

Stories of Our Lives

Case studies from the Chronic Illness Inclusion Project's emancipatory research on benefits and work

A RESEARCH PAPER FROM THE CENTRE FOR WELFARE REFORM

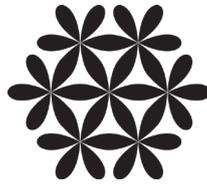
Catherine Hale (Editor)

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CHRONIC ILLNESS
INCLUSION PROJECT



**NATIONAL
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Introduction

“...one of the main social security problems today is the number of people whose incapacity is based on feeling ill (and therefore limited in their activities), claiming the sick role[...] often in the absence of commensurate disease or impairment.

...Most of these symptoms are part of everyday life and experience.

...They are 'common health problems' in that they are similar in nature and sometimes even in degree to those experienced by most (working) people.

...Common health problems are insufficient to explain long-term incapacity: - many of these people do not have any absolute physical or mental incapacity for most ordinary activities and most jobs in modern society.”

Waddell G & Aylward M (2005) The Scientific and Conceptual Basis of Incapacity Benefits.

The Scientific and Conceptual Basis of Incapacity Benefits promoted a narrative about chronic illness and disability which underpinned Employment Support Allowance, the Work Capability Assessment, Personal Independence Payments and most UK social policy on disability.

According to this so-called biopsychosocial model, fatigue and pain are common health problems that form part of everyday life. Those who claim incapacity for work are choosing to adopt the sick role as a lifestyle choice and shirking their responsibilities, according to this widely accepted narrative.

The people with chronic illness who took part in our research told a very different story. They speak of an impairment experience that is categorically and radically different from everyday aches and pains and tiredness. ‘Life altering’, ‘debilitating’ and ‘catastrophic’ were some of the terms they used to describe their impairment experience. Everyday life involves the careful rationing of scarce energy resources to an extent that society fails to comprehend.

The term we have evolved through collective deliberation to describe this is “energy impairment”. The case studies presented here are of people with severe or moderate levels of energy impairment explaining how and why the world of work as it is currently structured is beyond their reach.

There is broad agreement among civil society and the UN that welfare reform policies based on Waddell and Aylward's model of chronic illness have not only failed in their objectives of including more disabled people in the labour market, but have caused widespread harm and despair.

It is time policy makers listened to us. These accounts provide not only insight into the dramatic impact that chronic illness can have on our lives, but also the seeds of policy solutions for any government committed to

improving the life chances of disabled people with chronic illness.

In Autumn 2018, the Chronic Illness Inclusion Project held an extended online focus group with 20 participants on the subject of social security and work. Our focus throughout the project has been on our lived experience of chronic illness, as opposed to the official narratives that shape social policies and programmes.

One of the issues we discussed was the impact of energy limitation, or energy impairment, on work capability, and how employment fits, or doesn't fit, with our day to day strategies for energy management. Together, we developed the idea that our daily lives consist of various domains of activity: self-care, health management, domestic and financial management, parenting or caring duties, social and leisure activities, and employment, education or training. Despite our different medical conditions and diagnoses, we all agreed that living with chronic illness entails making tough choices, from hour to hour, about how to spend our very limited energy across these various domains, in order to meet our material needs for survival and our human needs for social connectedness and a sense of purpose.

Melissa, Bill, Fiona, Karen and Ann are the pseudonyms of 5 of our focus group participants. Here they share their experiences of how they allocate their limited energy, how the social security system and employment structures fail to deal with limited energy, and their vision for a society that better enables them to flourish, whether through more inclusive forms of employment, or through a social security system that supports their strategies of self-care and wellbeing.

Figure 1 shows how limited their overall energy levels are, as a percentage of the energy available to a 'healthy' or non-disabled person, and how it is distributed across the domains of daily living.

