on poor the disabled and the defenceless. I witnessed people in extreme discomfort every one of them in serious distress after being made to wait up to 3 hours beyond their appointment time.

I was informed by the assessor that they deliberately double book the appointments on the off chance that someone doesn't turn up the result of this is misery, distress and unnecessary expense for people already struggling on benefits. I witnessed people in extreme discomfort every one of them in serious distress after being made to wait up to 3 hours beyond their appointment time. I was informed by the assessor that they deliberately double book the appointments on the off chance that someone doesn't turn up the result of this is misery, distress and unnecessary expense for people already struggling on benefits. I witnessed family after family turn up for appointments only to be told that they would not be seen.

One such family, four adults and two children, explained that he had used the last of their money to pay for the four hour drive they had had to make in order to attend. He was met with a shrug and was told "take it up with the DWP" at which point he became justifiably upset only to be met with complete indifference and the G4 security guard rose to his feet. This has been done for cold heartless financial reasons if someone does not turn up for their appointment the assessing body lose out on a fee and rather risk this they are prepared to make the sick, damaged and disabled endure a process that for many in that waiting room was nothing short of torture.

Another damaging effect of this despicable practice is the effect this has on support workers because they had made one man, who was in obvious agony, wait three hours past his arranged appointment it meant that two other people whom the support worker should have seen that afternoon were left high and dry and this again was met with complete callous indifference. It has to be stopped and criminal charges pursued on the perpetrators of this inhuman system.

Thomas

Kirstin Maguire, aged 33, – I was a London based Writer/Poet, Director of an Arts CIC & Mental Health Trainer/Manager until complications with fibromyalgia & chronic fatigue syndrome in late 2015. Now in my 20th year with these conditions, and more that developed since, I have been largely housebound for three years, with numerous prolonged periods bedbound. Due to my experiences, the following is particularly concerning those dealing with chronic illness/invisible disabilities. I'm so grateful for this debate and urge you to make the changes needed by so many thousands of disabled people in this country with the urgency required.

Key Stats (context):

– Chronic Pain Conditions affect 42% of our population – Most chronic illnesses affect 4 times the amount of women to men. In the case of

fibromyalgia, 75 – 90% of people diagnosed are women

– Most research to date has been carried out on male subjects – People of colour are 2-3 times likelier to have a chronic illness and less likely to access services – Many of our older people are dealing with 4 or more chronic illnesses at once – The rates of attempted suicide rates have more than doubled from 21 – 43% of

claimants since the Fit To Work Assessment has been introduced. That's almost half of disability benefit claimants who have attempted to take their own lives compared with 6.7% of people in the general population. To the best of my knowledge, in recent years, the Government have stopped gathering data on completed suicides in this community. Added to this:

– 1 in 10 suicides are linked to chronic illness – Every day, at least 1 person in the UK takes their life because of their chronic

illness – People with fibromyalgia are 10 times likelier to take their own life than the

general population – Carers are paid up to £64.60 a week if they work at least 35 hours a week. That's a

maximum of £1.84 an hour. The reality is most carers work far longer hours, sometimes around the clock, reducing even that hourly rate significantly. – In an ageing population, chronic illness rates are set to rise exponentially over the next

20 years – In the 1980s, there were 6,000 social housing properties in the UK. At present, there's

closer to 2,000. This shortage is forcing housing teams to increasingly provide temporary accommodation on a long-term basis. The housing crisis is a public health issue and the disabled and sick are suffering the most, being placed in unlivable conditions with unscrupulous Landlords when they're already extremely sick dealing with debilitating illnesses

Key issues for this debate:

Restricted perception of the huge variety of chronic illnesses

– As a recipient of benefits, how you look is inextricably linked to your income. Points are

deducted for being well dressed or wearing makeup and groomed hair at the assessment. There's rumours this bleeds into social media – e.g. people having benefits cut because of a photo on facebook where they were groomed. As someone going through the system, it's incredibly difficult to distinguish what's rumour and truth, as you're widely isolated and any encounter with the benefits system is a nerve-wracking assessment process. The impact of this on the individual is we feel quite literally dictated to, on how we're allowed to dress ourselves because we are sick. Many people, like myself, have spent decades pretending to be more well than they are by the time they reach this point. It feels a further erosion of your identity.

“Good days and bad days”

The form itself acknowledges that with most conditions there can be 'good days' and 'bad days' and asks you to fill in the form based on bad days, but there's a dichotomy in its implementation. Someone assessed on a 'good day' simply loses on it in the current format.

The incredibly narrowed set of symptoms assessed in the form and assessment don't account for numerous factors or symptoms. – e.g. in the disability assessment you're asked if you can put your arms behind your back and how long you can sit for. A lot of people experiencing chronic illness are used to pushing themselves beyond their comfort zone and hiding pain in order to do usual things. Add to that, hypermobility is common in chronic pain conditions, this exercise is uninformative at best and misleading in many cases. Invisible disabilities often involve numerous body systems – in my own case for e.g. central nervous, immune, circulation, neurological, digestive, endocrine, and lymphatic systems plus others are involved. All of which are, for the most part, invisible. None of which would impact me putting my arm behind my back at an assessment. However combined, they result in a complex plethora of symptoms that mean I'm largely housebound, and at times, bedbound. This is making people with invisible illnesses often feel an obligation to make something invisible visible, due to lack of understanding. This can often mean a further loss of identity and restriction to how you the person would like to be seen in the world when so many opportunities for being who they thought they were have already been taken.

Replication between PIP & ESA

– Work capability assessments determine if you are eligible to receive Employment & Support Allowance (ESA). It's made of 2 components: A form and a face-to-face assessment. Most people applying for ESA are likely to also be applying for PIP.

There's replication between ESA and PIP assessments. Their forms and assessments are so similar they're almost indistinguishable from each other. This means that essentially, sick people are going through the same process twice in order to access funds from two different benefit payments.

Reassessments

Reassessments are a huge source of ongoing stress. Even with a deteriorating condition, you will be reassessed. It means the person dealing with debilitating illness and/or disability never feels safe about their income or their future.

The reassessment period is as bureaucratic as the initial assessment. Each time you submit the form to be reassessed, you have to revisit all the very personal difficulties again and submit reams of accompanying paperwork that date back throughout your condition. In my case, for example, that's paperwork dating back for the past 20 years, so a large proportion of it is the same paperwork everytime I reapply. This is damaging to the environment, time-consuming on all sides and bureaucratic. If it's decided the reassessment process is really necessary although we know most of these illnesses get worse, could the original forms and accompanying documents be kept on file and could the form be changed to be an update on symptoms since the last reassessment instead of the same as the original form? At least, this would mean people only need to communicate their illness over the past couple of years or so, rather than several decades worth of information and so much inevitable replication in forms. It also means they would only need to submit the accompanying medical paperwork since their last reassessment. This would make the process less of an ordeal for the person applying, less paper for the environment, and less time for Assessors going through the same paperwork upon each reassessment.

If PIP and ESA need the same information, can they share it rather than the individual going through the entire process twice with different agencies?

I've come across anecdotal evidence on facebook groups that some people are receiving ESA but refused PIP or vice versa. Given the striking similarities in the assessment process, I find this confusing.

The questions in the form for both benefits are extremely personal and can be distressing with limited support in general and little to no emotional support. Genuinely, my first one was a horrible experience – suddenly you're answering questions about your bladder and bowel movements and all the lack of abilities you fear most. It's a highly intrusive process and is entirely communicated via a form, making it even more isolating

– A points-based, one size fits all model makes it extremely difficult, if not impossible, to

communicate the impact of chronic illness in a limited format – As the form and assessment are exclusively based on symptoms, I'm unclear on how the process assesses an individual's capability to work. You're asked about your ability to eat, prepare a meal, wash, go to the toilet, find places and communicate etc. How does this establish if you're capable to work? There is no evidence I've seen of consideration of the type of work that might be appropriate for the individual despite the decision made

Assessment Centres

– **Assessment Centres are often inaccessible, meaning you need to attend one further out, (the majority of mine have generally been an hour and a half away in areas in Essex that I wouldn't be able to access by public transport because of my condition) where you are likely to need someone to drive you there. They're often in pedestrian areas that are difficult to walk to. Often, the Assessment Centre is at the back of a large building, often with cameras. Part of your assessment is you're asked how many stops you had to make from the front door. People with chronic illness are generally used to pushing on through high levels of pain. This creates a distortion and means if they really push through to get through the assessment (as many do) it is likely to play against them financially**

Assessments

– The Assessor and individual being assessed have no pre-existing relationship. Arguably, this is for fairness. However, it also means that the individual has to present a comprehensive case in limited time, while the whole process is set up in such a way that you feel judged. This is more feasible for some conditions than others. In honesty, I would think the relationship between a patient and GP would be a far more reliable source of information as they will have seen the individual on an ongoing basis and have greater insight into how the condition is affecting the individual – There is a culture of fear which starts with the form, is exacerbated by the lack of support, knowledge or a contact and is at its highest around the assessment. This links into a profound fear in the individual caused by the condition itself. This is compounded by a pressure to be seen to be sick, as in the culture of the benefits system and creates a vicious cycle. It's also completely at odds with medical advice – which, in chronic illness is, to keep pushing yourself. Therefore, following medical advice means you're penalised by the benefits system. – Potential for unfair comparisons between individuals – e.g. My records show someone who struggled through their childhood, adolescence and throughout 20s to attend school, university and work. On paper, this might make me seem more “worthy”. However, I was unusually young when first becoming sick. I had youth on my side and was able to tolerate high pain levels, brain fog and widespread symptoms in a way that someone diagnosed later on in life might not be able to. Equally, people's experience of chronic conditions differ wildly, including onset of condition and how that presents and develops. In my case for example, although I managed to push through extreme pain and symptoms for almost two decades to study and work, I had no idea I would become as sick as I am now at any point in this diagnosis, let alone by early 30s. – On benefits, there's no way to govern income, save or recover from debt – hand to mouth existence with no chance of respite – Benefits come with lots of unknowns about income. The individual is left to navigate a complex system through different benefits systems. Sometimes, significant periods may lapse before people realise they are entitled to another payment. This is only backpaid to the day the

application was submitted

Lack of link up between Health & Social Care

– A medical professional generally signs you off. There is no link-up between Health and Social Care. Once the medical professional has made that decision, the individual is left to self-manage a complex benefits system that is not within the referrer's knowledge base and where the sick person feels entire alone, unclear and under suspicion. – There are contradictions in known symptoms between healthcare and benefits process. e.g. it's widely known in the medical community that hyper-mobility is often linked to chronic pain and that a number of disabilities and illnesses are largely invisible. The points in the assessment are based on how limited rotation and movement are. This can be very misleading in the case of chronic illness or chronic pain

Payments

– Benefits are staggered, each on a 4 week cycle, meaning the recipient is paid smaller amounts multiple times a month, complicating payment for larger outgoings such as rent and bills – If there's an admin error made by staff, the claimant has their benefits cut and it can take months to get the money paid. This happened to me and it also triggered the housing team to cut their money, so I had no income at all for months because there was an admin error in the disability benefits system

The “Mobility” Component

– The main benefits are made up of two payment components: Daily Living & Mobility. Each has 2 tiers of payment. I'm unclear how the 'mobility' components play out in the case of people with mental health difficulties or learning disabilities and I haven't been able to track down the answer on public records. Anecdotally, I've been told that people with mental health problems do sometimes get the mobility component e.g. if they are agoraphobic but again, it's not always the case. I think the 'mobility' element adds several complications for people with invisible illnesses, incurable long-term conditions, learning disabilities and mental health problems. This could potentially mean a significant injustice for those diagnoses in accessing income they're entitled to.

Lack of advice/advocacy

– From my own experience, there's a significant gap in advice and advocacy. I have

always felt listened to and respected by staff carrying out the assessment. However, the support around it has been disappointing. Here's examples:

– I've called DWP and they don't tend to tell you what you're entitled to in general.

The conversations are far more specific to difficulties with a payment, putting all the onus on the individual to find the benefits in a particularly fragmented system – I went to a charity based in east London to find any information on benefits and

how to complete the form. I was deeply saddened to see the support available. In a largely multicultural part of London, a number of people were BAME and had English as a second language. I didn't see any Translators. It was cramped

waiting conditions on a first come first served basis. People were queuing for at least an hour outside the door before it opened. They put a note on the front door when they were full and closed the door in people's faces with no explanation. The woman offering the help and advice was doing it pro-bono and works in the city. Upon realising that I had a degree and had worked in mental health, her entire tact changed from domineering and largely undermining to more receptive and respectful. This indicates an injustice. I have no knowledge of what it is to be a person of a minority ethnicity going through this system, but this experience deeply concerned me as this was meant to be support for people. Anecdotally, I have since learnt this is indicative of a bigger struggle for BAME people in the system. Having worked in mental health and social justice, there were several gaps in ensuring accessibility of services for black and minority ethnic communities – I also went to Citizens Advice on two different occasions (years apart) and asked

them for advice on benefits. Both sessions clearly demonstrated their lack of knowledge and resource. In fact, what was clearest was their own grievance with the current system, making it a nice exchange on a human level but unhelpful in any practical way

Subsistence Level

Due to decisions made around managing their condition, either through the position applied for, reduced working hours or on benefits, people with chronic conditions are often at risk of a consistently low income. At subsistence level, there's enough to survive but not thrive.

Employment Restrictions

– Some benefits allow you to work occasionally, but going through the system, it's unclear whether you are in that bracket or not leading to uncertainty over employment rights – If a person is fit to work occasionally, the wages are capped by the benefits body, not by the employer. Therefore, if the individual was in a profession that commanded more than a low income prior to becoming unwell, and were well enough to work a few days every few months or a few days a year, it's likely that income would be well over the capped amount. This means people might have to turn down opportunities that would assist financially and ensure their skills and knowledge was more likely to be up to date and relevant.

The Upshot:

– The benefits system is complicated, fragmented and multi-faceted. Information and

support is limited and the information inconsistent. – Stigma feeds into this hugely as the fragmentation is reinforced by a benefits system that

leaves you feeling powerless, down about yourself; and for some; with a feeling that following medical advice will impact perception and the income you're entitled to.

Additional Comments:

This document addresses the issues within the disability benefits system specifically, i.e. ESA and PIP. Therefore, it doesn't account for the many issues with housing and other benefits that add a huge layer of complexity to the experience of the sick person, where we're often worrying about very urgent problems such as imminent eviction and not being able to find a home, amongst other issues. This is furthered by a buckling NHS, whose target based services can't manage chronic illness on an ongoing basis, leaving people to cope on their own with a limited range of drugs, already proven to be largely ineffective and little to no ongoing specialist care. It's worth baring in mind, the disability benefits system isn't the only system failing the disabled. It's a vital starting point but the reality is we need wider policy reform to bring it anywhere near up to standard. How we treat the sick isn't in a vacuum, rather it's a direct product of our society and says a lot about its values. Is this what we want to be saying?

I did not understand anything. My carer was present and took notes. What was in the report is not what was stated by my carer and appears to be fabricated so as to avoid the awarding of points. It has been physically and mentally draining. The panel said if I contest the decision as I have already been awarded mobility money then I will likely lose everything. This is making me worse as stress makes my condition worse.

Elle

When my DLA ended I was told to apply for PIP, and of course I got no points at all in spite of years of evidence of serious, long-term health problems. I appealed, was turned down, went through mandatory reconsideration, was turned down – I can't tell you how awful that year was, I went hungry often to feed my now-teenage daughter, and I couldn't buy her shoes for over a year. 14 months I waited for my tribunal, it was cancelled three times at the last minute with no explanation. I'd almost given up any hope at all by the time I got there. At tribunal I was awarded 5 years PIP, with a year back-paid, on no new evidence at all, just what I presented in the very beginning.

It was a crying waste of time and money, the DWP didn't save a penny through this cruelty – in fact, it must have cost a lot more to administer all those appeals and an actual court appearance (can you believe that? We have to take the government to court just to survive) than it would have done just to leave me to get on with what's left of my life. And the damage it does is incalculably wide – my daughter was at college through this year, and she got so depressed that she couldn't continue. I'm sure she's not unique in having her life chances diminished by these discriminatory policies.

It has not made me ill, but it has made me angry, frustrated and dismayed.

I had a home assessment, the HCP was polite, kind, & seemed, at the time, to understand what I was saying. The assessment lasted almost two hours, and we chatted about one or two other things, to do with, but not directly related to, PIP & ESA assessments. I felt quite positive about the way it had been conducted. I didn't feel intimidated, disbelieved, or humiliated, the male nurse was polite, kind, and, or so I thought at the time, very understanding of my situation. He didn't ask very many questions, but, I am someone who offers up information readily, perhaps too much information, sometimes! So he didn't really need to. Therefore I cannot really comment on his skill at gleaning information by using the correct questions/follow up questions. I imagine with some people it is like pulling teeth, to get the info required, then again, I sometimes feel that they don't really want to know, they just want to be able to tick a "yes" ,or "no" ,box.

Where do I start!?! I put in a claim for PIP after several years on DLA for agoraphobia. For 10 years apart from going into the garden I never left my house, I have improved a little & can now go about 10 mins from home, although I still feel anxiety when I do this. I can go about 1 to 2 miles from home but only in a taxi as I can't use public transport, again I still feel anxious doing this. I cannot go anywhere unfamiliar on my own. The report said "I can go out" I have had OCD for 53 years takes me 3 to 4 hours to bathe this causes extreme frustration and I often sob and bang my head on the wall in frustration but, until recent years I did this everyday of my life, I just got up really early to get to work etc!!

I applied for PIP in December 2016, after 6 months of being off work sick. My health was declining and I saw there wasn't going to be any way that I could return to work, so I decided to apply. It took 4 months from sending my application to receive a face to face assessment. They gave me a home visit after I stressed how sick the ESA assessment and travelling 1.5 hours made me.

My assessor seemed like a nice guy. I explained to him how I couldn't take the suggested medication because of side affects and he stated "it's horrible stuff , good job you aren't on it" the whole assessment went this way and he made me feel a little less nervous. I was a wreck before hand and the assessment came on a bad flare day.

I had my response saying I scored 0 points. Even though ESA saw I was so sick they put me straight in the support group, no questions asked. I appealed the decision which obviously as everyone's does, it failed. I went to tribunal and even the tribunal staff were appalling towards me, and constantly made me cry. One of the women, a "disability expert" said she didn't and couldn't believe I didn't have many friends, whom of which I have lost from being ill. The whole experience has made my anxiety 100 x worse, it's made me more reserved, and since May 2018 (when I had my tribunal date) my health has worsened considerably. I thought it was just a flare, but it is now August and there is no improvement, so I strongly believe the worsening in my condition is because of them. I had a nurse assess me, who seemed to understand the medications I had listed having reactions to, but had absolutely zero understanding of any of my recognised conditions: ME, Fibro, POTS, asthma, anxiety and HSD. Horrible. I was led into a false sense of security.

I was awarded DLA after breast cancer treatment went seriously wrong. I got MRSA infections in my surgical wounds that left me terribly scarred, internally and externally, my skin stuck to my ribs in some places. It took years of surgery, z-plasties and transplants, moving tissue from my back and stomach to replace the stiff, inflexible scar tissue; I needed the nerves cut on one side of my torso just to sleep at night. I still need to prop myself up to sleep, I can't lie on my back or one side. Every day is a day of pain and fatigue.