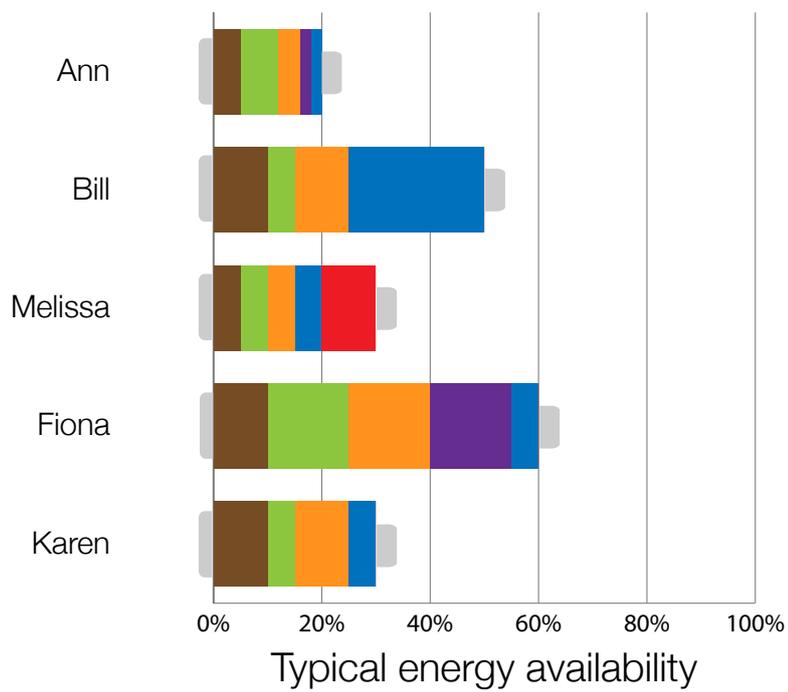


Figure 1. Use of available energy across the five case studies

Case Study I: Melissa

AGE 38. MATHS AND COMPUTER SCIENCE GRADUATE. PART TIME SYSTEM'S DESIGNER FOR AN ENGINEERING COMPANY. PREVIOUSLY AWAY FROM LABOUR MARKET FOR 20 YEARS DUE TO SEVERE ME, FIBROMYALGIA AND DEPRESSION. MODERATE ENERGY IMPAIRMENT.

I have dramatically limited stamina and capacity compared to a normal person. I currently work, 5 hours a week, from home. It's a huge struggle to manage that much while also taking effective care of myself so my health doesn't degenerate.

I need to rest frequently. On a good day I can do four 25 minute blocks of work as long as I rest for at least 30-60 minutes between each block. If I try to work continuously for longer than 25 minutes, my concentration and focus degrade to the point where I'm not doing anything productive.

I've been ill since my teens and I've spent a huge amount of my life bed bound, house bound and generally isolated. The only things I do are my job and a small blog that I do when I can. I socialise with my friends perhaps once every few months in person and online as much as I can.

The more I've recovered and tried to interact with society, the more walls I run into that are there because government and society don't understand chronic illness. So many of those walls seem to be there just because no one ever thought about us.

Work

I don't think someone becomes a practical candidate for work until they actually have "free time" above and beyond basic self care and health maintenance work. For instance, generally speaking, socialising isn't as important as personal care, but I know that I try and ignore my need for socialisation for too long, the need overwhelms everything else, depression kicks in and personal care becomes impossible.

I'm thinking of getting Maslow's hierarchy of needs tattooed on my person. I want to work where I can. I'm learning a lot about myself, my capabilities, how to deal with people, gaining skills and confidence. It's helping my mental health. It's not making my M.E. less severe.

I don't think I'd be able to work in an office environment any time soon. I really need to be able to go lie down to rest several times a day. I need to be able to control the temperature of my environment (fans, heat pads, etc) and other environmental factors (noise, light) which means I'm limited to working from home for the foreseeable future.

Travelling is a stubbornly enormous energy expenditure so it's incredibly difficult for me to go anywhere away from home, be functional in that location, and then get myself home again safely.

I have to view work as something that I do in the free time I have left over after my main job which is keeping myself as healthy and functional as possible. I have a lot of commitments: things that I need to do to, things I need to avoid, appointments I need to go to, to stay healthy. All those things are required to get me to a point where work is possible.

Work is only possible because my job was carved out especially for a chronically ill person, I don't think I'd be able to work for someone else otherwise. I've been given fairly independent control to do some low priority work renovating the intranet system for a company so there are no hard deadlines to meet and very little pressure. My colleagues are understanding about arranging meetings around my needs.

Benefits

The benefits system imposes ridiculous financial costs for attempting work outside of some really unrealistic criteria. It would be easier and more financially secure for me if I were to not try and work for instance.

My experience of the ESA and PIP assessment processes are that they're luck based. When I was at my most well, I scored 8 points on the PIP form, then after the huge relapse triggered by being declared fit for work when I was totally housebound and often bed bound again, I scored 0 points on the PIP form. So much seems to be based on what assessor you get and whether they're competent or honest or know anything about your condition. That makes reassessment terrifying.

There's no income security. I don't trust the system to honestly assess the level of help I need because the criteria are so ignorant and impractical and because the assessment process is completely unreliable.

The lack of income security means I don't make long term plans or decisions. I also know that if my income drops, my health suffers. The activities I do to stay healthy cost money and there's a very noticeable link between my income level and my health.

I live in fear that I'll be re-assessed and the government will decide that I don't meet their criteria and then my life and health will fall apart again.

I know that at the worst point of my relapse I was in danger because I couldn't take care of myself at all and there was no one to do it for me. That fear and general lack of safety is a drain on my already limited energy. I think that if I felt safe from being thrown into destitution and extreme illness at the whim of someone who doesn't understand my illness at all, I might be able to do more.

The freedom to work, research, study, without being scared that the government will punish me financially, would make a really huge difference. I'd love to do post graduate studies. I think that it would be one of the better ways I could contribute and achieve independence.

But I can't because I don't have the money to pay for them and I can't work enough hours to qualify for a scholarship.

I'd love to see things like remote attendance for events become more normalised. 'Safe space' rest areas in public buildings would make a huge difference.

Case Study 2: Bill

AGE 57. WORKED IN THE BANKING SECTOR UNTIL 2009. AWARDED EARLY RETIREMENT ON MEDICAL GROUNDS. INELIGIBLE FOR ESA. RHEUMATOID ARTHRITIS, OSTEOARTHRITIS, ANXIETY DISORDER, OCD. MODERATE ENERGY IMPAIRMENT.

When I was 12, I was diagnosed with juvenile rheumatoid arthritis. Now aged 57 I have many deformities caused by the disease. I have pain all the time. I am fatigued all of the time. I suffer depression and quite severe anxiety and elements of OCD. My symptoms are highly erratic and they make it impossible for me to work anymore as, even on a very good day, I can never be sure if I will last a day. The fatigue caused by working would make it impossible to work the next day.

Fatigue is so terrible and it can hit you at any time, even if you haven't done anything.

I just live my life as much to the full as possible, but I am different. I am slow. I am inconsistent. My pain and weakness and fatigue varies from minute to minute, day by day, week by week, year by year. Even my wife finds it impossible to understand or keep track of my fluctuations.

I worked for 30 years through my illness. I no longer feel the need to work for somebody else to justify my existence.

I am a member of an arthritis charity and help them as much as possible. I am trying to help those who may feel that not working for someone else means you are 'of no use to society'.

Work

What is work? Getting up, gardening, personal care, living and getting necessities done, helping others? It seems that 'work' means work for someone else and paying tax. Well we can't do that because we can't commit to doing anything by someone else's timescale or needs.

'Work' means being watched to make sure you are performing well. Being expected to work as quickly as others. Being worried about being sacked for 'underperforming'.

We don't fit 'normal' life. We cannot fit with 9-5 on the same days every week. We are the wrong shapes for the wrong employment holes. This is not

our fault, it is the fault of a system that only works for some.

Until society can accept certain conditions as they are, employment will continue to be problematic for a lot of us. None of us does ‘nothing’.

My ideal job is living my life to best extent, within my own means and in my own house. I have a job already that is more difficult than any other job: getting through the day. It should be understood that we have very tiring and painful and stressful existence already, as chronic illness fighters.