While I was still struggling to recall information or manage to make it through the assessment, he was reassuring and said we could take as long as we wanted, but when the report came back for MR, I saw he had lied about everything I had told him, twisted everything and plainly made stuff up. The report said because I used to have a fairly complex job, that would mean I can still do it now – completely ignoring the fact I am too sick now. It was ridiculous. Every single aspect of that report was a lie, that he had constructed off his own back. It's made me so much more sick, and honestly even months on I am so unwell that now, ironically, I need PIP more than ever.

Robyn

I think they want to see me dead. I was treated like a criminal my only crime is that I am ill. When I paid NI contribution I thought it was my safety net, how wrong I was. I might be homeless soon.

Nobody cares.

Elaine

The assessor for PIP told me it does not matter if I am in pain or takes me ages as long as I can do something. I managed to get zero points for everything from an indefinite DLA claim. Lost my carer and cleaner and don't know what to do now, social worker cannot help as now I am no longer in need of support officially. Waiting for my appeal but I have been warned it could be at the end of 2019. What am I going to do?

Daisy

I don't understand why this government feels the need to repeatedly hound the most disabled people of this country. We can't deal with this. All we want is to try and live with our conditions as comfortably as possible, and work on getting better or living the remainder of our lives without being killed off early. 100 deaths a day – will I be one of those because of this government? Will you? Why isn't more being done to end this despicable treatment of the most vulnerable? Why aren't those orchestrating this being held accountable?

I lost my carer's allowance but that does not mean I can go out and work (if only!!!) my husband needs someone with him at all times. Even more so now because after PIP he is now suicidal and his mental and physical health have now deteriorated. Because of our financial problem my mental health is not doing very well, at times I feel like running away or set myself on fire. We are now appealing but the waiting time is horrendous. I believe the reason they are doing all this is to get rid of all ill people, I see no other reasons. I can see the effect this has had on my husband, it is really bad, they are killing him, slowly and painfully.

We hadn't even received the funding before he had to have a review. This is ridiculous and again, all down to cost rather than meeting the person's needs. Social Services have withdrawn some of his care package as the council have had funding reduced by 460 million over the past few years. We are both sick of assessment after assessment to obtain basic services. The home dental referral has also taken months. Austerity is a deliberate, ideological attack on the most vulnerable. We both feel stressed and isolated. I pity anyone new to the system as it is clearly on the verge of collapse.

Wendy

Losing the care element of PIP meant that non dependent deductions apply, we lost all our housing benefit and most of our council tax, adding an extra financial burden. So now my young adults are responsible for the rent and council tax, we also have an overpayment to try and clear.

So less money coming in but more money to find and this has left us in a financial mess with some bills not been paid. My husband is appealing but In our area the wait is 41 weeks. A very long time with the added stress and anxiety of how bills will be paid, my husbands health conditions made worse by the added stress.

Jenny

The NHS is sinking fast. At our local CAB, they offer hardly any help, no money and thousands of requests. Social care is a disaster and agencies are short of staff and unable to recruit. Our MP is also overwhelmed with personal cases and does not get any joy with the DWP, they don't listen to her. It is all part of a deliberate plan.

Ginny

I sit here on Death Row. The last weekend of Summer – a Bank Holiday weekend.

I will spend all the sunny hours, ... into the dusk,..then to night hours, often till dawn, writing my appeals.

I won't be out in the sunshine.

Death Row prisoners don't get that choice.

With 4 working days to go I can't be

There is no District Court Judge, No Fifth Circuit Appeal, there is no Supreme Court.

There is not as yet, even a Lawyer.

There is no pleasure in my life.

Hasn't been for years.

I am alone in my Cell.

I am alone in my life.

My last female friend, who has been supporting me, cut those ties on Wednesday ... she said she can't go on, it is making her ill.

For people on death row that is reality.

She did well, she lasted longer than most – She made to the 2 year mark.

Bizarrely, even though I am on Death Row.. I am also suicidal.

Last week when I sat in Soho Samaritans, ... on a Thursday night.

I was imagining all the different reasons people were suicidal.

I realised, my reason was different.

I am suicidal, because someone, can't do their job properly.

In fact are refusing, to do their job properly.

Are being obstructive.

Being negligent.

(That someone should be read in the plural because there are many someones)

And you know what is really sad They are people employed by an organisation.

Tasked with Health.

Weird uhh ?

A government organisation.

And no, its no even subcontracted out....

I'm not even dealing with minions who could be forgiven – although I'm not really one for forgiveness.

A five year War does not allow for forgiveness.

A five year War bring distrust, fury, exhaustion, ill health, white rage.....

Oh and Suicidal feelings.....

I could never understand, how people didn't think, of the lifetime of flashbacks for the Train Drivers.

I never thought at any point in my life I would have to hold onto the fence at my station, when the train I wanted to catchcame in.

Underground Stations prove more difficult as there are only benches, – I sit down always.

Other days I have to stay indoors because buses, the posh Boris buses where I used feel like a princess riding out into the world.. seem tempting

Some days I can't go into my own kitchen for my kitchen drawers hold catering knives.

Oh those days I grip onto the mouse of my computer & write emails requesting help... which will be ignored.

Most days however, I love my knives as they chop fruit and vegetables, – essential for a life long vegetarian who's aiming for veganism as my nirvana.

I do cry though, because I am too tired to use them to make yummy meals.

When crossing Vauxhall Bridge last week, whilst heading to Ruby Wax's Frazzled Cafe in Victoria for support.... I stopped & contemplated.

I thought if I put my bags down there by the railings, they would know who I was ... Note past tense.

I thought about how I would climb on to the bridge railing.

I can still see in my minds eye 10 days later, the people on the bridge, including two men in grey suits walking towards me.

I wondered what they would do, how their lives would be changed.

I wished it was a sunny day, water might be warmer.

Ha, and then I realised not only could I not climb the bridge, footwear was not suitable, but also rail was way too narrow.

So I would slip off into the water even if I was unsure of my decision.

I read the notice on the Life Buoy which informed me that the river police should be called.... I wondered if the would find me....

“ Don't kick off till Monday ” was what my support worker had said ... It was Thursday evening

Oh Hounslow Clinical Commissioning Group what have you done.....?

Notes

My Death Row experience is very real to me.

My crime is that I am the mother of two vulnerable disabled young adult sons, with complex medical needs.

My Appeals that I will be working on, are more reports & letters. Ones that won't be read or understood but are demanded.

I already work 168 hrs a week caring. So in-between caring, sobbing & despair, I am typing. I am a two fingered typist on a good day, one fingered on other days.

My day starts at 6am & finishes at 1 or 2am. I then start the night shift. Providing backup for night staff I employ. (soon I will not have night staff as previous budget running out).

Hounslow Clinical Commissioning Group have withheld for 15 months with no explanation awarded NHS Continuing Health Care Funding.

This funding was awarded in June 2017 following years of fighting. Complex Assessments, crate loads of Medical Reports, plus a huge dose of blood, sweat and tears on my part.

Both of my sons were recommended 168hrs a week care to enable them to live as normal lives as they can.

There was then a staling point – It all went quiet.

We had some previous funding, we muddled along. I used all my younger sons funding to pay for older sons medical support worker of his first year in Uni. I kept waiting for the funding to start.

It didn't, so I spoke to the ombudsman. He said stop shilly-shallying woman, start complaints procedure.

The Director of Joint Commissioning requested a meeting at my home on 19th of June 2018 – A meeting where they asked leading questions & bullied my sons & myself.

I was impressed, they thought they were so above the law that they did this in front of witnesses. For example they told my 21 & 18 yr old "To go to bed early" & not to expect to live a normal life as normal people did.

When asked why they were here. They said because they wanted to meet my sons & learn about their lives. They were told but "You have all that information". " So why are you here ? " their reply was this " BECAUSE I can & BECAUSE I want TO "

Because my sons can walk & talk, The Director of Joint Commissioning decided that 40 hrs would cover care needs of 168hrs a week (they are not a medic) – they have refused along with a colleague to provide any explanation as to how they, or Nurse X, if she exists, came to that conclusion.

Nurse X is shadowy figure who is hinted at. But who has never contacted me in 15 months or provided his/her medical opinion in writing.

Death Row is a lonely place – We now have 4 working days to get my sons back into education. Without nursing staff they cannot attend. All previous funding will run out in approx 2 weeks time. This means I will have to sack most of my carefully recruited & trained nurses & medical Carers (who hold degrees in medical science or similar).

Because no staff means that my sons will die, the Director of Joint Commissioning and their colleague will be potentially attending 2 inquests. Or three inquests if, I have to do all the care because my health is so destroyed I just can't do it anymore even if I wanted to.

London Borough of Hounslow refuse to accept there is a Safeguarding Risk.

There is, but they cannot be bothered to investigate.

I have had my request of a Serious Case Review rejected as they all believe their own manufactured fairy tales.

Notes Re my Suicidal Feelings

To anyone anxious – I am fighting to survive – I visit & phone Samaritans, I have booked & emergency appointments with the Listening Place – Suicide Befriending, I visit the Frazzled Cafe, I have a therapist.

No GP is of no use (another story).

Whilst it may seem strange, I am completely sane – My Suicidal Feelings are caused entirely from situational distress.

I alternate between empowerment & desperation. I cry a lot, I have less patience with the incompetence that I am surrounded with. I stand no shit.

I also sometimes laugh – but it is very dark humour. I can retell a tale of despair from the morning to be something very funny by nightfall.

I swear an awful lot – it makes me feel better, but does surprise others, which I find in itself amusing.

How Can You Help

Find me on Twitter @SarahSpoorUK

Sarah Spoor

I was forced out of my job after asking to be able to work at home some of the time. I'd worked there over 10 years since the company started. They ignored my doctors detailed letters.

What happened at my assessment was nothing to do with my illness. the decision was lazy and baseless and ignored my doctors supporting details. I've been dehumanised and battling depression ever since. I am too scared to go back. I've slipped through the cracks. I now get food parcels from my family. I DON'T LIVE I STRUGGLE TO EXIST

Dehumanised

Lies lies, they wrote lots of lies about me. They said I go out to see friends daily, I never go out without my support worker. They wrote I attended the assessment on my own, it is untrue, my support worker was there with me. I never go anywhere on my own. They said I go out jogging every day! Where did they get that from? I am an agoraphobic bipolar woman with painful rheumatoid arthritis and Crohn's Disease, do you really believe I go out jogging?

They wrote that I don't rock back and forth and I can give eye contact and reached the conclusion that my mental health is great. They wrote I have good complexion and look healthy and well kempt. I got 0 points overall. I had indefinite dla, how is that possible? They took everything away from me, my future, hope and dignity. My support worker told me to appeal but I said no, the first stage was sheer torture, I can't do it anymore, I'd rather starve.

Camelia

Here is not great. I am trying not to catastrophise but the facts are: Dads agency has ended its contract for his care and I have had no contact from the local authority whose Dept for Children Adults and Health has failed Ofsted and awarded a £3m contract to a firm that immediately almost went bust and now "functions" via a CVA.

People are taking retail jobs because agency is so unreliable, low paid zero hours. Small agencies don't have locality contracts, big ones are in trouble, so there is a staffing crisis.

Carer

I am not going to survive this, they removed the money I needed for my carer twice a week to take me out and help me wash, for the extra heating I require, my cleaner, the fruit and veg I am supposed to eat.

My heart is not ticking well I am out of breath and have angina. I also have arthritis, depression, diabetes, chronic pulmonary disease, gastritis, glaucoma and neuropathy. I am on my own, my wife died two years ago. My son is going through a painful divorce and now Redundancy. I don't know what to do now. I spent all my savings.

Anon

Because I have waited a year for a tribunal and have felt invisible. Like this hell is 'nothing'. That somehow these things are all in my head. Somehow my pain is my own doing. I read a comment somewhere today. It said something like, 'Don't blame the DWP. Don't blame the government for all this. This is down to individuals not preparing for their assessments properly.' Really? Is that right? I struggle to prepare a cup of tea. I do blame DWP. I do blame the government. They have answered none of my questions. They wash their hands of us. We are nothing to them. I am nothing.

Anon

It's left me feeling dejected, miserable, worried about how I'm going to manage as I keep experiencing continual cutbacks from various directions. I've lost my confidence, my assertiveness and my determination. I'm isolating myself in so many ways, and that isn't like me at all. I'm probably clinically depressed but I'm doing nothing about it. I'm losing weight and having more and more health problems. When I had good support (DLA plus Personal Assistants funded by way of Direct Payments from Local Authority) I looked so much better and my mood was better and I had fewer relapses. As that support is reducing I'm deteriorating rapidly.

I'd been on DLA (Higher rate Mobility and Care) for ten years when I was told I had to apply for PIP instead. The Form was soul destroying and much of it didn't apply to my condition or my needs, and it didn't really let me say what I wanted to say – or I thought they would ignore any of my extra Notes. However, staff did grant me an extension to the 'closing date' and I appreciated this. This was followed by a face to face assessment in my home – which I neither requested nor wanted (in my home). I felt I had to send my family out for several hours as I didn't want them to hear the reality of what I needed to tell the assessor. I've never let my family know the true extent of my disabilities, or how bad the prognosis was.

The assessment session was rushed. The assessor made far too many presumptions and tried to put words in my mouth, e.g. she put nearly all of my difficulties down to one of my conditions when actually it is the other condition that limits my abilities. I tried to correct her and explain, but I soon realised that she didn't really want to know much from me. She raced through the physical assessment, wanting me to perform certain movements or actions but she showed no interest in whether or not I could do these movements/actions safely, repeatedly, and within a reasonable timescale. E.g I can raise my hands above my head with difficulty, but I can't keep doing it several times in an hour or in a half day, and I can't link it to a practical task such as getting a biscuit tin out of a cupboard.

I thought I would probably get the higher rate for Daily Living, and the standard rate for mobility since they have cut the distance to 20 metres – but several weeks later I got the letter saying I'd got the enhanced rate for Mobility and the standard rate for Daily Living activities. I hadn't lied about how far I can 'mobilise' as she never asked me. As I was sitting in my manual wheelchair throughout the assessment she must have presumed I used it permanently – when actually I don't, and although I can't walk more than 50 metres I can walk more than 20 metres on most days – but she never asked me. However on the daily living section I was one point short of getting the enhanced rate, and I was puzzled by this, as were friends and family.

In another section I told her I needed support to take my medication, both physically and psychologically. I can't stand taking pills that do slow the progress of my illness yet make me so nauseous, and physically I struggle to get them out of the packet because of poor coordination and limited sensation in my finger tips. I rely on other people to get the tablets out of the packet and to make me take them – otherwise I would be tempted to not take them. The assessor reported that she saw me propel my wheelchair 4 metres without assistance, and that if I could do this then I must have the strength to open a packet of tablets and get one out – so I scored nil points on that section too. There were other inaccuracies, which if corrected would have got me the extra point that would have got me the enhanced rate for Daily Living activities.

Several months had passed since the start of my PIP reassessment, and by then I was sick and tired of all the stress and uncertainty. I knew that if I did challenge the decision then I risked losing everything, and after all I had got the higher rate for mobility which I didn't expect and if her assessment had been more accurate I wouldn't have been entitled to it. So I decided not to take it any further. It meant losing £27 per week, but I could just about cope with that loss. Unfortunately I've since found that I've lost other things that depended on me getting the enhanced rate for Daily Living, and now I'm struggling financially but I definitely wouldn't put myself through that assessment process again. Appalling. Hard-faced, overbearing, bullying, ignorant, thoughtless, unwilling to let me explain or elaborate or give any answer that was more than one sentence. She rephrased everything I said and I could see that her report was then going to be very inaccurate. She made me feel less than human. She sapped my confidence. I managed not to break down in tears while she was in my house, but as soon as she left I was emotionally drained and I cried for ages. Please see earlier answers.

She kept saying things like, 'So your pain is down to the problems with cancer,' when actually my pain is more to do with the other neurological condition that I have, but she ignored me when I tried to correct her. She asked one question and she wanted a one-word or a one sentence answer. Then she went on to the next question regardless of anything I wanted to say. Her version of my situation was so inaccurate. Causing me financial difficulties, limiting my usual activities and involvement with other people (e.g I've given up my voluntary work because I can't afford to do it) and the whole system and continual cutbacks and the need to fight for everything has left me so dejected I really don't see any value in being alive as a disabled person. It's taken away my strength (of character) and independence, my ability to have fun, my enjoyment of family activities, and now I'm really worried about my future. My health has deteriorated and I haven't got the energy or resilience to recover from relapses as quickly as I used to. I'm run down and feeling powerless and useless.

Freda

She did not ask me many questions. I suffer from a rare genetic illness that affects only 1 person in 100 000, it has several degrees of severity, mine is very severe and got a lot worse in the past 10 years. It is relatively invisible to the naked eye but I have symptoms similar to those of fibromyalgia. My day can be hard with some days a lot worse than others, and my diet is very limited, have problems chewing and swallowing and all my food has to be minced or liquefied. I also experience frequent blackouts. The struggle to feed myself, wash myself and get dressed were not acknowledged in the least. It is like I am completely fine.

One of my specialists, my social worker and my MP wrote to them explaining that I do need help given that I am in a lot of pain and have no energy. Their reply was that I was assessed by a very qualified disability assessor and that PIP is not about diagnoses but about the help one needs to deal with daily life. In their opinion, the bored woman is the ultimate expert on the effects of my rare illness on my daily life. Still got zero points for my reconsideration. I can't afford my carer anymore and I can't go and live with my mum, she is 90 this year and not very mobile. Some days now I don't eat or get up at all. When the pain is bad, I can't make anything to eat or have a wash. What hurts the most is that they treat you like a malingering scrounger there just to milk the system. It is hard enough to accept that you are ill and all your limitations, being accused of making everything up is too much to bear. Bored and uninterested

Cygnnet

I started claiming pip after a change in circumstances three years ago. I have fibromyalgia M.E depression and anxiety I found the form difficult to do so got my support worker to help. I found it very exhausting and was anxious from start to finish. Assessment I had a lovely lady who actually understood fibro, she didn't make me do any exercises I couldn't manage and she was friendly. I was awarded enhanced rate for both components for four years.

Now I am up for review the renewal form was not as bad as the first. A lot hadn't changed but some had got worse. I received a letter for an assessment which I could not attend, I have now lost my support worker who came with me. I asked for a home assessment and was granted one. I am still waiting for a date. Even though my first claim went through smoothly it still caused a lot of anxiety and worry waiting for the decision to come through.

The anxiety then caused more pain. The assessor for my first claim was lovely, she understood fibromyalgia and how bad it is, she saw I was anxious, I was not forced to do any task I was unable to do. Very long, I think it was over one and a half hours, I was exhausted. The assessor didn't ask me many questions she typed her answers from my claim form. She tried to make me feel at ease she could tell I was anxious. I never asked for the report, I was not aware at the time you could do that. The points given were correct. I think there was one or two where I didn't agree. Luckily I did not have to appeal the decision which saved a lot of worry and stress. Now I am up for review I am anxious I won't get an assessor as nice as the first one.

Anon

I am having to tell my entire life story of being raped as a child, being put into a house of hell, Chadswell Assessment Centre, which was pretty much the same as Fred West's house except in Rocester Staffordshire, over and over and over again, being spied on wherever I go, if I go for a walk round there's people watching me, my lawyer was murdered, the gangsters are laughing their heads off it's horrible and I keep having to try to explain over and over why I keep having fits it should be bloody obvious! Kind, and confused at why their manager keeps sending me to assessments Horrific.

The stress of having to talk about the past is horrific, being actually forced to go to a place to talk about those things is horrific. It took days to recover from the trauma. I couldn't stop crying. It's like pulling scabs off huge massive wounds. It didn't even get that far. Both my assessors walked out, they both sent me home, both said I shouldn't even have been brought in I don't go out by myself any more, I can't because every time I have a fit I get sectioned. So in effect I am a prisoner.