I get up nearly every day. I leave the house. I can drive. I can walk (huge differences in how far each day, randomly). I can use a pen. I can move about. I can wash to a point. I don’t smell. I keep fairly clean. I participate in things verbally. I am well educated. I can sing in a band. I have friends. I am involved politically.

However I am extremely challenged by pain, by fatigue, by exhaustion, by my disability, by deformity, by the side effects of my medication.

Can you see how ridiculous it is to decide that a chronically ill person who does not work is lazy and does ‘nothing’? We should start by showing how much it really takes to just survive.

But apparently, doing something when you are able means you should be working. Like, if you are crossing a road somewhere, you should be at work.

We have to hide ourselves away, even when we are having a good day, or moment, or couple of hours.

Assessments

Nobody can become a part of this benefits system without a great degree of stress and uncertainty about the future. We are made mentally and physically worse off.

We need to find a way to make those who don’t have chronic pain and fatigue accept the true extent of our battery charge. Shame there is no measure of fatigue and pain test that you clip to your arm for a month and it measures our mess.

We hear in our own heads, the ‘20 metres’ and the ‘wash our own backs’ from the PIP and ESA questions. This is not how our conditions work. They cannot be defined by a specifically exact limitation. We are not robot invalids or something that can be measured like that.

We have to change the test and rewrite it ourselves to make it fairer. I would say WE name any job we could do and exactly how and what tools would be needed and do we need to work from home. It could be something like we are paid for what we do as we go along and we get bonus payments in our benefit if we do such and such work.

If I could be paid above usual benefits for whatever extra I could do, that

would maybe work out ok. Like, for instance, a telephone job to do a survey or other such work, as and when possible.

If you have a disability that is recognised it must be accepted that you require a certain amount of money to help you achieve a certain standard of life.

Case Study 3: Ann

AGE 63. TAUGHT ENGLISH AND MATHS IN SECONDARY EDUCATION UNTIL 2009. ESA SUPPORT GROUP SINCE 2010. CHRONIC OBSTRUCTIVE PULMONARY DISEASE. SEVERE ENERGY IMPAIRMENT.

I manage to paint for a few hours a week but only when there are no other demands on my time (doctors, hospital, family and so on).

I have turned my living room into an artist studio so that when I'm able, I paint etc. I wouldn't be able to travel to a studio - even if I could afford it - so this is my solution.

I take part in art groups, workshops and exhibitions. These are becoming less frequent though. Tiredness and fatigue are the major factors in this - I just cannot, cannot, face the mountainous climb to shower and dress.

I find myself slipping away with the self-care now. I'm no longer as clean as I was.

My house is becoming dirtier by the year. I couldn't invite anyone in now, it's too embarrassing. I have a carer but not for enough hours, she does what she can.

I refuse to feel guilty for my lack of work. I started work at fifteen years of age. I brought my kids up alone - and worked - and put myself through night classes, university, became a teacher. I've done more work than most in my lifetime and it's that work that has put me in the situation I'm now in.

In the end there was NOTHING else. I had to have someone in to do everything at home. It was the most dismal and fearful life. Trying to maintain a normal facade at work whilst collapsing in a heap at home.

I worked through an OFSTED with pneumonia because I couldn't let people down. It was stupid.

Energy Resource Management

It is often said that COPD stands for Can Only Plan Daily and that is absolutely true. I have got to the stage now of not booking anything in advance. This morning I've had to cancel a hospital appointment. My sleep pattern is so erratic and energy levels so depleted that I can't predict how long I will stay awake.

If I were working, just the acts of a) washing, b) dressing, c) driving to work and d) getting from the carpark to the desk would be more than I could accomplish in a day so there would be no energy left for work. I wish it were different.

The medical profession should take fatigue more seriously. They make no effort to explore the tiredness I feel or to try to help with it. They just say it's part of the condition.

My day is reduced to four hours now. That's all the time I have, the other twenty hours are spent 'asleep or knackered'

Once tiredness starts, I can't do basic tasks such as counting (money), making decisions, etc. I won't drive at all because my driving becomes erratic. I make bad decisions, I'm blunt, clumsy. My spatial awareness is affected. I can't find words, particularly nouns and can't string a complete sentence together.