I know I've been stalked, my GP is involved in that, I'm in the process of complaining about him, and I probably am paranoid, people tell me I am but it's with good reason as I have actual proof that I've been stalked and persecuted. So I am finding it hard now to trust anyone at all. It's very hard to live like that. Music and art is the only way I can switch off. It's wrecked my life.

Barbara

I have problems with basic calculations – it runs in my family, but this was ignored. The test for budgeting / calculations at my face to face assessment was to take a very small number from a larger number. That was it. My hearing mood and mobility were “bigged up” / exaggerated to make me appear a serene picture of health. Limp euphemistic language used to describe my actual problems. The tone of the report I found to be almost sarcastic. At my face to face assessment, I had to sit for 2 hours waiting to be seen. At least three people who the receptionist had phoned to ensure they were coming, were sent home on arrival. One girl who explained she had taken a day off work and had an operation the following week begged to be seen, but she was sent home, so I suppose I was lucky to be seen at all. Another person with pain on sitting down also had to wait two hours like me. A man who could hardly walk at all was waiting a long time too. He should have been seen at home IMO. I was turned down for PIP and have asked for a Mandatory Reconsideration (still waiting to hear back) and will probably need to appeal.

I had to put in a new claim as my payments on my previous (successful at appeal) claim were stopped. I had filled out a review form and was asked to be at home for a face to face. I could not be available for this. I was in an impossible situation at home, I asked DWP and ATOS what I should do, and for more time. I kept them informed. (My elderly Mum was having a cancer op, and my daughter with autism was going through a devastating housing & MH crisis.) I was told I was “non-compliant” and my PIP payments stopped. So that's why I had to do a new claim, and I also put in a complaint, on advice. For both, the review and for the new claim, I was told that any evidence I had sent in older than 2016 could not be used as it was “too old” and “historical”. Bearing in mind it took years to get my health conditions diagnosed, and imaging carried out by NHS (waits for referrals, appointments and imaging etc.) Therefore it would take an equally long time to get fresh evidence? So DWP only looked at a small fraction of the evidence I had sent in. There's loads more I could add.

Primrose

Esa no problem, they could see I am not fit for work. PIP is a joke, they are really laughing at us playing with our lives. The report they sent me is not about me, it is about some other person. Someone strong, fit who looks well. I limp and shake, struggle breathing, I walk slowly and have to stop but apparently I now walk normally with a normal gait. No breathlessness at all. I look great and healthy. My problems all gone, I am HEALED!

My memory and concentration are bad and the drugs don't help, side effects are nasty things. Woman there wrote that I knew who I was, where I was and could tell her about my diseases, I don't have any problems and I don't need any help with anything. She gave me no points for anything. I am fit to run a marathon, it is a miracle, they cured me and I am ever so thankful.

Jim

Being sick or disabled, your focus should be on getting better, or managing your condition/s as best you can. Your focus should not be on whether or not your disability payment landed in your bank account on time – meaning you're safe for two weeks until its time to worry and fret all over again. 2am on payment day rolls around again and I'm sweating, I feel sick, I'm slipping into a panic attack – will it be in or not?

Am I going to have to spend the next few weeks battling with the DWP to try and find out why I've been taken off and try to reinstate it? How will I cope without money? How will I pay bills? How will I feed my pets, pets that provide invaluable comfort and assistance? Will I be able to get help from anywhere? Will my family or friends be able to help, if I even have any?

Am I going to get bailiffs coming to my door over missed payments? How will I get to my appointments without the money to pay for transport? Will I be evicted? Will this latest denial finally be the one to kill me off? Sick and disabled people have enough to worry about, financially, physically and mentally, we do not deserve to be subjected to this type of torture. We did not ask for this, we should not get it.

Dawn

Where we live we didn't even get discharged to a service as there isn't one. The local primary care was being sold off so there was less than no services for a child who needed 24/7 care, lifting and handling and couldn't walk. I couldn't work so had to apply for benefits. They are not automatic, you have to supply medical evidence and it takes weeks to be processed and even then it doesn't mean you get anything. The school at first were dreadful. My child was bullied and excluded by both staff and pupils. My child had a statement but this was ignored.

Both my child and myself have had to endure the exclusion by other parents and children so we are very isolated. Other parents seem to think being a bigot about a disabled child is acceptable. I have had to learn to fight for everything, learn the law and be my child advocate. We live in poverty and the insecurity around benefits is horrific, I lie in bed awake at night wondering if what we have will be removed and then how will we eat? Everything we have is second hand and it's hard work constantly having to search for clothing and household items, the constant rationing of utilities and resources is also exhausting. Sometimes I wonder why we go on, we are so hated in this country.

I fear for my child's future in a country that hates and despises disabled people, sometimes I think that ending it all for both of us would be a better option than living like this. If I wasn't here then who would care for my child? What sort of life would they have without me to care for them and protect them? Why are we hated so much?

The medical report was an outright tissue of lies. I have lost everything. I even had to give my dog away because I couldn't look after him anymore. My life is torture. My heart is broken. I don't know what's worse the constant physical pain or the mental torture. I cry all the time. I wish I had died instead. I am ashamed to live in a country which is deliberately ethnically cleansing its poor and sick, while hypocritically championing human rights and sending a fortune abroad while its own people suffer. The rich here get richer and the poor die. Great Britain, I don't think so! The only reason I wish I were rich was so I could expose these liars, though I doubt they're capable of shame. I pray Karma turns on them.

Chris

Report was pure fabrication and earned me zero points. Sent Mandatory Reconsideration end of May – and , nothing- no acknowledgement or decision. Universal Credit has been disastrous, started application – one unfortunate incident sorted out, now another one. Seems work coach sent me email notifications to log into my online ‘diary’ to read new messages. I didn’t receive any emails. (Also, as under GP sickness certificate was told I didn’t need to log in each day, for now). Only discovered a problem when attending UC initial interview with work coach. So embarrassed to discover I didn’t have an appt listed. – And also learnt my entire claim had been cancelled!

All because piece of evident ‘hadn’t been shown’ to DWP staff and I didn’t respond to emails. A small pension, previously declared on ESA claim, housing benefit claim, and added to UC application form . Also taken with other evidence to set up my UC claim. They insist it hadn’t been with the paperwork, it was!] So, very little income, unable to keep rent arrears up to date – and stressing myself to death. Just can’t face making a new claim. An extremely unfair system as rigidly one-sided – claimants disadvantaged through each step.

BEWARE OF UNIVERSAL CREDIT APPLICATION!!

Melz

I had a friend go with me, or else I wouldn’t have got there. I couldn’t look at the guy, I was so anxious and stressed. I cried when it was over. The guy who helped me complete my form said it was fairly accurate, apart from the mobility part, which we expected. To be honest, I haven’t read it. I know I should but I can’t face it, it will bring it all back to me. I am receiving less money than I was before (lower rate now, I was on middle rate before) and no mobility component. My son lives with me as my carer, and is able to claim carer’s allowance. I feel sick even now thinking about the process and that I will have to go through it all again in 2020.

Mig

The examination of my legs gave the assessor so much information that she deduced me capable of walking 20-50 metres, safely, as often as I might need and in a timely manner. This suggests I should telephone wheelchair services and arrange to return my electric wheelchair. As i no longer fit the assessment criteria for the loan of the device.

My mental health has been completely disregarded, it seems in the report I requested. My taking an antidepressant has been labelled as merely a first line treatment, my extensive history seems minimised to provide less context. That i take the fluoxetine at twice the standard dose was ignored. My referral to clinical psychology for yet further therapy was seen as fairly insignificant.

My pain therapy is stated to be for moderate pain. The NHS describe Tramadol as 'for moderate to severe pain' and I find the need to take the maximum dose 5 to 7 days per week. That in addition to 2700mg of gabapentin per day. I concede I don't take the maximum dose of gabapentin – this is contraindicated due to the risk of serotonin syndrome due to taking fluoxetine. That some of my medications can help with more than one thing has been ignored.

The assessor repeatedly stated I take nothing for anxiety. She disregards that many ME, Fibro, POTs, MCAS patients cannot tolerate a lot of the sedating drugs. She ignores that gabapentin helps with anxiety. I am massively offended to be represented by the assessor as someone who has exaggerated her conditions and symptoms on her forms. My conditions are not moderate but the whole of the report is such that I am justifiably perceived as much more capable than I am.

Karen

I was a nurse before I got ill, I know what compassion and empathy are, these people have none. I have paid into the system enough and I, like everyone else, deserve to be respected. This evil system must be stopped immediately, every day there are new victims and the suffering increases. I am lucky I have some support but not everyone can rely on other people and not only we are denied financial support but the implication is that we are making things up and are therefore dishonest as well, you know adding insult to injury. When you are a law abiding citizen that is too much to take. No money and kicked in the teeth.

MiMi

Hi all...well where to begin. Since my husband's diagnosis of his rare heart condition it has been a struggle. One of many admirable qualities as a person was his ambition and drive to work hard and provide us with a fabulous lifestyle. He worked long hours and at times away from home, his portfolio of qualifications and achievements are phenomenal and he was well known and respected within a large field of professionals. To cut a long story short for want of a better phrase, his health began to deteriorate. But still he continued to try to push the boundaries and continue to thrive in his career.

Sadly at the end of last year his health had plummeted so severely that he began taking periods of time off work. Accompanying my husband's heart condition he sadly has other medical conditions requiring treatment with prescription medication and combined all of these problems played a huge factor to the position we are in now.

Taking our lifestyle out the equation, to witness the man that is my best friend and family become so terribly unwell to the extent that it had a such an impact on his daily quality of life was heart breaking. And for the first time there was nothing I could do to fix it for him.

My husband has experienced multiple admissions to hospital, injuries as a result of falls, trialled on multiple medications, seen numerous specialists and discriminated against for his conditions. Worst of all he feels he is not the man he once.

After being deemed unfit for work for the rest of his life, the impact that had mentally was astounding. It became necessary for me to resign from my career path to take care of my husband as working and being afraid for his well being and leaving him to try to fend for himself became dangerous. We had never been in this position before...and so the benefits process began.

Never have I experienced such a lack of compassion for human beings. Especially those who are affected by ill health or disabilities. The process is in my opinion in need over a huge overhaul of its staff and policies and procedures. The daily perils of life for some people are overwhelming enough due to poor health without the trauma of being made to feel like you are cap in hand begging for hand outs.

Whilst I appreciate that sadly people do abuse the system that is not ALL people!

A disability is unique to its owner and there is No one more qualified to talk about the condition than the individual that has it. Yet sadly it would seem this isn't taken into account by the " medical professional" who does PIP assessments.

In brief, our professional assessor boldly admitted she used Google for my husband's information about his condition. For an overview ok a valid comment but Google does not explain how it affects my husband. Her primary focus was pushing mental health and a total lack of compassion for that topic alone. She discussed herself and failed to even try to understand how hard this whole process was.

The report.....zero points.....!!!My only response to that is spend one day in my husband's shoes and then score him nothing. How could this be possible. I couldn't even begin to comprehend this decision.

Mandatory reconsideration.....still zero point!!!!

Access to medical records, cardiologist letters, GP signing him off for life. Heart medications, 6 other daily medications. Adaptions to our home. A blue badge holder. Regular admissions into hospital. A professor of cardiovascular science monitoring decisions over my husband's heart condition from his London based hospital. A full explanation into a day in my husband's life. Detailed explanations of the condition and a precise explanation of an arterial spasm.HOW DO YOU NOT SCORE A SINGLE POINT!?

Again the stress and anxiety that this caused placed more on my husband's shoulders. When he said to me, do they think I'm lying? I don't understand I would give anything not to have this wrong with me and have our life back. For me at that point I thought I have to fight for him. And that's what I am going to do. I have spoken with so many people from a fraudulent solicitor taking money from us to assist in the Appeal process, disgraceful in itself. Staff at assessment centres, PIP departments, citizens advice, forums for advice, doctors and various other organisations.

I am disheartened to say that I discovered many people are enduring similar problems to ourselves, and I'm a little ashamed to say I had little knowledge of the dreadful ways that individuals with disabilities are treated. I'm sure like many others I could continue to write pages of flaws in treatment and the benefits process, just aswell this voice page doesnt allow you one small box to record your life in unlike a PIP form. To anyone reading our voice I wish you every success in fair treatment and may you receive the help you need.

A Wife

She wrote I enjoy cooking and I bake cakes. I am physically unable to cook and bake cakes and my diet is severely restricted, I wouldn't be able to eat what I cook. I sent the letters of four hospital specialists, my social worker and my GP, they ignored those. My MP wrote to them and was told that I was assessed by a specialist fully qualified to conduct this assessment and what she decided trumps all other evidence. She was not even a doctor and she struggled to understand medical terminology. The appeal system is difficult, I appealed in December last year and I am still waiting for a tribunal date. My depression is really bad now, I can't afford the part time help I used to have, life is very difficult now. They also lie and get away with it, I am very angry.

Sarah

My score in my PIP assessment? 0. I 'appeared well', presented myself well, had a 'good grasp of language', was a former teacher (as if this has anything to do with it)... it goes on. The errors and, frankly, lies in the report were staggering. I produced a 20 page report on everything they got wrong.

Quite clearly not a single word of it had been read for the Mandatory Consideration, which merely spat out exactly the same points as appeared in my assessment. A waste of time. At the beginning of this year, I received a letter from DWP. No consideration of my mental state, no consideration for what might be going on for me. It stated that because I hadn't notified them that my PIP had stopped (I had no idea I had to), they had been overpaying my ESA.

I owed them £2500. I had one week to contact and they threatened court action. This pushed me to an edge I haven't been to for a while. The woman from DWP who I spoke to on the phone was so concerned for my health, she contacted my GP and put a complaint forward herself, telling me there was no way I should have received a letter like this and in this way. Thus far, nothing has come from that complaint. I had one week to respond.

But one year on, I am still waiting for a tribunal date. I have contacted them four times, every time being told 'should be in the next week or so.' I'm financially struggling. The conditions I was working so hard to try to control by using my PIP benefit to get support (things like massage – a few sessions on the NHS really don't help folk with ongoing pain, supplements, and saving for private psychotherapy – the mental health services have let me down badly, amongst other things) have all worsened. I can't afford to do these things. I am juggling the basics. I, and so, so many people out there, am being penalised for being ill.

It is very interesting to read the responses DWP have given to Damian Green, who happens to be my local MP. He has been palmed off with the same nonsense that we are getting. There is no interest in helping, no interest in addressing the errors they have made, no recognition of what this is doing to people and how much this is impacting. And they have washed their hands of waiting times, simply blaming the tribunal service for the delays.

This has been a long, worrying, sometimes dangerous year. It's hard enough managing these conditions and trying to stay on the planet. DWP's cruelty does so, so much damage – from invalidating serious, debilitating conditions to pushing the disabled into debt. They are hoping that we are too weak to fight. They have taken so, so much out of me personally. But they haven't taken my voice.

Nic

I have brain damage from a hit and run car. I suffer from depression anxiety short term memory loss extreme fatigue all of which have negative impacts on my every day life. I have been refused the full rate of ESA and turned down for PIP.

The ATOS interviewer completely lied in her report. I had a witness at the interview. I have a letter from my witness (social housing officer) stating what he saw was the opposite to what was reported. I gave this to the DWP for PIP mandatory reconsideration. With a further 6 supporting letters from healthcare professionals. Both Atos and DWP refuse to handle the complaint about the lies.

Paul

But one year on, I am still waiting for a tribunal date. I have contacted them four times, every time being told 'should be in the next week or so.' I'm financially struggling. The conditions I was working so hard to try to control by using my PIP benefit to get support (things like massage – a few sessions on the NHS really don't help folk with ongoing pain, supplements, and saving for private psychotherapy – the mental health services have let me down badly, amongst other things) have all worsened. I can't afford to do these things. I am juggling the basics. I, and so, so many people out there, am being penalised for being ill.

Social services are aware but apart from ringing and then accepting the continual excuse that they have staffing issues at the agency, they have done nothing to help at all and I have nobody else at all to help me. I feel dirty, shamed, confused and dreading every phone call. Yet there is nothing I can do it seems to get the help I desperately need. Other agencies have not called or emailed back. I am beyond tired and my needs are forgotten.

G.

Another 'voice' comes from the blog written by Barely Surviving. The blog's aim is 'to let people know just how hard life on benefits is' 'My blog tells the truth about the brutal reality that is life on universal credit (and most benefits). 'I had to leave my job due to personal and health related issues, it wasn't an easy choice to make but as my anxiety and physical health issues deteriorated I had no other choice. During my time on universal credit so far I have been sanctioned for being unwell, insulted by my work coach and punished for being unfit to work. I didn't ask for my illnesses, no one does, and we shouldn't be judged and punished for it by strangers behind a desk who don't know how to be supportive or sympathetic.

Every time I go to the job centre I am made to feel ashamed, guilty and worthless by the staff, they just don't seem to care what happens to us at all. 'That brings me to the reason I am writing this post today. I want to tell you my truth, the things you don't see on TV. Firstly I don't live in a palace or a mansion I live in a one bedroom flat, I have a living room, a kitchen a bathroom and a bedroom. In the living room, I don't have any furniture, no sofa or TV nothing just a lightbulb hanging from a ceiling.

The kitchen has only the things that it had when I moved in a washing machine, a small fridge, an oven and a microwave all things that I rarely use to save electric. The bathroom is a shower, a toilet and a sink all squeezed in to the tiny room and finally the bedroom, a mattress on the floor and a wardrobe to hang up the few clothes that I have.

I spend most of my time in the bedroom because sitting on a mattress on the floor is better than sitting on the floor. Most days I don't go out so it could be days before I have a conversation with anyone, it's boring and lonely. I don't see any of my friends because we live too far apart so I often miss out on a lot of stuff, because I'm not around a lot me and my friends have started to become very distant, hardly even talking now.

I could go to a coffee shop just for a change of scenery but I don't have the money to buy anything and although a few places may not mind if you buy something or not, I feel uncomfortable and embarrassed just sitting there. I don't have a TV so I entertain myself sometimes with Netflix on my phone, but how many episodes of 'The vampire diaries' can you watch before your eyes hurt and you need a break? When I do go out it's either for appointments at the hospital/doctors, which I've started to look forward too because it gives me the chance to go outside and be out of the house for an hour or two, or to the jobcentre where I'm made to feel uncomfortable and ashamed and punished because I only applied for 1 job that week.

I'm starting to feel isolated from the world. I feel like I'm missing out on life, I'm not doing the things other people my age are doing. I'm not enjoying life. My flat, the one place I spend a lot of my time, the one place I should be comfortable and be able to call home, feels like a prison. A place where I am trapped from the outside world and completely forgotten about. On top of all that there's the health issues caused by being on benefits, issues I've only started to have problems with in this one year of claiming universal credit.

To start with the problems I previously had, the reason why I'm out of work in the first place, are being made worse due to having to walk 40 mins to the job centre and 40 mins back at least once every two weeks because I don't drive and don't even have the £4 bus fare to get me there. Then there's the depression, being locked in my flat alone for hours and days at a time has caused me to become severely depressed to the point that I have considered suicide. The depression also makes my anxiety unnecessarily worse which limits me even more. Sometimes I do feel I'd be better dead than suffering the long, slow death that my life has become.

The final health issues I have are caused by not eating and lack of nutrition. I have developed many deficiencies because I can't afford to buy good, healthy food. My blood pressure and cholesterol have also risen so much since being on benefits. My health is so bad, it's having a big impact on my day to day life but it's all okay as long as I do my 40 hours per week jobsearch, right? You can read the entire post here and you can also read other articles by

Barely Surviving here <https://barelysurvivinguc.blogspot.com/?m=1>

I thought you might be interested in my book, 'Austerity's Victims', which has now just been published. It is based on my work as a volunteer advocate for Cornwall Advocacy. Its aim is to show how adults with a learning disability have been affected by government austerity measures since 2010 and to bring their situation into the open. It concentrates on five men in Cornwall with a learning disability, precisely comparing their income and spending with national and county averages so that the extent to which they have been left behind becomes clear. It also examines their quality of life as the support they are given shrinks.

In those five case studies, the men's spending is compared with the Minimum Income Standard of the Joseph Rowntree Foundation as well as UK and Cornwall medians. Their spending averages 48% of the UK median, 55% of the Cornwall median and 71% of the Minimum Income Standard. It goes without saying that their income is below the relative poverty threshold.

From the case studies, other common features emerge as well as relative poverty.

- All have had their support hours at home or their day centre attendance cut. Three of the men who have support hours have seen them cut by an average of 27%. The other two attend day centres: one now has his place only half-funded; the other has had Adult Social Care funding removed completely.
- When the book was published, two of the five men had had their benefits cut. One failed to have his DLA transferred to PIP. The other, a man called Danny who suffered a life-changing brain injury in 1980 and who is referred to in my opening paragraph, was suddenly deemed 36 years later to miraculously have changed and therefore be fit for work without his Employment and Support Allowance. Since publication, one more man has fallen foul of the system.
- To state the obvious, their quality of life has suffered. Most of them lack the friends that we all take for granted and so loneliness is a real problem.

For all the men in the book, their lives fall a long way short of the 'wellbeing' the 2014 Care Act says they should be experiencing. One component of 'wellbeing' is 'personal dignity'. If you read the chapter on Danny and his Work Capability Assessment, his tears at the initial outcome showed how little 'respect' (another word from the Care Act) was shown to him. 'Personal dignity' doesn't even come into it.

The links below show where 'Austerity's Victims' is available.

[Print version](#)

[Kindle](#)

Neil Carpenter

"It's 3am. I'm lying awake listening to the wind.

A dustbin (or something), just fell over.

I'm glad hubby secured the garage door.

The rain has warped the wood. It seems I do all my 'best' worrying at night time, and even though I try very hard to sleep, insomnia is a lifelong thing, but it's worse now.

I used to like the nights. I loved the calmness and the feeling that the world is all mine.

It used to be my most creative time, so I was never worried about not sleeping.

Now though, I'm either lying awake worrying about the future, -being without hubby, the Cerebral Palsy getting worse, or the WCA.

If I do sleep, I often have nightmares about the WCA itself -not even so much the outcome.

A recurring one is I'm sitting on a chair in the assessment room.

It's very dark and there is a panel of people watching me, judging me.

They know it and so do I.

They shine coloured lights in my eyes, and keep asking me more and more questions -like a quick-fire quiz show – and I can't answer.

It's too fast and I can't think!

Most of the nightmares are similar to this.

In some they come to my home, and they are judging the things I have.

They are invading my space, where I once felt safe.

There is suspicion – and an uneasy atmosphere which I can feel, even in sleep.

In the dream (whichever version it is), I feel panic.

I want to try and get away from the questions, judgement, – (and feeling like I'm not worth it), but in the darkness I can't find a door, – and I'm trapped!

They get closer and closer and questions get more and more personal, along with 'why should WE pay for YOU'?! You're a drain on society'!

It goes on... I usually wake up shaky and sweating!

Sometimes I've cried out.

My muscles tense and spasm which increases my pain.

I either can't get back to sleep, or I don't want to, in case I have another one.

No one should be going through this on their own home – as a result of government policy.“

Helen Sims

You can read the rest on Helen's blog here <https://t.co/jnJMcswo32> and while you are there, have a look around, there are lots of blog posts and poems on how it feels to be a person with a disability in the UK today.

I had my first stroke at 5 years old, by the time i hit 30 I had 4 more and lost most of my sight and wanted a career so went to college and university. Then started back to work at 40. Setting up a support group claiming working tax credit for myself with my equally disabled husband. It took 4 years to get the disability element and 7 k a year they simply would not pay.

That includes rent which dropped 50% and frequently would be delayed a month which then put my payments out. Driven into debt and under constant threat of eviction we just about managed by putting all of our DLA into the rent and now I'm facing universal credit with a 20% drop in income and the loss of the businesses we started. We don't meet the minimum income.

BB.Buster

I've gone from a great salary to being unable to work due to a heart condition. I will be honest and admit it never crossed my mind what disabled people go through to get on in life when I was working and enjoyed a comfortable life.

I'm so ashamed of the way people with disabilities are treated it's scandalous. I'm currently fighting an appeal for PIP after being scored 0 at the mandatory reconsideration stage I was ridiculed by the DM for my inability to work and with stand cold conditions.

Don't understand the appeal process and we were actually robbed of £200 by a phoney solicitor who said he would take on my pip appeal.....there is actually people out there taking money off people who are the most vulnerable and only want help. Life for me has become such a struggle now.....I only asked for help.

Despondent

I am still being hounded by them, called into the jobcentre and asked what I am doing, threatened with sanctions. I would really just like to be left alone rightly or wrongly it is how I try to cope with the circumstances I am in and have lived with for many years. It is difficult to live fearing a phone call or a brown envelope through the door. I now also have to worry about the coming of universal credit, I wonder if it's worth it.

@redtailshark159

Significant chunks of my ESA report were clearly copied and pasted- my name changed halfway through, and I was extensively questioned about whether I was dating my flatmate.

My PIP application took 18 months of anxiety and stress where I could only afford to eat soup, including the mandatory reconsideration and the tribunal hearing, which was held in an actual court with a timetable saying "(my name) Vs the DWP. That really hit.

The government Vs the disabled.

Daisy

The fact that I am in pain and need a carer a few hours a day to do my shopping, cooking and help me washing was not even acknowledged. The detailed report sent by my doctor was also not acknowledged. I paid a carer and a cleaner twice a week with my DLA, now I have to be on my own and some days I can't even get up now, don't eat, don't wash, nothing. Nobody cares anymore if you are ill, you are a burden nothing else. I could not appeal, not able to go through that again anymore, assessments are a torture

Elizabeth

Having to prove that I am a disabled person, when my chronic and incurable impairments are fully documented by the NHS is an absolute insult, frightening, degrading and a whole waste of public money.

The so-called Welfare Reforms have not only cost the public more but also stripped the most vulnerable of the very necessary safety net that anyone, at any time, might need. It is a Human Rights atrocity, documented by the UN, the NAO, the EHRC among others.

Jan U

I'm meant to be saving up for a wheelchair, but I cannot save much and no doubt I'll have to use that money when my ESA stops. I'm housebound, in constant pain and my mental health is suffering. Please leave me alone, I want peace.

Dawn

This view of our disabled community seems to have been all too readily accepted and regurgitated by our media and general public. This acceptance has both shocked and terrified me in equal measure. Have people always thought so little of people who are disabled and different? How was the majority so easily persuaded into turning a blind eye to the suffering and persecution of our country's most vulnerable individuals? I

just don't know how this happened to us as a country. I no longer have any piece of mind. I no longer believe the UK has a social contract to take care of the most vulnerable in our society. I no longer believe I live in a country that will take care of my very vulnerable children when I die. I have no hope for a life well lived for my disabled children when I am not here to fight for them. I have no peace anymore.

A sad and scared parent of two valuable and worthwhile UK citizens.

With her DLA she used to pay for a cleaner four hours a week and someone to do her shopping. Now she is on her own, with the money they give her she can barely afford to eat! I try to help her but I work and have two kids, not easy for me & I live one hour away from her. It is a big worry. She can't handle it, she can't go out.

The social worker gives her a person for 15 minutes a day but that is not enough to do the shopping and all the cleaning. She says there is no budget to give her more. It is obvious to everyone she needs more help. With her doctors and social workers she is now going through the appeal procedure, unfortunately we were warned it could take over 18 months. What one is supposed to do in the meantime?

JoJo

One of the worst experiences I've ever had, benefit reforms from DLA to pip. The two assessors pressurised me for 1 hour 35 minutes and kept on dismissing anything that I said that wasn't on their stupid computer. The worst of it was many of the things were never even added to the report. I secretly recorded the assessment along with my partner who they didn't like being in the room. I have around 12 pages of an appeal that I can share with you please contact me.

Two assessors who looked at me strangely and eye brows were going up and down. I knew as soon as I got to the assessment centre that they were making negative remarks about me as I overheard within the reception area from the assessment room these guys playing the system the f*cking fraudster. At the time I didn't think anything of it.

Az

Many participants were being characterized as intentionally homeless for reasons that were often unfounded or unsubstantiated. The council were frequently removing homeless people's possessions. There was also one incident where the police officers had removed food from someone who was begging and was given it. I spoke with a man who was living in a tent and the only homeless charity in the town wanted him to sign up to the local bidding scheme knowing he had little or not access to a computer.

This particular man told me he had gone for a job in the council as a refuse worker. At the interview they informed him that they were aware that he was homeless and could not be considered for the job. This particular charity also frequently told me after me interviewing service users that they were liars. They also openly told me that they "don't like to feed junkies" I observed times when some service users were denied use of the washing machine and not been let in at all. They aimed the service at those who were able to keep appointments and sign up to job websites etc.

What was clear is that the local authorities approach to homelessness was in fact making the homeless more vulnerable. But more than that it's the attitude of key players that will ensure the most vulnerable will be neglected. I found that actually it was the churches who were picking up the baton really...it was the churches that were feeding them washing there clothes letting them have access to shower and treating them like human beings. One church I went to was not only feeding the homeless but people on low incomes or benefits who couldn't buy food...giving them clothes and food. Sadly but all to expected the research was not published. However I hope that people can see how those in power are too busy trying to justify their positions to help the destitute.

The sociologist

After he had worked all his life paying into a system which ultimately failed him. Or the older people who lose the ability to walk after a hospital stay as they are left in their beds. This is a few examples of a system failing it's most vulnerable people. I don't think this is the fault of the staff, the problem is further up the line.

A.M

This combined with my health problems, a shrinking NHS which is not providing an adequate service, lack of social care together with the present very hostile environment existing for sick and disabled people, has turned my life into a living hell. I was forced to move from ESA to Universal Credit in December 2016 because I unavoidably could not attend a medical assessment, the reason being accepted by the DWP.

However, I was still moved onto this benefit and not only lost the Severe Disability Premium but was told that I would receive no money for living or housing for 6 weeks. I was forced to get help from the Council who reluctantly gave me food vouchers but criticised me for paying my bills such as mortgage, energy, etc. I felt very embarrassed and degraded by all of this as I have always paid my bills on time.

Since the changes have been made to the welfare system the whole benefits environment has become very aggressive and the DWP totally and deliberately ignored my illnesses and disabilities. There were suddenly demands to adhere to and a timetable of activities that was not possible to achieve and the DWP would not even talk about this but just threatened to take away benefits.

This affected my mental health and all of my other physical problems all made far worse to the extent of ending up in crisis or at A&E or even being temporarily held at a police station. The claimant is classed as fit for work until they spend weeks proving that they are not and having to jump through lots of hurdles and involving an army of different Health Care Professionals, voluntary organisations, support workers, family and friends and support workers helping to make this happen.

Much of what you wrote in the journal was ignored. Complaints were also ignored. Disability was ignored and everything made difficult and if you telephoned you were just passed from person to person or from one department or organisation to another with nothing to show for all the effort. I kept on escalating issues which never seemed to end as the matter would end up with decision makers who rarely make a satisfactory decision if they make any decision at all. With DLA I never had to phone as everything worked and if there was a problem, everything could usually be sorted out with one call. Universal Credit staff taking the calls have no authority to do anything but just to pass on messages and escalate and escalate. It took a year to sort out payments with endless mistakes involving endless calls which were physically and mentally too painful to make.

I had to constantly stay away from home with my family as the stress was getting too much and my physical health deteriorating and I was not able to cope. Delays with the Support for Mortgage Interest payments caused problems with my mortgage lender and meant that I could not move onto a competitive fixed rate and had to stay on the standard variable rate as well as incurring charges. Now, I do not use the online Universal Credit journal and I try not to phone them at all as phoning is very difficult for me. Regarding the Work Capability assessment, after obtaining the letter from my GP saying that I need a home visit, I eventually received an appointment and arranged for my Occupational Therapist and Support Worker to be present at my home.

The day before the appointment I received a call cancelling the appointment because the Doctor was unavailable. Then they transferred my file to another department, then saying that I had to get another letter from my doctor. Further, the DWP then sent me an aggressive letter warning me about missing an appointment and told me to fill in the enclosed form saying why I had missed it. I went onto Universal Credit December 2016 and now in June 2018, I still have not had this assessment so the dread of this is constantly hanging over me.

I do not want to recall the tribunal stage as it is too painful. However, the Tribunal awarded me PIP at higher rate for both care and mobility indefinitely saying that I should never have been put in this situation. I have found it really difficult if not impossible, having ten different conditions to keep obtaining the evidence required in the form asked for by the DWP.

I was seeing a different HCP every time I went to an appointment so they did not know me or know what I was doing at home. This included my GP surgery so it was very difficult to obtain the paperwork needed especially when the information required was not looking at the actual illness or disability. All the paperwork would also take up time and cost money which are both in short supply. I expect that this can be obtained privately if you pay for it and can sort it out. The Assessment process was farcical and clearly designed to fail you and lies were told or key points missed out in the report and my assessor was a physiotherapist so was not qualified to assess all of the different conditions that I have. It was just a tick box exercise with a lot of staring at the computer screen. You would think that all of this would be enough to endure, but in April I received a letter from the DWP saying that in 8 weeks the support for mortgage interest was being turned into a loan with interest added.

I would barely have enough equity to downsize and move so I cannot take the loan and now have to move as quickly as I can. Again, this is also problematic because I cannot get any help to facilitate this so I am stuck. My health problems are far worse that they were in 2016 when these changes began and now I have stopped attending health appointments because this has become too difficult. The standard of service from the NHS has certainly gone down since 2010 and I noticed many good HCPs that were looking after me have left their posts, moved on, retired or emigrated. The number of appointments and quality of care have gone down.

I lived in my pyjamas for months and that was deemed acceptable. I cannot look after my feet and legs and put on and take off the compression garments or properly apply the dermol lotion for instance and this has been neglected causing lack of mobility and infections. This is just one of many needs neglected. Then there is the diabetes, heart disease needing triple bypass, neuropathy, retinopathy, hearing difficulty, prostate problem, breathing problem, gall bladder removal, sleep apnoea and serious mental health issues all neglected.

The constant demands of dealing with benefits means that there is no energy left to keep up with the demands of my personal healthcare. It also puts a strain and a burden on friends and family who have to step in and help sort out the mess caused by failing healthcare, social care and welfare reform especially as this has now been going on for so long.

I have no life at all and if this carries on I hope it all ends soon. I live in total insecurity and on a knife edge with worsening health where anything can happen and there are constant threats, harassment and abuse by the DWP and the present Government. What absolutely shocks me is that the public do not seem to know anything about what is going on.

There is nothing in the media whatsoever about these abuses and the misery being inflicted on sick and disabled people and this makes me feel very alarmed and worried and fills me with despair. I hope this statement is not too long. It has taken a long time and I have had a lot of help with it but I think it is worth the effort to see if something can be done about this terrible situation.

Steve

I have been on ESA now for 10 years. So far I have had 5 assessments in that time. I had to rearrange the last one, as on the day my anxiety and stress were so bad that I threw up. Each time I go to these assessments my health has got worse, through worrying about how we will manage and dealing with the DWP.

We have not lived for the past 10 years, we have existed. I would not wish this hell on my worst enemy.

Ann

Care plans and health plans are not met for the persons needs things get missed and this is why errors happen and unexplainable deaths, which has been highlighted many times. So my voice and many others would now like this to be actioned and monitored and to highlight the flaws in the system and to now correct this. Better monitoring an accurate system with a named person in each department. Services to meet the person with a Disability needs and health related issues.

Also Care in the community is failing and the CQC need to monitor more frequently and correctly, I have mentioned issues above so all this needs correcting now. Why I have highlighted this is because I as a Carer have had many years dealing with issues my son is 44yrs with a Severe Learning Disabilities, Autism, Epilepsy, Challenging Behaviour. He is at present recuperating from a fall which he had been in hospital and now in supporting living care.

I also am Challenging with a petition relating to benefits changes within the DLA to PIP and long term conditions because they took away the indefinite claim attached to the DLA and never replaced it in the PIP people have fixed assessments times now. I did send it to Parliament at 10,000 but now to be heard in Parliament is has to have 100,000 signatures, the Wow petition did highlight my petition in parliament but they make it hard win. I will fight on with my petition until they listen.

Dee

Let down badly this last 2 weeks by the care agency we rely on here. Had to pay my cleaner extra yet again to cover their essential cleans not touched for 2 weeks. Had to do online shops all week again or starve, had nobody here when the driver delivered on Wednesday and my back seized completely trying just to get the freezer stuff away with the driver and he had to rescue me off the floor.

No hair wash for me friday so that will be not done for 2 weeks if they turn up next week and had to cancel attempt to get for a mammogram. Todays call dropped last moment yet again. The bins are over flowing, I shall have to see to the laundry offend or please and sit on the mucky floor to do so, floors are in need of washing (tesco drivers in and out and a wheelchair user indoors), essential cleans still not done ... welcome to caring England ...

G.

I have now been put in the support group but I live in fear that at any time this entitlement could be taken from me. My PIP is currently going through review and I don't know what I will do if I lose that. For PIP and for ESA, there is always the stress of the assessment process and the possibility that a so-called 'healthcare professional' with minimal specialist training, after seeing you for an hour or less, could decide you are 'fit for work' despite the evidence provided by consultants, GPs, psychological support workers and other qualified individuals who know you and your condition well.

Add to that the restricted access to mental health and other specialist health interventions – for example, I was allowed only 12 sessions of CBT to deal with the symptoms of PTSD – and cuts to funding for services like the CAB, and it becomes clear that the Government is making it harder for disabled people to live as well as they could. Then add in the sense that you can never be disabled enough to justify the support you can manage to get, drawn from news stories like the recent one saying the DWP uses CCTV from supermarkets to spy on disabled benefit claimants, and the upshot is a truly toxic atmosphere that makes me feel as though my very existence is a burden the state (and society at large) is very reluctant to bear.

TW

I'm a health professional in a specialist community team. I have seen the social issues that are impacting on service users increasing dramatically year on year. Whilst our team is composed of highly skilled therapist's we find all our resources stretched as we are primarily sorting out social issues.

In particular we deal with benefits, homelessness, real poverty and hunger this leaves no time for users to use our therapeutic skills to help people manage their condition, return to education and employment and give back to their communities instead they remain unwell, struggle financially and become dependent on welfare for life.

Previously, around 10 years ago people made good recoveries from psychosis and reestablished productive healthy life's as they were supported by a reasonable housing and benefit system gives them space to recuperate and us time to engage them in therapy for long term independence. I have seen people having their pip assessment returning with 0 points despite clearly voicing delusional beliefs during the PIP assessment.

Stressed, disillusioned and traumatised NHS staff

I lost a lot and missed out on so much becoming chronically ill 25 years ago, my daughters growing up, my marriage, the final years of loved ones, my business and career, making positive life choices.