Sometimes I want something so much that I will force myself over the hurdles, just to take part, knowing I will pay the price later. I'm not sure just how dangerous it is, putting pressure on my heart like that.

The trouble is, when people see me doing this, they don't see the massive struggle I've had nor the consequences afterwards. I know people have said, 'Well, she can walk, I've seen her!' My legs work perfectly fine - It's my lungs that don't work.

Being on benefits

I often post on social media, pictures of my dog out on her walks with the caption that I 'took her to today'... Then it came to me that people thought I was saying I walked her along those long lanes or stretches of beach. How can they possibly think that, unless they think I am faking my condition and lying? The truth is, I drive eleven miles to pick up my son and then on to a place for Lexi to run. I sit in the car and watch them on the beach, etc and then drive the eleven miles home again.

A regular fear I have is when I post pictures of my paintings online, the thought that someone might be judging them in terms of sales value and report me to DWP. I don't sell them. I'm not well enough to go down that road.

Employment

I probably would have lasted in work a whole lot longer had I had support. Someone to just carry my pupils' books from my car to classroom would have made an enormous difference. My classroom was at the very far end of the school so you can imagine the effect that has on someone with limited lung capacity.

I was a GOOD teacher. With some help with the peripheral physical aspects I could have continued teaching for a lot longer.

Aspirations

I would like to stop having to worry about bills and money. Disabled people certainly need more money for things related to their conditions.

More things could be online - guided tours round art galleries, workshops (art in my case), university lectures - education at any level! They could all take place via a camera. Political meetings should be interactive.

What on earth people did before the internet, I dread to think. The problem is affording these things - £60 a month for line, wifi and mobile rental is a lot.

I could go to a lot more places if I had help of an escort. I pay £53 a month for bedroom tax. So between that and my internet, I have used up more than half of my DLA.

Something that was good for my health evolved in a social group held in my local library. The librarian had previously been a social worker. He made coffee and provided biscuits for people - it became the busiest library I have ever seen.

People would come to me for advice, writing letters, drawing, schoolwork... they in turn would sit for me to sketch them. Someone else carried out family history research. There was thriving local history knowledge. I couldn't begin to list the good that this group did for themselves and each other.

Case Study 4: Fiona

AGE 45. PARENT AND CARER. UNIVERSITY GRADUATE. EHLERS-DANLOS SYNDROME (HYPERMOBILITY). INELIGIBLE FOR ESA. MODERATE ENERGY IMPAIRMENT.

As far as most doctors are concerned, my condition is a minor inconvenience causing just achy joints. Unfortunately, that is a very common outcome for my condition. I was very lucky to get even a diagnosis.

Fatigue and brain fog make mental functioning difficult and limit the amount I can do in a day. I have nothing spare for work after doing what I need to do to take care of myself and my family. Brain fog means I don't have the cognitive abilities I used to.

Physical limitations due to pain and joint problems make specific physical tasks difficult- eg standing for a period of time, sitting at a desk for more than an hour or two, lifting things, repetitive movements.

I also have IBS which can flare up any time making it difficult to leave the house and requiring me to dash to the toilet with very little warning multiple times per day.

Life has been very stressful and insecure the last few years due to not knowing when we will be put into Universal Credit. Under in-work conditionality I could be forced to work as our income is under the minimum income floor. Currently I officially work 8 hrs a month, but it's PAing for my disabled sister so it's not the same as working for someone else.

Assessments

Working isn't just: "Can you do this task right now, or can you do this work today?". The cumulative impact and overall effect on someone's life should be taken into account.

I think it should take into account other commitments and responsibilities people have. For example, I have children at home and a disabled family member I care for several hours per week. Those responsibilities can't be dropped so instead I can do paid work.

The workload of managing our conditions needs to be taken into account. At the moment seems like it's the opposite. For example, me doing 4 sessions of exercise a week shows I am "capable". In fact, that exercise is essential so

I can retain my mobility, and it drains me and greatly reduces what else I can manage each day. But without it I'd just go back to a lower capacity and greater levels of pain and physical disability.