But my latest PIP Assessment is the closest to breaking me, the extended torture of pushing through the Appeals Process after a woefully inadequate Assessors Report left me £450 worse off a month and my management and care regime in tatters. Deliberate institutional harm by the Government and its lackeys.

Helen

I've just had to go overdrawn again so that I have something to eat for the weekend. The despair never goes away, every night, I can't help thinking of all the events that got me here. I'm sure the wealth of PTSD research is being used against chronic sufferers like myself to frustrate any pathway to a better experience of life.

It's ironic that my local museum is hosting memorabilia of my grandads war heroics against fascism, yet I'm left to suffer in extraordinary pain unnecessarily for 25 years, unable to carry on his family. Now with the dismantling of the NHS, I can see life becoming unbearable for a lot more people who will be neglected and kept ill.

James

I was suicidal, couldn't leave the house on a regular basis and had to reduce my hours in work. I couldn't access mental health support quick enough via the NHS so I had to pay (subsidised rate) to access counselling leaving me even more short of cash. I was diagnosed with Post Traumatic Stress Disorder. I only survive by borrowing money from friends and family and I often cut on food cost and skipping meals so I can afford to socialise with friends. I fear the future but rather not think about it, I may be dead by then.

Young Frog

ESA medical have recommended that I have a further medical in 18 months to see if the operation worked so that I could push myself in my wheelchair. If I can they will take ESA away and put me on Job seeker allowance. Was previously given DLA for life due to the damage to my back and now I have this with my shoulders and arms. The time limit was for 18 months from January 2018 but still having treatment for first operation. No way will both operations be done in 18 months.

All reports ignored by DWP. Broke down in tears today whilst having treatment not because of the pain but because of the pressure DWP are placing on me. I suffer from chronic anxiety and depression, meeting ICD 10 of world health organisation, so recognised world wide apart from the DWP. I also have PTSD again DWP don't want to recognise. Basically I'm f@#@@@ off by DWP not taking notice of any reports put in front of them.

Dave

I am an autistic person who finds it difficult to get full-time, stable work as a result of my condition. I am fortunate because of the support I have got from my family and the opportunity I was given via Employable Me last year, but the vast majority of autistic people I know are not nearly as fortunate.

Cuts to vital support services, combined with a lack of alternative avenues, mean so many end up isolated and trapped in a vicious circle, and the transition from DLA to PIP has made life ten times worse for them as PIP assessors routinely fail to take the impact of autism into account.

I was also on ESA for some time and it took me 18 months, as well as letters to my MP and repeatedly contacting my GP for basic information the DWP had already received, to get the payments I was eligible for because welfare reform has caused increasing delays to vital welfare payments. I am very lucky I never ended up using a food bank-I know people who have.

Alan B

Have a long term chronic illness, officially recognised as a disability, albeit hidden. Medication keeps me alive, but has some serious side effects, physical & neurological. Had obtained DLA (on appeal), which allowed me to pay for a carer, assisting me in my day to day life.

Obtained 0 points over the unnecessary passage from DLA to Pip, in Dec 2016. First Tier tribunal denied my appeal, on a very spurious basis. Have now (May 2018) received permission to appeal to Upper Tribunal, with help from my local Cit. Advice Bureau.

Similarly, have been on ESA since 2008. Was assessed 4 times. 1st & 2nd time: all fine, we recognise you are unable to work. 3rd time: you are capable of work, even though my health had deteriorated. Won on appeal. Same for the 4th time, but lost my appeal. Currently awaiting for statements of reasons, in order to launch an appeal to Upper Tribunal, also with help from my local Cit. Advice Bureau.

Meanwhile, living on very reduced means, having had to use food banks, and stressing like mad, which further impact on my general health, in a negative way. Cannot afford any kind of support. We do not hide in an offshore account the meagre benefits us disabled receive, we spend it BACK in the general economy. What is the logic of what appears to be a systematic persecution of disabled people? Current government should remember that us with disabilities can also vote.

Positivechap

I am in tears again as the social worker when asked again about help to get to appointments has said this morning on the phone that I am not their problem it is up to the NHS now, yet the NHS say I am a social work problem not theirs because I cannot go by hospital transport and just be left. Yet accessing appointments was always part of my package for years. Is this what is expected now that you go alone, be left, pee yourself in public as cannot get to a toilet and then sit in it for the several hours you can be left before taken home?

Do I sit in tears and then eventually panic in public and end throwing myself down a set of stairs? What the hells teeth has this country come to? I have no relatives or anyone who can help either.

G

I'm a carer for my partner, who has limited mobility and vision. Neither of us drive and we live 3 miles from the nearest town. It costs £5.20 to get there and back, £7.80 to get to the nearest Lidl's. My partner has a bus pass but is unable to carry much shopping.

I don't go out at all, most of the time we survive on canned food, getting fresh food is so difficult. Sometimes he can't move for several days, so we have to go without. I can't get a job because transport is so unreliable here. Everything is so difficult, I often feel like I don't want to go on any longer.

Elizabeth

The biggest problem for me is that lab tests are no predictor of symptoms and symptoms are no predictor of lab tests/ liver damage/ disease progression. That's well documented in the clinical research So every time I have contact with a benefits agency, I have to explain and reexplain. It's soul destroying. Aside from the fact that life has changed so much anyway, I am constantly on edge because I am so scared of losing an income I am saying this for the first time and not sure if I want it published but I've had suicidal thoughts – I figure that I have now got so little to offer any one, I might as well not be here.

The only thing holding me back is that I have responsibility for caring for other people. They're keeping me alive at the moment. If I was able to change anything at all, it would be that the powers that be recognise that for the most part, people do not want to have lives like this. People want to work, play, have relationships. So much of our time is spent on the struggle for mere existence that we don't get to live

Woman

8 years of no rises in packages and they expect us to buy in the same amount of care at the same rates as 2010, it just does not work and just expected to sit back and accept further cuts when your conditions have significantly worsened and needs have increased. Is it any wonder my mental health has gone down the pan again?

DLA to PIP had to be taken to tribunal too as their assessor magicked away all my spinal conditions in the report, but not in my spine itself sadly which do show clearly on MRI results provided to them. How many mental knocks or insults can we take? I for one of many am losing my will to exist.

G.

The appointment was at 9.30 But assessor arrived at 8.45 without warning. My carer was still showering me. I was exhausted and wasn't asked to do anything physical. My award was the higher for both care and mobility. However scoring from assessor was inconsistent. eg:-Washing and dressing award was 12 points. Preparing and cooking a meal was 0 points. I cannot stand at all I'm constantly in a wheelchair so I cannot cook, boil water etc regularly or safely.

My award is for 10 yrs given my age 69 and with progressive illness affecting my memory I'm already concerned if or how I can go through this again. My advice to anyone would be to get copies of your medical letter or ask for copies to be sent to you. Include these with your form, and any letters or statements you can get to send with your form. They do not always request these from specialists from hospitals or GPs. Request them yourself as soon as you get your letter to contact DWP to apply for PIP

Dustydi

I will repeat the procedure for the record: I took the lift down to the dungeon of my psyche(Zevon's Werewolves Of London is the lift music and Creedence Clearwater Revival – Bad Moon Rising), entered the 10 digit pin number, scanned my iris, scanned my fingerprint, said the passphrase and verified my voiceprint, finally the safe was opened which leads to the door behind which wolf(Mr Hyde)'s cell actually is the final locks was unlocked in my mind, the final safety checklist was run through and he was let loose on a medium chain, wolf potentially is a thermo nuclear weapon which can cause huge collateral damage, I said to him: "go play, you are on a medium chain for now but only in sniper mode to deal with this problem", wolf licked his lips and smiled at me then I allowed him to merge back into my psyche, sheep and sheepdog and blackdog fell into a resting state with one eye on wolf to make sure he didn't go too far as wolf took some control.

From January 2013, my latest claim, I was awarded Employment & Support Allowance income related, I am in the support group, ongoing status. Disability Living Allowance, my latest claim was awarded from June 2012, low rate care and high rate mobility, I received an indefinite award. Up to 2001, I was a taxpayer but basically had a full breakdown that year and could not function as a human without help.

I see a bit of myself in Alastair Campbell for example:
<https://www.theguardian.com/politics/2017/sep/15/alastair-campbell-on-madness-and-power-i-dont-mind-that-im-psychologically-flawed>

My details were passed from the DWP to Capita PiP and I was required to attend a face to face assessment in January 2018. After the assessment, I requested my report PA4 V3 and duly received it before the decision maker at the DWP had looked at it. Mad as hell is the only way I could describe my mood upon reading it.

I immediately completed a "reply and rebuttal" of the PA4 V3 and fired off the below letter(redacted version). " Capita PIP PO Box 307 Darlington DL98 1AB Dear Sir/Madam FORMAL COMPLAINT Date of consultation: [REDACTED] Place of consultation: [REDACTED] Time consultation started: [REDACTED] Time consultation ended: [REDACTED] Name of professional carrying out consultation: [REDACTED] Type of professional: Disability Assessor – Nurse I have received yesterday from the DWP my PIP Consultation Report Form PA4 V3 and I enclose:

Reply & Rebuttal Of PIP Consultation Report Form PA4 V3 Annexure 001: The client questionnaire. Annexure 002: Scanned letter from DVLA. Annexure 003: Picture of hearing aid kit. I went into the meeting thinking, I'll be polite and keep myself under control if I tell the truth then nothing will go wrong, all the stories about Capita PIP's maladministration of PIP face to face assessments cannot be true, how wrong I was.

Next time I will be demanding recording even if I have to buy the double compact disk recorder myself if I cannot find anywhere to hire one. I can honestly say I'm not sure where, to begin with the PA4 V3, after reading it several times I can honestly say [REDACTED] had some kind of bias against me, we had a disagreement about me referring to the client questionnaire and I believe [REDACTED] did not like me telling [REDACTED] the rules and this fabricated report is [REDACTED]'S revenge for having (to coin a phrase): "[REDACTED] nose put out of joint".

It would have been slightly more believable if I had got a few points here and there, but for someone with my range of disabilities for the length of time I have had them, how can a zero score be credible? There are procedural and factual errors and omissions all over the report.

There are complete fabrications, [REDACTED] has lied in more than one place. I would suggest Capita PiP never employs this [REDACTED] to do an assessment every again as [REDACTED] has brought your company into disrepute. I will be making representations to the DWP for revocation of approval of this health professional.

I also will be referring [REDACTED] to [REDACTED] nurse governing body as I intend to bring a complaint against [REDACTED] directly and see her struck off. [REDACTED] had a duty of care to me as a nurse which [REDACTED] has woefully not fulfilled and should never be allowed near patients of any type in the future. I am also considering a direct action defamation case against [REDACTED].

I would suggest you read the attached documents carefully and I warn you should I not receive the level of PIP I am entitled to due to this fabricated document I will bring suit against Capita PIP, in the same manner, Vanessa Haley secured a £5000 payment order against ATOS from the court.

And I will continue to bring suit every month for the loss of the level of PiP I am entitled to until I would no longer have been able to claim it, 65 I believe. I am completely disgusted by this maladministration and defamation by a representative of Capita PIP.

I would disagree, my own plan for myself was to start a business from home with a website to work around my disabilities, I have been studying law in my spare time also, if in the next year or two I can get an access to higher education certificate in law and criminology and in that time get myself well enough to attend [REDACTED] Law School but I may not be able to get myself well enough to attend and will have to do it via open university.

Now my thoughts are turning to, well maybe I should just give up and do what I had planned in 2001 buy the peaceful pill handbook https://en.wikipedia.org/wiki/The_Peaceful_Pill_Handbook and try to get the meds over the internet or get myself a suicide bag kit https://en.wikipedia.org/wiki/Suicide_bag Yours faithfully [REDACTED]"

So at the date of writing, I have an open complaint with the DWP, an open complaint with the NMC(Nursing & Midwifery Council) and Capita PiP have just sent their final response to my level 2 complaint so that is about to be forwarded to ICE(Independent Complaints Examiner)

Also, me being who I am, a person who can find out anything about anyone as long as it is on the Internet, decided to do an unusual tactic. I found my DA/HCP's Facebook and home address.

I on Facebook sent the following to the DA/HCP: "Please forward me you solicitor name and business contact details" No reply and I was blocked.

[REDACTED] has a business on Facebook so via the business messenger I sent: "Please forward me you solicitor name and business contact details" Reply: "Thanks for messaging us. We'll get back to you as soon as we can. Why?" My reply: "I intend to begin litigation against you in person and I will need to begin by sending notice of intention to your solicitor"

Reply and I was blocked: "Haha for what?"

So I sent the following to [REDACTED]'s partner: "Please pass the following message to your [REDACTED] as [REDACTED] has blocked facebook a recorded delivery version will be forwarded to your home address next week: Let us just check that I have the correct "[REDACTED]" first of all. I am assuming this is you: " Date of consultation: [REDACTED] Place of consultation: [REDACTED] Time consultation started: [REDACTED] Time consultation ended: [REDACTED] Name of professional carrying out consultation: [REDACTED] Type of professional: Disability Assessor – Nurse " If this is you my claim against you relates to the contents of the PIP Consultation Report Form PA4 V3 under maladministration and defamation(libel) or the offence of misconduct in public office causing me to suffer a monthly loss of £320 from April 2018 ongoing until the matter is corrected via a mandatory reconsideration or/and an appeal.

As Capita PIP will only consider complaints concerning the conduct of the DA/HCP such as being late or rudeness, the content of the report where there are allegations of maladministration and defamation(libel) or the offence of misconduct in public office become the personal liability of the DA/HCP. Before proceeding to a small claim against you as part of the pre-action protocol of any proposed litigation, I must first lay out my issue and make an offer to the proposed defendant to solve the dispute without recourse to the courts. There is also a previous authority to point to: A court has ruled that a disabled woman should be awarded £5,000 compensation by the government contractor Atos after a dishonest report by one of its assessors led to her being awarded the wrong level of benefits.

Vanessa Haley, from Huddersfield, told the county court in her written evidence that the assessor had tried to "impede her entitlement" to the enhanced rate of the daily living component of personal independence payment (PIP) by "falsifying" her assessment report. This may be the first time an attempt has been made to hold personally responsible an assessor for their conduct but as Lord Denning once said: "What is the argument on the other side?"

Only this, that no case has been found in which it has been done before. That argument does not appeal to me in the least. If we never do anything which has not been done before, we shall never get anywhere. The law will stand still whilst the rest of the world goes on, and that will be bad for both." Packer v. Packer [1954] P. 15 at 22.

Letter 1: "Dear [REDACTED] FORMAL COMPLAINT NOTICE OF INTENTION TO CONDUCT LITIGATION. Date of consultation: [REDACTED] Place of consultation: [REDACTED] Time consultation started: [REDACTED] Time consultation ended: [REDACTED]"

Name of professional carrying out consultation: [REDACTED] Type of professional: Disability Assessor – Nurse I have received from the DWP my PIP Consultation Report Form PA4 V3 and on Friday the decision letter, I have been awarded 0 points even after sending the DWP a rebuttal as they have only seemingly considered the PA4. I understand Capita PIP has some kind of clause in the contract alleging that disability assessors will not be held personally responsible for their actions but you cannot contract away the law. For example, if the individual who placed polonium in the tea of Alexander Litvinenko is ever found he or she will not be able to use the defence of a foreign government said I would be protected and not face any personal liability.

As Capita PIP will only consider complaints concerning the conduct of the DA/HCP such as being late or rudeness, the content of the report where there are allegations of maladministration and defamation (libel) or the offence of misconduct in public office become the personal liability of the DA/HCP. Before proceeding to a small claim against you as part of the pre-action protocol of any proposed litigation, I must first lay out my issue and make an offer to the proposed defendant to solve the dispute without recourse to the courts.

There is also a previous case to point to: A court has ruled that a disabled woman should be awarded £5,000 compensation by the government contractor Atos after a dishonest report by one of its assessors led to her being awarded the wrong level of benefits. Vanessa Haley, from Huddersfield, told the county court in her written evidence that the assessor had tried to "impede her entitlement" to the enhanced rate of the daily living component of personal independence payment (PIP) by "falsifying" her assessment report.

I allege that you personally are responsible for a loss beginning April 2018 of £320 per month and therefore I will be seeking to test the personal culpability of disability assessors using the small claims court system. You have until the end of April 2018 to forward me sums of £320 and thereafter the sum of £320 at the end of each month until such time as the DWP corrects the issue either with a mandatory reconsideration or/and an appeal, I understand this process can take up to 2 to 3 years that is the period of time I will be continually bringing cases against you should I prevail in the first test case.

This may be the first time an attempt has been made to hold personally responsible an assessor for their conduct but as Lord Denning once said: "What is the argument on the other side? Only this, that no case has been found in which it has been done before."

That argument does not appeal to me in the least. If we never do anything which has not been done before, we shall never get anywhere. The law will stand still whilst the rest of the world goes on, and that will be bad for both.” Packer v. Packer [1954] P. 15 at 22. Yours Sincerely [REDACTED] ”

Letter 2: “Dear [REDACTED] It has now been seven days since you collected my last letter from the post office and you have not engaged in the process of litigation. I would advise you with all urgency to seek legal advice as the court system has no sympathy for individuals who do not engage in pre-action protocols with regard to litigation.

You cannot avoid this process, I am going to name you on court documents as the defendant in person, not Capita PIP as I hold you personally responsible for your failure in either ex contractu or ex delicto. As it has not been possible to resolve this matter amicably, and it is apparent that court action may be necessary, I write in compliance with the Practice Direction on Pre-Action Conduct.

After considering the matter, I have decided the cause of action I will bring against you is nonfeasance and/or misfeasance and/or malfeasance. Nonfeasance is the failure to act where an action is required – wilfully or in neglect. Misfeasance is the wilful inappropriate action or intentional incorrect action or advice. Malfeasance is the wilful and intentional action that injures a party.

The Facts: I was granted by the DWP an indefinite award of low rate care and high rate mobility disability living allowance due to how my various health problems effect me on a day to day basis. The R(M) 1/96 principle applies to DLA to PIP re-assessments and are covered by statute and regulation in how they are to be conducted.

The Upper Tribunal made this decision(R(M) 1/96 principle) on 17 January 2018. As it applies a new legal principle, it only applies to claims decided by DWP after that date. I had an appointment for a PIP face 2 face on [REDACTED] which began at [REDACTED] and ended at [REDACTED] conducted by [REDACTED] a nurse registered with the NMC.

1) Hearing aids, I wear them in both ears, it was noticed on the right-hand side ear yet still awarded 0 points for the descriptor and the nurse was standing to my left when doing the physical so should have seen the left side or the nurse could have simply requested I take them out for examination.

2) Regulation 1.6.45 Prior to concluding face-to-face consultations, HPs should give claimants an overview of the findings they have taken from the consultation, including an indication of the fluctuation and variability of function they have recorded.

Claimants should be invited to clarify any points and ask any questions they have about the assessment procedure and asked whether there is anything else they would like to include. The HP should always attempt to respond to any issues or concerns they express. Regulation 1.6.45 was not complied with, had the nurse complied I would have corrected the failure(nonfeasance), mistakes(misfeasance) or purposeful and with malice attempt to impede my entitlement to PiP(malfeasance).

From you I will be claiming in the small claims court: If the court determines upon judgement nonfeasance £5000 compensation in line with what Vanessa Haley won in her claim against ATOS also £320 for loss of DLA in April and an order of specific performance of payment of £320 per month until such time as the matter is corrected by the DWP. If the court determines upon judgement misfeasance £7500 compensation in line with what Vanessa Haley won in her claim against ATOS plus a premium as misfeasance is more serious also £320 for loss of DLA in April and an order of specific performance of payment of £320 per month until such time as the matter is corrected by the DWP.

If the court determines upon judgement malfeasance £9500 compensation in line with what Vanessa Haley won in her claim against ATOS plus a premium as malfeasance is more serious also £320 for loss of DLA in April and an order of specific performance of payment of £320 per month until such time as the matter is corrected by the DWP. I have calculated these sums based on the previous case where a person has been awarded compensation by the courts and by the actual loss of DLA amounts from April 2018.

Witness statement of [REDACTED] Witness statement of [REDACTED] PIP Consultation Report Form PA4 V3 that was produced from: Date of consultation: [REDACTED] Place of consultation: [REDACTED] Time consultation started: [REDACTED] Time consultation ended: [REDACTED] Name of professional carrying out consultation: [REDACTED] Type of professional: Disability Assessor – Nurse A reply and rebuttal of PA4 V3. Various documentation from my GP and other medical professionals including a letter of support. Your twitter feed at [REDACTED]

Your [REDACTED]'s twitter feed at [REDACTED] Guardian news paper article written by Lucy Hawking <https://www.theguardian.com/commentisfree/2015/apr/30/katie-hopkins-life-harder-disabled-people> In accordance with the Practice Direction on Pre-Action Conduct I would request that you provide me with copies of the following documents:

A copy of your contract with Capita PIP, as this will bring into the light of the litigation your specific contractual obligations. A diary of your engagements during the months of Jan and Feb 2018 including all shifts at [REDACTED], all business engagements for [REDACTED], all PIP face to face appointments and details of how you manage your household of [REDACTED].

The PIP face 2 face process is supposed to be done in a specific manner this diary will bring into the light of litigation if you are spreading yourself too thin to do the job with Capita PIP in line with statutory requirements.

I can confirm that I would be agreeable to mediation and would consider any other system of Alternative Dispute Resolution (ADR) in order to avoid the need for this matter to be resolved by the courts. I would invite you to put forward any proposals in this regard.

This got me noticed by Capita PiP's board of directors, I was expecting the "you're harassing our employee letter" but this is what I wanted as part of my tactical plan, to circumvent the normal employees and talk directly to the power behind the phone (and yes I do mean phone, not throne, why talk to monkeys when you can give the organ grinder a piece of your mind). So I received the following (which made me chuckle as I would do this if the situation were reversed): " Dear [REDACTED], Complaint against [REDACTED] I write further to your letter of [REDACTED] to [REDACTED] regarding your PIP consultation of [REDACTED].

Please note that [REDACTED] is an employee of Capita Business Services Ltd and as such any claim you may have in relation to such consultation should be addressed to Capita (the Atos case you quote was against Atos not an individual employee and has subsequently been set aside). [REDACTED] was acting firmly within the scope of [REDACTED] employment with Capita and was not acting in a dishonest or fraudulent manner. We understand that following the consultation you have sought to contact [REDACTED] directly via social media; these approaches have caused [REDACTED] distress and [REDACTED] is currently off work as a direct result.

Given you are aware of the correct process to follow in relation to any complaints or concerns (following our letter to you of 12 March 2018) we believe your approaches may amount to harassment and we will not hesitate to contact the police or take other appropriate legal action if you make any further attempts to contact [REDACTED] or any of our employees directly via social media or otherwise.

I trust this addresses your concerns with the original assessment. Please, could you therefore immediately desist in any further communications directly with [REDACTED] failing which we will have no option but to consider taking appropriate legal action.

We did inform you by email of 12 March 2018 with the process that should be followed regarding claims against Capita and we provided you with a postal address for serving any claims or correspondence: Capita Group Insurance, Business unit: DWP PIP, 71 Victoria Street, Westminster, LONDON SW1H 0XA. Yours sincerely, [REDACTED]”

I replied as follows and to date have received no answer: ” Dear [REDACTED], I write in response to your letter of [REDACTED]. Firstly you have no standing to act for [REDACTED] with agency so I cannot discuss any matter with you and [REDACTED] should not have done so with you.

The sharing of my letter with a third party not employed under the rules of agency may be a breach of the data protection act. You claim [REDACTED] is an employee rather than a sub contractor, perhaps you could provide evidence of the exact relationship for me to consider such as a copy of an uncompleted contract.

I would also be interested in how Capita PiP vets the personal views of DA/HCPs in regard to benefits claimants in general as I believe this may be another “Sarah Goldstein” type situation where a Disability benefits assessor was sacked for vile Facebook posts saying she wanted to ‘catapult claimant back to s***hole he came from’.

You need to look at [REDACTED] twitter where she says she is aware of [REDACTED] tweets then look at [REDACTED] twitter feed, the reposts are somewhat disturbing and may indicate the views of the [REDACTED] household against whole groups of people based on the actions of a minority.

[https://twitter.com/\[REDACTED\]](https://twitter.com/[REDACTED])

[https://twitter.com/\[REDACTED\]](https://twitter.com/[REDACTED])

I agree the claim may have to be addressed to Capita depending on the exact contractual relationship, but it is a question of law more properly to be answered by the courts. Essentially can a DA/HCP be held responsible in their own name when there is a valid cause of action?

I am not aware the ATOS judgement has been set aside and doubt it as there has been no news of ATOS appealing, but I am aware it was a default judgment as no defence was entered. Perhaps you could provide evidence of such setting aside. It is however useful in determining levels of compensation as a matter of horizontal stare decisis in the small claims track. With respect, how [REDACTED] was or was not acting is a matter of a test of evidence again for a hearing should it come to that. As you do not act with agency as [REDACTED] personal solicitor would, I will not be discussing my actions.

I will make some general observations, however, firstly for Capita to report me to the police, I would have to be allegedly harassing Capita, I am not so you have no valid reason to report me, therefore, would be in danger of a charge at the minimum of wasting police time. [REDACTED] could, in theory, report me for alleged harassment, I will not be discussing anything with the police unless I am arrested and then only in the presence of counsel. Furthermore, any such report would open [REDACTED] the danger of a charge at the minimum of wasting police time.

Also, there is no history, I have never even had a parking or speeding ticket. But I would allude to you this also, my record of interaction with law enforcement in both this country and abroad is not only whiter than white it is shining and when my record is called up on the PNC any allegations will be processed with some scepticism by [REDACTED] police's force arbiter, if they even get as far as his desk.

For example, if you read this story:

<https://www.rollingstone.com/culture/news/animal-instinct-how-cat-loving-sleuths-found-an-accused-killer-sadist-20140319>

Where it says: “ John Green’s iPhone is buzzing with an incoming Facebook message.”, that message was caused by my research, below is the public post I made 4 days later. I was the first person the planet to link Magnotta with his crime and his subsequent actions when everyone else missed it and the intuitive leap did not go unnoticed.

I also enclose an anonymised version of a thank you from a trading standards department who received my assistance. I have acted entirely appropriately within the pre-action protocol for conducting litigation and any allegation of harassment will be strongly rebuffed. I enclose a copy of the Protection from Harassment Act 1997, perhaps you should familiarise yourself with the thresholds. With regard to civil legal action against me by Capita, I ask what possibly could be your cause of action? I would say there is none as I have acted entirely within the law. I have sent a final letter before action complying with the civil procedure rules. The next contact [REDACTED] receives will not be from me it will be a notice of claim from [REDACTED] County Court in the small claims track. [REDACTED] will then have the opportunity to enter a defence.

With respect the direction to the insurance company is a Capita procedure, it is not law, in England & Wales if a person has a valid cause of action against another person they have every right to test the cause of action in civil court. I believe I have a valid cause of action, 1 of 3 possibilities to be decided by a court. I admit to my knowledge it has not yet been attempted to hold a DA/HCP personally responsible but I am aware of many people who are considering this route, so I may not be the first to get into a court with this proposition, one of my favourite quotes is as follows: “What is the argument on the other side? Only this, that no case has been found in which it has been done before. That argument does not appeal to me in the least. If we never do anything which has not been done before, we shall never get anywhere. The law will stand still whilst the rest of the world goes on, and that will be bad for both.”

On appeal, the conviction is overturned as hacking is not within the legal definition of forgery. The theory of the case is this, let's assume a full-time DA/HCP earns 35k a year. They work for 48 weeks a year, 5 days a week doing 4 assessments a day.

Therefore 960 assessment a year. Let's assume 5% of those assessments are done incorrectly in some way. So 48 go to court against the DA/HCP in their own name, let's assume half of the claimants win. $24 \times \text{£}5000 = \text{£}120,000$ So a DA/HCP would have to have insurance in their own name and it would weed out the bad assessors as the more cases against an assessor the higher their insurance costs.

So as much as my actions are a matter of personal justice, it is an attempt to pivot a failing system(ESA & PiP assessments) into compliance with the law of England & Wales. While I have the attention of a Capita PiP board member, I would say this, the incentive and penalty system for DA/HCPs should work on accuracy of reports as follows, whereas at the moment it seems to be lets churn out as many reports as possible and not care as it will be sorted at MR or LT/UT.

1) DA/HCP produces a report.

2) DWP does not return for a re-work.

3) Report passes MR where no extra information was provided by the claimant. DA/HCP gets paid for that report if it fails DA/HCP gets a financial consequence.

4) Report passes lower & upper tribunal with or without extra info from the claimant. DA/HCP gets a bonus for that report.

Also, Capita PiP should just grasp the nettle and record all PiP assessments, I suspect this is why Capita has invested in <https://www.evidence-works.com/our-solutions/evidenceworks-irs/> I would also say Capita should incorporate the advice from the guide to judicial conduct into its advice to DA/HCPs, I have enclosed the page where it says: "Social networking, blogging and Twitter" and the Judicial Technology Committee was advised by an expert when formulating this advice.

The short facts of my case: I was granted by the DWP an indefinite award of low rate care and high rate mobility disability living allowance due to how my various health problems effect me on a day to day basis. The R(M) 1/96 principle applies to DLA to PIP re-assessments and are covered by statute and regulation in how they are to be conducted. The Upper Tribunal made this decision(R(M) 1/96 principle) on 17 January 2018. As it applies a new legal principle, it only applies to claims decided by DWP after that date. I had an appointment for a PIP face 2 face on [REDACTED] which began at [REDACTED] and ended at [REDACTED] conducted by [REDACTED] a nurse registered with the NMC.

The report produced from that face 2 face awarded 0 points for all descriptors, it is beyond the scope of this letter to list all the problems that will be more fully explored in the skeleton argument and evidence for the court but I will make 2 short points.

1) Hearing aids, I wear them in both ears, it was noticed on the right-hand side ear yet still awarded 0 points for the descriptor and the nurse was standing to my left when doing the physical so should have seen the left side or the nurse could have simply requested I take them out for examination.

2) Regulation 1.6.45 Prior to concluding face-to-face consultations, HPs should give claimants an overview of the findings they have taken from the consultation, including an indication of the fluctuation and variability of function they have recorded.

Claimants should be invited to clarify any points and ask any questions they have about the assessment procedure and asked whether there is anything else they would like to include. The HP should always attempt to respond to any issues or concerns they express. Regulation 1.6.45 was not complied with, had the nurse complied I would have corrected the failure(nonfeasance), mistakes(misfeasance) or purposeful and with malice attempt to impede my entitlement to PiP(malfeasance).

With regard to [REDACTED] being off work, if [REDACTED] is a full-time employee and if [REDACTED] is on paid leave, I would suggest [REDACTED] is having a lovely paid holiday by hoodwinking Capita PiP and using the time to obtain double income by spending time on [REDACTED]'s personal business, as you can see from the enclosed [REDACTED] made a business post on [REDACTED].

So I have requested a second look at my file at MR level and have an envelope ready to go to appeal should I not hear back from the DWP today. I have a solicitor and I will be looking at legal action against my DA/HCP, Capita PiP or the DWP or some combination, possibly all 3 will be dragged into court.

Very sick people are now failed by the NHS and the system. I work in a hospital & I can see how things are going downhill rapidly. They are also trying to blame sick people for the NHS's failure; if they were not sick the NHS would not be under strain and deep down it's their fault if they are sick. They could have looked after themselves properly.

They don't tell you the entire story how they are privatizing everything and creating a two tier system. Rich folks will see a specialist tomorrow while those with no private insurance or the ability to pay cash will wait 12 months. Or die before that. This is the plan.

Phil

Lose benefits=financial crisis=mental health BOOM + pain worsens. Get benefit back, recover, make progress, assessment, lose money, MH BOOM, pain worsens, get benefit back, recover, progress, assessment...

Successful job, chronic pain, disabled at 33. Mental health BOOM. Want to work again, but system keeps knocking me back. 3xPIP assessments in 40 months, 2xESA. Lose benefits=financial crisis=mental health BOOM + pain worsens.

Get benefit back, recover, make progress, assessment, lose money, MH BOOM, pain worsens, get benefit back, recover, progress, assessment... Never have enough time without financial crisis to get well enough to work. Each time recover a little less. Currently 7 months no PIP. MH terrible. Suicidal twice. Working? Haha! This system is slowly killing me.

Desperate

My experience began in 2015 when diagnosed with terminal breast cancer. I received a certificate to sort my PIP. I thought this was ok until 6 months later when i received a review form. I filled it in thinking this was the norm.

I was asked to a face to face but was in hospital with sepsis so could not attend. 6 months later i received another. . i did the same. Filled it and was asked again to a face to face. I then rang macmillan to enquire. They said this was not right and rang.

The DWP stated it was a mistake. 6 months lateryou get it! Another. With an appointment for face to face. I rang asked for a home visit but asked why? Lie after lie... that is all. They blamed me, my nurse, computers. I went to social media as i was devastated. It has been a worry for nearly 3 years. I think it is sorted..but we shall wait 6 months.

I have cried more about this than my terminal diagnosis. I now take antidepressants and worry about money always. This has to stop.

Krissy

I had to give up my job to care for my husband who has a degenerative condition, he needs to be washed, fed, dressed, taken anywhere. He can walk slowly and for not very long but he is very unstable on his feet and falls very often, also has a lot of muscular pain which can be agony. The pain keeps him awake at night. He is also very depressed, he tried to kill himself twice by banging his head against the wall, he needs supervision at all times. Life was hard before but now with PIP he only gets standard care and can't get a carer or motability any longer.

A paramedic from Atos decided that he can look after himself and he is fully mobile. I used to get Carer's allowance and my contributions for my pension were paid, now I get nothing and we are both housebound with no car or help to pay a taxi fare, as we live in a rural place. I am 62 with two years contribution to go to have my pension. Now either I leave my husband and find a job or I care for him, live in hell and lose my pension altogether.

Caroline

I got my PIP assessment back a few days ago. It makes no mention of the electric wheelchair I use every day because I wasn't in it when they saw me.

My mum drove me, we parked right outside, and I can walk that far. She wrote such things as I looked "well-kempt" and "well-nourished" as well as "no cognitive impairment". I have ME/CFS and rested days beforehand and afterwards. She cannot see my pain or my fatigue. She has no idea how I eat or whether I did anything independently. I agree that day I could speak to her for half an hour, but I did lose my train of thought.

I am even more annoyed at the "you had no upper or lower limb restrictions" I told her it all caused me pain and I couldn't lift my arms above my shoulders. I have hyper mobility, no my movement wasn't restricted! I'm not on strong pain relief because I have to concentrate and the pain relief did not ever relieve pain!!

And I can "plan and follow a journey unaided" but only if someone else is with me the first few times and I have my phone so I can quickly contact someone for support.. I really need mobility part of PIP and I'm on the edge of daily living due to everything causing pain and fatigue but that theoretically it is all possible..

Lily

I have had fibromyalgia (plus other related illnesses) 15 years when the benefits all changed I was put into ESA Working Group, I couldn't cope with the constant phone calls from the job centre asking me to attend meetings weekly my depression got really bad and I didn't want to leave the house or talk to anyone.

I appealed this and lost the appeal. The doctor was very patronizing and belittling, he would not let my husband help me and he wanted me to remember how I felt 6 months previously to know why my health was worse. He asked me how my husband's health was too. He had recently had a stroke and had angina. Which I now realise is why I couldn't cope with the pain and my help was so bad because I was having to help to look after my husband. The doctor completely ignored this and he made me feel like I was nothing, he said why do you not want to work there is nothing wrong with you.

He asked did I get any other benefits and I said I got DLA and he said how on earth did you get that. I left in tears. I have since got PIP enhanced on both but the way in which I was treated caused more problems to my health, I no longer wanted to leave the house, and even now, I still only go out when someone is with me, and this is very seldom, I don't want to talk to people and worry about the future, my husband is unable to claim any benefits, he tried to claim for PIP and was told they understand you are ill but you do not fit the criteria. This illness has completely changed my life I was outgoing, worked full time even when my children were young I worked, but the way I was treated by the doctor at my tribunal made me feel like I was scum and that all I was after was money. I was working at a job I loved when I had to give up due to my health.

The way this government is treating the sick and disabled is disgusting. I haven't left the house in months as I do not want other people to judge me like the doctor did. I did try to appeal about the appeal but was told by another judge that if I continued with my complaint I would be causing the Doctor to lose his job and he would have no income at the time I decided to stop the appeal but I wish I had gone ahead, the Doctor didn't care that he had left my husband and I without any money. I always thought that if I got ill and was unable to work that I would be entitled to help, after all I had worked since I was 16 and paid into a system. Now I worry continually about what the future holds for both of us.

Sarah

- 1- Pressure to not admit people – fair enough – but can be overdone and mean people are not admitted who should be
- 2- Bad experience esp for elderly frail in hospital, especially A&E, so they won't go back even if that seems the best course for them
- 3- Lack of capacity in emergency social care – so people have to be admitted as there is nowhere else for them to go
- 4- Lack of community social care so people end up stuck in (sometimes dying in) hospital when they would rather be out
- 5- Slow response of social care from council so that realistically most of our referrals for social care are emergency ones
- 6- Ambulance service overwhelm so that sometimes people wait for hours on the floor or even with chest pain and we get called to cover 999 calls they can't get to
- 7- Housing crisis- I dictate 1-2 letters a day re people's problems
- 8- Stress and anxiety caused by benefits reviews and assessments. We don't have a great deal of input strangely now into the original benefit application forms so we tend to only see the fall out eg the distress in anticipation or after the assessment
- 9- The common finding that at review benefits assessments are reviewed in favour of the claimant but financial issues common whilst in the process of assessment
- 10- Consequent low morale in the medical (and other associated professions) associated with the sense of failure to deliver adequate care when resources do not permit ,but where provision of adequate care is seen as a personal / practice responsibility
- 11- Increasing complexity (age new treatments etc) and increasing cohorts with multiple morbidity / age – but no increasing resource to adequately serve that need
- 12- Short sighted cost cutting choices – eg health visitor numbers district nurse numbers gp numbers – all below full complements –tendency for the loudest voices to be heard and consequent further entrenchment of the “ inverse care law”
- 13- Removal / scarce resources for independent housing / benefits advice – bht are good .cab now very hard to get appointments – but my experience is successful benefits appeals need you to be very switch on or have support from an organisation with experience of what “ boxes to tick”

AGP

My name is Lisa Bloor and I'm an unpaid carer. I think it's important people know what carers like me go through because of a very much broken system.

My daughter was diagnosed with "brittle" asthma when she was three years old and she is now nearly 15. People and assessors often misunderstand the condition and don't know the difference between "brittle" and "regular" asthma.

For a brittle asthmatic it's a chronic condition, where every wheeze and cough is potentially life threatening. As parents and carers we know the risk even more so when my daughter's friend Kevin sadly died in 2015 age 11 from the same condition. Katie has to have someone with her around the clock 24/7 ever direct or indirect supervision. Someone needs to be there to help with her medication and call for an ambulance.

Even as I write this I'm sat next to my daughter in hospital as she's on oxygen and nebulisers and just hoping that the medication works and she doesn't end up in high dependency again or worse still on a ventilator in the ICU. We struggled for the first couple of years the cost of frequent hospital admissions going to and from the hospital.

Appointment after appointment, test after test really did push us to the limit. My partner works but Katie needed and still needs me around to support her so money was beyond tight. Then one of Katie's care team said you know you should be able to get financial help.

So in 2008 we put in for disability living allowance. Ok the form was really repetitive but not too hard and easy enough to fill in. We sent it off with medical evidence and it came back awarding her with high rate care and high rate mobility. To be honest I was really shocked she was awarded the high rates but like her medical team said she couldn't even get up stairs with out help at that point.

Roll forward to about 2014 and the whole system became a total nightmare. We put in Katie's renewal although her mobility needs had gotten a little better her care needs was very much the same. They refused the claim took all her DLA away.

She was 10 year old taking 8 different medications a day anywhere from 3 times a day to 24 times a day. In and out of hospital several times a year and had several appointments with respiratory specialists, nurses and Physiotherapists.

So you might ask where is the accumulated impact. Well it's simple, when someone loses their DLA so their carer loses their allowance.

Does the persons care needs just vanish? No they don't and carers like me are left in limbo penniless, stressed and beyond breaking point.

Not only do we have to care but now we also have to fight for basic financial support of the person with a disability. When I rang them to ask why they had taken her DLA the women was very off handed saying "Katie could take care of herself".

I said are you for real what am I suppose to do stick her in a corner and say take as many of those tablets as you want she's only 10 years old and well she's at it she can ring her own ambulance and don't forget she can clear get her self to hospital appointments.

Katie can barely talk when she can't breath yet they can say she doesn't need any help. The DWP lady then said it doesn't effect her education. At that point I was crying so upset and frustrated.

I asked if she read the evidence as she will find a supportive letter from the head of school clearly stating that Katie struggles to keep up with her education, her average attendance is often 60-75% at best.

She often cant go out during playtimes, PE and misses a lot of school because of hospital admissions. So I had lost my carers was in panic mode, how can I find a job and look after Katie, what will happen if I'm not around to get her help.

If there is no one there, no one to care then that places my daughters life at risk. It also adds further pressure on the NHS as no carer would mean they would need more hospital admissions. None of it makes sense, they are not saving money by doing the things they are, it's just putting pressure on other services and unpaid carers.

Needless to say we won the reconsideration after two rounds. Then in 2017 the letter arrived for the renewal time again. It's hard to put in words how it makes you feel. The dread and stress starts from the moment that letter arrives.

I rang the carers allowance unit explained that it was with reconsideration but sadly they wouldn't wait and removed my carers. We won again and I put in the claim for carers it took them 13 weeks to deal with my claim. What are carers suppose to do exactly? Live on fresh air.

Why are we being pushed to beyond breaking point and left to suffer all to often in silence? I already know that we have to do all this again next year once Katie turns 16 and are switched to PIP. Just the thought of going through the hell again makes me feel sick with dread and stressed out.

I know PIP is harder than DLA to get them to understand so I can easy envision having to go to full appeal. My daughters medical care is staying under paediatrics until she is 19, so you have to wonder if the hospital can still understand the level of support she needs than you would think the disability benefits system would? But I doubt they will sadly.

The system has been slowly eroded away to the point where there is no safety net anymore. You're made to feel like you are begging and a scrounger or a liar, when all you want to be able to do is care.

But who cares for the carer?

Lisa

I was in receipt on a 5 year award of DLA. It was due to run out in September 2018 and was won at a tribunal 4 years and 3 months ago. After the heart attack I did my duty and informed the DLA department to inform them of the change for the worse in my health. I was informed that I had to make a claim for pip and did so the moment that I got the form in the post with the help of Bromley CAB.

I went to the appointment to see the organisations medical representative (Atos) but before I went I did inform the PIP department that I was going to make a recording of the event and was told that I needed to provide 2 sets of recording equipment which I did. The representative made me sign a document in order to record the event and the assessment went ahead. Later I got the report turning me down for pip.

After reading through it I was able to spot that a few of the representatives answers were the opposite of the conversation that occurred during the event.

I requested a mandatory reconsideration based on the changed made by the doctor, pointing out the changes and reminding them that recordings were made to prove this. That was ignored and turned down. I then put in my letter of appeal. and a week or so later my DLA was stopped 9 months ahead of the time set by the judge when I won the original tribunal. I did remind the PIP section that they have no right to overturn the judge's decision and I was ignored. I am now on Zero income.

I explained to pip that I need the DLA as it was winter, I am taking blood thinners every day and this means I will feel the cold several times harsher than ever before and it is likely to be detrimental to my new health condition. Again it was ignored. I suffered the winter snow feeling very ill indeed and unable to keep warm without the DLA to pay for the extra heating needed 24 hours a day and was ignored. I am about to suffer again as we expect another cold spell in the coming days.

After waiting for a date for my appeal after going beyond the advertised time limits and after receiving a call from my coronary nurse telling me that PIP had sent him a form to fill in but explaining that he was not qualified to do so. He had spoken to PIP explaining the fact that he is not qualified to answer but was told to do it anyway.

I spoke to PIP asking why they were requesting important information from an unqualified source and was fobbed off but more worryingly when I had passed on the security questions in order to proceed with the call the

She said she will look into it and let me know in a day or 2 and went on to explain that they do not have the recording I made when being seen by Atos so they now consider that no recording was made. The call ended. I sat back and considered the call and suddenly realised. I had just been informed that a decision had already been made and I had not yet had a date for the appeal.

This sounds highly illegal considering the lies Atos made, the time taken so far, the fact they overturned an award won at appeal, the fact there is a file on PIP's system saying a decision has been made and the fact they have lost, mislaid or thrown away the recording made with Athos so they consider that my evidence proving the doctor lied means nothing.

I got the call yesterday telling me that the 6 to 8 weeks to set a date followed by 4 weeks for the appeal to happen is now 6 to 9 months before the appeal will be heard. This is obviously going to be more than a struggle for my health. If it takes the full 9 months then from the point of claim to appeal date will have been 18 months. I find this to be totally unacceptable and need your help.

I had an appeal date only to sit down and be told they need more evidence from My doctor and even though I got My copy a couple of weeks ago there is no new date so I remain as a zero income citizen unable to afford more than very basic meals, losing weight and feeling weaker by the day affecting my ability to return to a reasonable level of fitness and health.

This is sick and twisted behavior from a government that was elected to protect the citizens from hardship yet instead we are made to suffer while their pockets are forever full.

Colin

My husband and I moved to where we are for work and he had an accident broke his back and so life on benefits started. A few years later I was diagnosed with fibro and it has gradually got worse. I am now bedroom-bound and haven't left the house in years.

My son has just had a letter to say he is no longer entitled to any benefit. A paramedic made assumptions that because he can play computer games he is quite capable of looking after himself! I now have to fill in forms for a tribunal. I have no idea if I will be able to attend.

If I don't go my husband and son won't go without me! We moved here because we wanted to work and there was none where we were. I have worked since I was 10 and only stopped to have my son. We didn't choose this life, we don't want this life.

I am sat in dread knowing that my daughter and I will be thrown of DLA soon and have no idea how we will all cope. No wonder people are killing themselves! Will people finally realise what is going on when all the disabled parking spaces are free because we are all DEAD!

Jools

There was no social housing so we were forced to take the only home that would take us on. It is not really suitable for my needs but no social housing. At the age of 11 it was my son's 5th home.

Also in 2016 I had to fight the local authority to get my oldest son into our choice of school for his needs - Autism, Anxiety & learning difficulties. Later in 2016 my 8yr old son became suicidal, he was eventually admitted to hospital in January 2017 and we found out that due to cuts to his school and staff losses he was one of many special needs children who had fallen through the gaps. He had gone almost 4yrs without any assessment of needs or support.

I then had to battle the LA to agree to assess and then fight for a school suitable for his complex needs while they tried to force their own schools on him. Thankfully due to legal aid I eventually won that battle a few weeks ago but cuts to legal aid for educational negligence has been removed so I have no way of justice for failures to my son. Fighting this battle put me in hospital and almost lost my son's their mother.

Two weeks ago the dreaded brown envelope arrived for PIP, I have been battling for my family for three years and now don't have the strength to face this one.

Jasse

Osborne blocked any assessment all cuts to disabled despite EHRC, Social Security Select Committee and now The UN saying they should do. Sadly i believe they will ignore the recent findings, but well done to all the groups that got it so far, DPAC and Black Triangle and many more. No-one asks to be sick or disabled, its not a lifestyle choice. I am talking to you today to ask that we all keep the pressure up in whatever way we can.

We are fully aware the party came into power and purposely laid the groundwork against us by a drip drip, drip of hideous accusations that we were all scroungers and a lot of us were able to work. We have seen increased attacks and abuse on disabled people, and the Tories were probably thinking great their plan was working, now the cuts.

Osborne was utterly confused at his last budget when he announced he was cutting PIP to pay for a cut inheritance tax for the top 10%. He couldn't understand what the problem was, hay it's only the disabled, our backers our the top 10% why is anybody bothered! That's how removed from society they are, how little they care and how they are othering disabled people. And i would be here all day on Cameron's use of his son to ignore questions on cuts at PMQs.

I know for myself you get paranoid that people are watching you, what if they see me on a good day, oh god is that the postman with a brown envelope! They have instilled fear into sick, disabled people and their carers. Listen to Dennis Skinner's story at the WOWpetition debate to hear the horror of a terminal cancer sufferer. I have got sicker and more disabled over the last 2 years, with breathing problems and breast cancer..

In theory i should feel able to go back to PIP to seek more support. I haven't, I'm scared like many if I raise my head above the parapet i will loose everything. The system has me cornered, and frightened, but hay they will know now, I will await the brown envelope! Look i'm waving i must be fit for work !! Me and Richard II

They have made us a new underclass, Thatcher did that with single mothers and poorly paid workers. In my book they want us to disappear. We are a bunch of lazy scroungers sleeping when other's are working. The blinds are closed on our pain, our sickness, our helplessness and our fear of each and every day, and what new cut will hit.

The Government refused to investigate Dr Wood's accusations on people found too sick for work by doctors were having their decision overturned by the private companies. The private companies who have secured millions taxpayers money to run the system ineffectively, with huge delays and false findings. But they are only doing what the Government asked. They thought we were all fakers, found out we weren't so they just slashed everything instead. The only liars are the Tory party when they claim they support us.

We now know private companies have cost taxpayers £39 million in appeals. But the fear can not be measured by cost. Exacerbating our symptoms can't be measured. But we need to speak out in any way we can. Get our voices out there. Use podcast, letters, anything send it to us and we will put out on twitter and facebook. Share them continuously wherever we can. Get the truth out there we have our voices heard. Also if you could send a copy to your MP, tell them you are going public.

We need our voices heard, we need to empower ourselves to do something. The more we get the greater the impact. Please take this opportunity to speak, to shout, to say how it has impacted your life. Carers we also want your voices, you too are joined with us in the fear of what is coming next. Having to fight to survive.

Whilst you save this country billions. This Government had one ideology, cut the state, the NHS, public sector and welfare. We need to fight for them all. Give us your voice , or written word, anyway you can, let your MP know. On the back UN findings we need to shame them to act as a duty care to assess impact all cuts disabled people.

Over 200 000 people signed petitions calling for a cumulative impact assessment WOWpetition and Pats Petition. We need to fight on.. I will have my voice heard, please send of yours to share. Details will be on our site WOWpetition.com, at our twitter account [@wowpetition](https://twitter.com/wowpetition). Let us all get it off our chest and share with the world what they have mentally and physically done in the UK. Back up UN findings. Let us take back control in any way we can.

I will have my voice heard, please send us yours to share. Details will be on our site WOWpetitionforum.co.uk , at our twitter account [@wowpetition](https://twitter.com/wowpetition). Let us all get it off our chest and share with the world what they have mentally and physically done in the UK. Back up UN findings. Let us take back control in any way we can.

Michelle

When I looked at the report I had to double check it had my name on it. I have never seen so many lies in my life!

I scored zero points and lost the money for my carer. They said I go on holidays, can cook meals, bake cakes and enjoy knitting. They said I was articulate, had good concentration and could express myself well but I don't see why that matters. I can't cook for myself, without help I only eat sandwiches, yoghurt and cereals. I have not had a hot meal for months now. My kitchen is tiny I can't go in with my wheelchair, I can only stand for a minute or two just the time to grab something from the fridge. I have not had a proper bath for months, I use a sponge for the parts I can reach. I get online shopping as I can't go shopping for myself for as long as I can pay for the internet, then I will starve. Even online shopping is a struggle, I need to put things in the kitchen, it normally takes me the entire day, one thing at the time, 20 minutes rest and then another one.

My family lives the other side of the country and we are not on very good terms, I can't ask them. I need a new wheelchair but forget it now, I can hardly eat.

As I scored zero points the council cannot help me, I am no longer classified as disabled in their eyes.

I think we are doomed. Nobody cares about us disabled. I am appealing at the tribunal but it is a 18-24 months wait here, what shall I do in the meantime?

Cathy

I applied for PIP as I have had severe Epilepsy all my life which has not responded to treatment and left me unable to work. I was awarded 0 points for both components. I went through the MR process – same again. I contested this at Tribunal. The panel had access to my medical records including details of hospitalisation. I could hear them upon leaving the room saying they ‘did not believe me’ and ‘how could I need help as I have a degree?’.

I only received the mobility component in the end as I cannot drive. Nothing to help pay for my carer. This has taken over two years. The assessor claimed they were a nurse. I recall nothing of it as was recovering from a seizure according to my carer who was there at the time. All I know is I was in bed at the time and had to be woken to be asked questions I could not answer. I did not understand anything.

My carer was present and took notes. What was in the report is not what was stated by my carer and appears to be fabricated so as to avoid the awarding of points. It has been physically and mentally draining. The panel said if I contest the decision as I have already been awarded mobility money then I will likely lose everything. This is making me worse as stress makes my condition worse.

Elle

It has not made me ill, but it has made me angry, frustrated and dismayed.

I had a home assessment, the HCP was polite, kind, & seemed, at the time, to understand what I was saying. The assessment lasted almost two hours, and we chatted about one or two other things, to do with, but not directly related to, PIP & ESA assessments. I felt quite positive about the way it had been conducted. I didn't feel intimidated, disbelieved, or humiliated, the male nurse was polite, kind, and, or so I thought at the time, very understanding of my situation. He didn't ask very many questions, but, I am someone who offers up information readily, perhaps too much information, sometimes! So he didn't really need to. Therefore I cannot really comment on his skill at gleaning information by using the correct questions/follow up questions. I imagine with some people it is like pulling teeth, to get the info required, then again, I sometimes feel that they don't really want to know, they just want to be able to tick a "yes", or "no", box.

Where do I start!?! I put in a claim for PIP after several years on DLA for agoraphobia. For 10 years apart from going into the garden I never left my house, I have improved a little & can now go about 10 mins from home, although I still feel anxiety when I do this. I can go about 1 to 2 miles from home but only in a taxi as I can't use public transport, again I still feel anxious doing this. I cannot go anywhere unfamiliar on my own. The report said "I can go out" I have had OCD for 53 years takes me 3 to 4 hours to bathe this causes extreme frustration and I often sob and bang my head on the wall in frustration but, until recent years I did this everyday of my life, I just got up really early to get to work etc!!

In recent years I have developed arthritis in several places and a motility problem with my esophagus which causes constant reflux, When I bathe it is like a 3 to 4 hour workout, this causes pain with the arthritis and terrible heartburn/discomfort from the reflux, this is on top of the mental anguish already described. I started putting off bathing everyday, it was the choice of the lesser of two evils, feeling dirty and disgusting, or bathing and being in pain during and for several hour afterwards. The gaps between baths got longer & longer over the years I now only manage about one bath a fortnight I spend 10 out of every 14 days feeling, dirty & disgusting also I cannot get dressed if I don't feel clean, this is part of the OCD I think, I can wear a dressing gown but not day clothes, this means I don't go out. So this is having a knock on effect on the agoraphobia.

But the report said I don't use aides for bathing so – 0 points. I normally take 400 mfg of Tramadol a day and have done for 10 years. Recently my GP wanted me to come off them to see if they were causing another health problem excessive sweating. On the day of the assessment I was down to just 50mg a day I told the HCP this and explained why I wasn't taking my usual, needed, 400mg a day. The report just said that I take 50mg seemingly my actual prescribed dosage was "not relevant" or at least that's what I was told when I complained about it. Also the reliability criteria seems not to have been taken into consideration at all as regards how long it takes me to bathe, and the fact that I cannot get dressed, albeit that this is caused by a mental problem and not a physical one it is, in my opinion, relevant.

Altogether I scored 0 points, zero, zilch! It is the fact that I got 0 points that has spurred me on, there is no way that that is right!! I am very angry, and this is making the reflux worse, I also feel agitated, feel I won't be able to rest until I get this sorted. I feel as if all that I said and explained and the great lengths I went to to help the guy understand how I feel has just been ignored and I may as well have talked to the cat!! Although I say I am angry and determined to see this through, I think it has upset me too, I have been crying on and off, and I slammed the phone down on my son the other day, over something that I wouldn't have done a few months ago.

Haven't heard from him since! If I had missed out by a few points, but felt that my struggles had at least been acknowledged, I would be disappointed but I wouldn't feel angry and upset, as I do now! I am a strong person, and, luckily, able to express myself and not afraid to do so! Going to a Tribunal (apart from the being away from my safe place) doesn't phase me one bit, but how do people who are shy, not very good with words, expressing themselves, manage. What about those with social phobia or those who feel very ill? This must be horrendous for them, and it shouldn't be happening. People don't mind assessments, but they expect them to be thorough, honest, accurate and fit for purpose. It shouldn't be like this, it is cruel to those who are very ill and /or those who struggle to put their case forward.

Norma

I now have anxiety attacks. and find talking on the phone and leaving the house difficult, I was fine and hadn't had anxiety and depression for years decided I was not depressed enough or I would be dead, despite having tried to kill myself after being given 0 points twice, the phone line is hostile and when I first became disabled I was refused a DLA application form at all. Some like torture, anything that they could find to upset or intimidate you they would then "you wont have said that" "your with a terrorist or a racist which is it?" one tried to bargain with me about how much money I get regardless of entitlement, when I said no dropped it anyway.

Money removed regardless of variability of disability, stalking used to obtain information, gov failings in providing the adjustments to property and access to help used to prove ability to work.

I was left for three months without help and unable to leave my home due to anxiety and was told there is no physical reason for my disability, there is a situational one and that I the governments failings and hostility. This is my 8th (I think, I lost count) round of assessments for one thing or another, and I was happier, I have lost my independence, and the access to help that has been there for other people is not there and has left me contemplating killing myself, having police and ambulances turn up because other people have worried about my mental health, I probably have liver damage from an attempt to take my life, because there is no help there or the access is difficult and with depression and a physical disability its just adding barriers that do not need to be there.

Feeling Hated

The part of UC that isn't being heard or understood. Is that those waiting who are in Esa support/esa wrag are constantly left in fight or flight mode not able to plan for big purchase or the future. Having to try and save the five week short fall in income out of extremely limited budgets especially if they like me are not accessing PIP, but have multiple health issues, because of the wholes in pip process and atos lies. and as we know 20% are not dealt with correctly due to bureaucratic errors from dwp. 20% of three million is a lot of people who could lose homes end up dead on the street.

Especially people like myself who are not supported, have no support network and woman would be at massive risk to crime, especially as I have been involved in a lot of anti fascist campaigns puts me at greater risk again. The thought of being made homeless at fifty with degenerating discs, shoulder pain, gastric disease and shoulder pain, asthma and tendonitis. Really does not thrill me one bit. N yes as you know I wasn't lazy when it come to delivering for labour. Because if a military back ground I may appear healthy whilst door knocking.

But I'm not as fit bone wise as I look. I'm personally not able to afford to heat my flat and have cut to three hours a day, I eat rubbish n cheap near out of date food as it is, and my only luxury is the Internet (only because I got the travel pass eventually). And I use a tumble dryer cos I live two flights up. But actually I like this home and feel happier and safer here than I have for years. The other thing is the transition if it goes right will cost me approximately £1100/900, that's 5 weeks rent, at £65.00 approx not sure how this affects council tax either but 5 weeks full council tax would be £130.00 and the £613 over I get 5 weeks plus the week. And that's if it all went swimmingly. My total welfare a year with degenerate discs ect is 10600 this is about a ten% reduction in a year's income. If you did that to workers they'd go on strike. Plus the law has stated that's the money what we need to live on. So government breaking its own laws.

I already use charity shops and buy most stuff second hand. I don't smoke and I don't drink. My only social life is the politics I do. It's simple things like constant stress. I spent 8 years arguing to get a spinal scan cos I knew was more than muscular. It's the constant fighting for everything. I worked long and heavy hours and when I worked, a physically demanding job along with endurance military competitions I did uk wide and in Holland. and served a winter tour of Bosnia. So like most soldiers. They retire young with a pension. TA soldiers don't. And trust me I didn't just do my 32 days I used to do 99 days. And for 6 of 8 years maintained it with full time work. I didn't just sit talking and travelling for a living. And I thought ok I burnt out.

So being trapped in fight or flight puts us at risk of high blood pressure, stroke heart issues, and as they type who likes to plan so I can stay out of debt etc. And I currently can't do that for fear of having to save £1.000 out of an income that's at 43% of median income and under poverty level with physical but hidden health issues. The issues people like me at the bottom suffer us systemic and psychological stress positions. Both with accessing decent health care esp mental health which often is poor or not appropriate to the root causes. Dealing with benefits systems ie being left on hold for hours n a half n no one answering. The whole system is designed to stress already sick people. Hence the 43/47% of esa claimants attempting or succeeding in suicide. It's inhumane to treat people like. We wouldn't remove money for dog food and shelter off our pets so why do it to humans unless it's a deliberate attempt to cull unwanted working class people who have become sick often because of our labour.

I'm an ex combat medic and I worked for nhs and learned about the illnesses I dealt with. So I'm not as unintelligent as you and some people may think I am. For years I have tried to get people to report on the insecurity and stress surrounding austerity but will anyone print it in the press or discuss it. No, why because dwp does not listen to claimants, our parties want claimants to be voiceless or controlled by middle class people with illness who have no understanding of those totally relying on esa or UC and it's impact. And that is why I have a nasty attitude with people at times. Because you refuse to listen or allow unemployed none working sick and disabled a voice. Even in Labour. And the labour disability was being manipulated.

Trust me I know what's going on and it's not nice. And as Cameron said you, s are in it together. I believe to cull off those you all see as useless eaters. Bit by bit. Hidden hense all these halts delays kill a few more in the winter streets. 449+ homeless dead in our streets how many will it be before you all act. DWP claimants aren't all alcoholics and drug abusers and the ones who are are driven to it because of life and stress. And I want the stress impacts and cost of that to nhs and policing said in Parliament. Start listening to those you are being cruel to or the tories.

People aren't lying.

MPs money went up by 10% claimants in my case in 8+years re esa since crash has went up buy £8.00 JSA has been frozen. Inflation up 6% rent cut made to pay council tax bedroom tax, parts. People having to move houses. Cos of bad housing n bedroom tax all reducing my income twice. Twice in 4 years I've had to financially recover from house moving to get a decent ish home. All lost income then facing UC. I do hope you attend the Wow cumulative impact debate when it happens. This been delayed think because of budget.. But that there for me personally is some of the impact.

A life of worry, misery and stress arguing for decent treatments helps no one. 15 months for autism test wait, 8 months for a bathroom assessment 15 weeks n counting to get physio. Why do you think that is. Well because for a starters my recent pip assessor was a occupational therapist. How many nhs staff are working to punish sick and disabled in capita atos and ias. Instead of working to help people recover and get medical needs and sods sorted.

Maria

I'm an autistic woman, have ADHD, sensory processing disorder, fibromyalgia, 3 bulging discs, degenerative damage to my spine, scoliosis, 8 fibroids, dyspraxia, double vision and restricted gaze to the right.

I have been disabled all my life but avoided applying for PIP all these years because I knew I would not be able to cope with the stress it would cause me.

Applying for PIP has made me suicidal with a plan. I was in mental hospital for 4 weeks, sectioned for a day and have been to A&E 18 separate times by ambulance that NHS 111 called for me.

Filling in the PIP form and having to state how disabled I am, and how badly it impacts me for every PIP activity has left me suicidal. I had never told anybody how bad things were and suddenly I was having to tell the DWP.

I'm autistic and cannot communicate with strangers because it causes me overwhelming distress. To try to avoid being assessed my PIP2 was extremely detailed, setting out in 52 additional pages all the reasons I cannot complete each activity safely, to an acceptable standard, repeatedly and in a reasonable time period. Yet the assessor did not read my PIP2 at all.

I had a home assessment. I was on my own because I didn't have anybody to be with me. My assessor was a nurse from ATOS, completely clueless about any of my disabilities.

The first thing I told the assessor is that I'm autistic and cannot communicate with a stranger, and the reasons I cannot complete each activity safely, to an acceptable standard, repeatedly and in a reasonable time period are explained in extreme detail in my PIP2. Yet the assessor failed to make reasonable adjustments under the equality Act 2010 and told me she had to hear it from my mouth. Unknown to me she was forcing me to tell her verbally because she had not read my PIP2 at all.

The second thing I told the assessor is that I was in extreme pain and bedbound and was forced to get up to open the door or she would have failed my assessment and that I would be returning to bed as soon as she was gone. The assessor didn't record this at all in the assessment report.

I was forced to explain all the reasons I cannot complete each activity safely, to an acceptable standard, repeatedly and in a reasonable time period. Yet the assessor did not record these reasons at all in the assessment. She did not record 95% of reasons I can't do the activities.

The assessor does not mention in the assessment report at all that I am autistic, have ADHD and sensory processing disorder other than in the list of conditions she wrote "autism/ADHD", therefore believing they are the same condition.

My autism, ADHD and sensory processing disorder severely impact on all the PIP Daily Living and Mobility activities, but the assessor did not record at all in the assessment report how they impact on the PIP activities.

The assessor did not at all read any of the medical letters I provided and makes no reference to them in the assessment report. She completely ignored the letter from my GP, explaining how my conditions impact on the PIP activities and contradicts my GP.

She completely misinterprets the letter from Moorfields Eye Hospital, which states I have double vision and restricted gaze to the right, claiming my sight is normal.

What little the assessor recorded, she blatantly lied about my responses to her questions and what she observed.

The assessor asked me do I go to the corner shop. I replied no, I had never been. She recorded in the assessment report that I go to the corner shop.

The assessor asked me if nobody is available to go with me appointments on my own, will I go on my own. I replied I cannot go to appointments on my own safely, to an acceptable standard, repeatedly and in a reasonable time period.

I told the assessor I need someone with me on familiar journeys because due to autism, ADHD and sensory processing disorder I get lost going to familiar places most days.

Due to ADHD and sensory overload from autism I cross the road without looking every day so can't go out on my own safely.

My senses get swamped and I get extremely distressed on public transport so need to be accompanied.

I'm suicidal with a plan and want to throw myself under a bus, so cannot go safely out on my own.

I have double vision and restricted gaze to the right so can't see the cars and cross safely.

Yet the assessor didn't at all record this in the assessment report.

The assessor lied I said I can go to appointments on my own because according to her I go to the corner shop I've never been to and can go to appointments on my own. She did not at all look at what I'm able to do at some point in the day on most days. She completely ignored what I'm able to do safely, to an acceptable standard, repeatedly and in a reasonable time period.

Appointments are just a few days a year, not most days. In fact I've been discharged from five hospitals for missing an appointment because I didn't have anybody to go with me. My GP arranges patient transport to all appointments. I have a disabled Taxicard and a member of Dial-a-Ride, which are both door-to-door transport services for disabled people.

Despite having severe mobility problems and ticking on the form I can walk less than 20m and most days at some point in the day I cannot walk outdoors at all, the assessor did not carry out any physical examinations.

Despite not carrying out any physical any physical examinations, the assessor lied that she had carried them out and that the results were normal.

The assessor set a trap for me to walk up 4 flights of stairs when i was in excruciating pain with the aim of declaring I have no mobility problems. She pretended she needed to see the hoarding in my flat. the hoarding in so bad that I had the assessment in the communal hallway.

I walked in extreme pain, very slowly, with one hand on my back and the other hand on the banister. The assessor walked behind me and was forced to walk very slowly too. I have fibromyalgia and have severe fatigue. By the time I got to the top of the 4 flights of stairs I was on the verge of collapsing. I have asthma so was wheezing.

Yet in the assessment report the assessor blatantly lied she observed me walking up 4 flights of stairs with no pain or discomfort, at a normal pace and that I showed no breathing difficulties throughout the assessment.

Despite not walking up the stairs safely, to an acceptable standard, or in a reasonable time period, and despite stairs not counting for Moving Around under case law [2016] UKUT 240 (AAC), the assessor decided walking up 4 flights of stairs is equivalent to 400m, so I am able to walk over 200m.

The assessor did not at all consider what I am able to walk most days, which is at some point in the day I cannot leave my home at all because of severe pain, extreme fatigue and feeling very unwell as a result of sensory overload from autism.

The assessor did not at all consider what I am able to walk safely, to an acceptable standard, repeatedly and in a reasonable time period.

I knew the PIP guidance states the assessor must give an overview of her findings at the end of the assessment, but the assessor refused to, in breach of the guidance. Obviously she refused as she had not recorded the reasons I told her I'm unable to do each activity safely, to an acceptable standard, repeatedly and in a reasonable time period on most days at some point in the day.

The Decision Maker's Guidance states the decision letter must list my disabilities but it does not list them at all.

The Decision Maker's Guidance states the decision letter must be personalised at specific but it is a template that is not at all specific to me. My PIP decision letter was almost identical to my neighbour's despite us having completely different disabilities.

The Decision Maker's Guidance states the decision letter must explain all the inconsistencies in the evidence, but there is no mention of a single inconsistency because the assessor did not at all read the 52 page PIP2 or the medical evidence.

I asked for the assessment report and was shocked at the blatant lies and the assessor's complete failure to record the reasons I'm unable to do each activity safely, to an acceptable standard, repeatedly and in a reasonable time period on most days at some point in the day.

The Decision Maker's Guidance states the PIP decision must explain all the inconsistencies in the evidence so I asked the DWP to explain them. I'm autistic and can't make phonecalls yet I was forced to repeatedly call the DWP to complain as they take a month to respond to emails. I had to ask for an explanation of the inconsistencies more than 15 times. Each time I waited up to a month, the reply refused to give any explanation. Obviously, the Decision Maker had not read the 52 page PIP2 or the medical evidence so had no idea what the inconsistencies are.

The DWP completely refused to explain to provide an explanation of their decision which complies with the Decision Maker's Guidance. The absolute maximum deadline for a Mandatory reconsideration is 13 months so the day the deadline expired I was left with no option but submit the reasons for a Mandatory Reconsideration without an explanation from the DWP of their decision.

The stress caused me to be suicidal with a plan. I was in mental hospital for 4 weeks, sectioned for a day and have been to A&E 18 separate times by ambulance that NHS 111 called for me.

For the Mandatory reconsideration I submitted a 200 page of the reasons the PIP decision was wrong with a very long list of errors of law, legislation and case law and guidance the decision does not comply with, and a total of 30 medical letters,

I thought the DWP can't possibly keep the same decision with all the errors of law and medical letters I had provided.

The DWP deliberately made me miss the on month deadline to appeal by emailing me the Mandatory Reconsideration notice 14 days after they wrote, leaving me only 14 days to appeal.

The DWP did not at all read the 200 page Mandatory Reconsideration or any of the 30 medical letters. They repeated the same as in the original decision and some reference to the assessor's lies that go to the corner shop, can go to appointments on my own and can walk over 200m because walking up 4 flights of stairs is equivalent to 400m.

The DWP did not respond to a single error of law I asked them to reconsider. There is no mention of a single error of law in the Mandatory Reconsideration decision letter.

The DWP Mandatory Reconsideration completely contradicted the medical letters and did not refer to them at all.

I'm autistic and can't make phone calls yet I was forced to repeatedly call the DWP to complain as they take a month to respond to my emails. The DWP agreed they would reconsider the Mandatory Reconsideration again as they had no responded to any of the errors of law I asked them to reconsider. However, the day the one month deadline to appeal ended I receive a letter stating that they would be reconsidering their decision. The DWP deliberately made me miss the deadline to appeal.

I kept ringing the DWP to complain and every time the DWP refused to respond to why they had not reconsidered any of the errors of law I asked them to reconsider and why there was no mention about any of the errors of law in the mandatory reconsideration notice. Every time they deliberately hang up. The DWP then told me they would not be responding to any further calls from me and would hang up.

I continued to ring and every time they refused to discuss their failure to respond to the errors of law and refused to give me any explanation of the inconsistencies in the evidence. The DWP refused to explain their decision, stating they had already explained it despite refusing to provide any explanation, which I've been asking for a year and a half.

I have not yet registered my PIP appeal and have now received an ESA Work Capability assessment form. I'm in my early 40's and have been signed off sick all my life and have never worked. The DWP are not at all complying with the 2016 guidance that ESA claimants in the support group with serious conditions that will never improve will not be reassessed.

I cannot cope with the stress. I'm autistic and ADHD and very much struggle to write. Due to my autism I can't multitask and can't fill in the ESA WCA form and appeal at the same time. I'm suicidal with a plan. I can't take any more. I'm so ill and PIP is destroying my life.

I have worked as a support worker in mental health and now I do volunteering as a welfare adviser. I don't think it is possible to write down exactly what is going on, I am witnessing systemic cruelty every day. Last week I saw a disabled child who was severely malnourished. Do you think that his parents are negligent or addicts? No, they are two lovely people who had a severely disabled kid and struggled to make ends meet in the past few years. The move to UC was the last straw for them, I have seen despair in their eyes. If someone did this to a dog or a cat there would be thousands of enraged people on Facebook demanding justice, but it is a disabled child and no one gives a damn. Some even say that they should not have had kids if they were not able to support them.

The worst part is that there is very little help, writing to MPs is nearly always an utter waste of time, most are powerless or they might not care at all. The rest is down to luck, some areas have no CAB left, or the advice available is so oversubscribed that they might have to wait weeks to speak to an adviser for 15 minutes. They will give them a pamphlet or two and direct them to the food bank.

Then the tribunals, another postcode lottery... It is often not too bad, but there is no guarantee. If they are unlucky they get a panel of Daily Mail readers who will make them feel guilty and uphold the decision. People are forced to represent themselves, unfortunately they can't afford legal representation and they easily fall apart after a few nasty questions. We must be careful how we advise people, for some going to tribunal on their own is more they can cope with. We should not advise people we know nothing about. We need more people working in the communities, actually holding people's hands, we desperately desperately need that.

Deb

I've been through hell with all the cuts to the NHS and benefits, and the changes to welfare. I'm severely physically disabled and have other health problems that also cause me problems daily. It's hard to know where to start with all the things.

My wife is my carer, I need help all the time and every day from her to survive and get by. I can't cook for myself or dress, and need help in the bathroom. I need her help with everything. I don't know where I'd be without her.

We were made homeless a few years ago because our landlord was selling the house. We had to find somewhere else to rent, which was very hard. The local council had nothing and I needed either an adapted house or bungalow. On top of that, most agents and landlords didn't want to know if you were on benefits – even if only on benefits due to disability. There is a huge stigma created by horrible people.

It had been a struggle with money after the government cut the local housing allowance. It was a huge cut and had a massive impact. We'd all gone without food at times because there simply wasn't any money. Our utility bills were out of control because I get very ill if I get too cold and we're obviously at home most of the time. With so much going out on rent and so little coming in, there was just not the money to pay all the bills. We used a foodbank but you can only use them a set number of times. The foodbank couldn't provide for our son's dietary needs either.

Thanks to the kindness of some very special people – who were strangers – we were helped to get a bungalow with adaptations in the private sector. But the letting agent and landlord wanted twice the normal deposit and bond because we are reliant on social security. But we're only on benefits because of my disability and problems. No one seems to care about the casual discrimination.

But it's with thanks I can never express that the person helped us with this. The council had nothing and were stuck. I don't really blame them because their hands were tied too. This is at the hands of the government.

There are not many adapted homes on the private market, but most that come on are very expensive. We found one that could have been suitable, but it was 3 times the rent of what it would be otherwise.

Rents are so expensive even in cheaper areas. The local housing allowance does not cover even the normal rents, so even after getting discretionary housing payments, other money you get supposed to buy food and pay bills goes towards the shortfall. There's nothing to cut back on and the money you get just doesn't come close to what is needed.

We have a motability car and we had to sleep in that at one point. It was very painful and cold. I was very ill for weeks afterwards. I nearly lost that too when I was moved to PIP. Next worry on that is the replacement next year. Need a lot of money to get one I can use and get in and out of.

I use the NHS a lot, most weeks. But one clinic I used to go to was closed because of cuts. Staff told patients, so we all knew. Another clinic that I need, I'm supposed to be seen every 2-3 weeks but I now have to wait 6-8 weeks between appointments, which leaves me in pain I need not be in. Again, cuts, staff told us, they've restructured and cut jobs. Fewer jobs means fewer appointments and less cover, so there's more cancellations on their side and then that creates a backlog. It's a mess compared to what it was 10 years ago. I had weekly appointments back then.

The cuts have affected all the clinics I use. One of them, I now have to travel across the country to a hospital because the clinics were axed due to cuts near us. It's hard for me to travel, and I'm now waiting about 8-10 months between appointments, when it used to be a few weeks.

I need a second wheelchair for outdoor use. I cannot get this on the NHS because it's limited what you can get, and it's different from region to region. Because of my needs I need a custom one and these cost thousands and thousands of pounds. There's other things I need that I can't get on the NHS too. I'm living with all these extra problems and all these extra worries and pain just because of money and cuts. It's okay if you've got money, you can just buy these things.

We have so many extra expenses because of my disability and health problems. They come to just over £550 a month. I know that it's a lot more for some people with disabilities, but £550 is hefty still. This is after taking into account PIP, which falls way short of the help people need.

Since 2011, there's been cut after cut – big cuts at that too – and changes from the government that has taken from us more and more. It's left us with nothing close to being enough to live on, never mind anything else.

I've felt suicidal a few times in the past. I've been close. But pills, counselling and words only help you for so long. It's when someone makes a difference to your life that keeps you going, at least for a while.

I'm really worried about the future. Life is just bloody awful every day. You get the feeling the government want you dead. That's how we feel. You're constantly confronted with unavoidable costs you just don't have the money for. We just simply don't have enough coming in to pay what we have to pay out. It's an endless debt cycle that we can't get out of without help.

Darren B