Also, more consideration needs to be given to the cumulative effects of work. Sure, I can sit here and think and write this for half an hour. But could I do it for another half an hour, and another. Then could I do it 5 days a week? Reliably? The answer, unsurprisingly, is no.

Also, level of suffering and difficulty should be considered- quality of life should matter too!

Work

I've been out of work pretty much since 1995! I'd like to work a few hours a week from home doing some kind of simple computer tasks.

If I could improve my computer skills that would increase my employability. But then I could barely manage a 6 week, once a week evening class last year so training is not really going to make a difference for me.

If I had no other responsibilities and lived alone in a small flat I could probably manage to work part time.

My mental health would benefit from me being able to earn an income, but my physical health would quickly be wrecked and I'd have to give it up and be back where I was 6 years ago when I left my little school job.

What I could do would be affected by brain fog specifically. A lot of flexibility would definitely be a big help.

I'd need to work a limited amount of hours per day and per week and preferably be able to take breaks lying down as that helps when I get really tired and my head gets extra foggy and spaced out.

I often wonder, who on earth is supposed to want to employ me?! They could pay someone to do my housework etc so I could work, but I'd rather just do my own housework!

My nightmare scenario would be to work, then come home and have to lie down in a stupor and not be present as a mum for my children.

Or having to give up important health maintenance tasks like physio/ exercise. If I traded that for work, I'd go downhill and be back to doing neither.

None of that could help me. The idea that work can help heal a chronic, incurable medical condition is absurd.

Belonging

I have almost zero life beyond my home life. I don't have any friends, in terms of meeting people solely for social purposes.

Most of my energy for doing things outside the home is used up by my weekly visits to take my sister out (she's disabled and can't go out alone). A few times a year I get to meet ups which relate to my spiritual path. That's very important for me and brings me a lot of joy when I can get there.

In addition, things I'd like to take part in usually cost money and even a few £ a month is a struggle for me.

For me, one major way I am still able to contribute to society (I hope) is in how I am raising my children. I may not be able to "get out there and do stuff" but my children can, and they are very motivated to do so. Watching them become active politically and in other ways in society is a great source of joy for me.

Security

I have little choice at the moment but to be in a relationship with someone who will pay to feed and clothe me and give me a home to live in, with the extent of my freedoms depending on the extent of his agreement. That's not a situation that makes me feel good about my life and my personhood, regardless of what I would choose if I had independence.

Loss of control and choice in my own life due to being dependent on someone else is something I find very painful.

It would make a difference if I had some money coming in with my name on it, legitimising my contribution to the household.

In terms of having freedom and choices, the biggest thing would be just to know I can get the support that I'd need if I were to become a single parent.

It's scary knowing I'd be unlikely to even get ESA. It's a very vulnerable position to be in to depend on someone else for everything, especially when children are involved.

Case Study 5: Karen

AGE 61. WORKED AS A SENIOR MANAGER IN NHS UNTIL 2012. GRAVES' DISEASE, THYROID EYE DISEASE, CHRONIC FATIGUE, ANXIETY AND DEPRESSION. ESA WRAG SINCE 2012, THEN SUPPORT GROUP SINCE 2015. SEVERE TO MODERATE ENERGY IMPAIRMENT.

I was a senior manager in the NHS and have also worked as an Advocate for disadvantaged people. I loved my work and now I'm no longer able to work I feel I have no place in society...

I have an autoimmune disease called Graves which causes an overactive thyroid. I went undiagnosed for 3 years and told it was "just" anxiety and depression. My initial symptoms were very severe. I am now on anti-thyroid medication and although a lot better than I was I am still unable to function as a 'normal' person.

I will have a run of a few weeks of feeling 'better' but still have chronic fatigue, brain fog etc, then I will get up one morning and feel very ill physically and unable to function at all. This is because of an increase/decrease of specific hormones in my body.

I now have zero confidence in anything I do and no longer have the physical or emotional strength to work in a regular job. It's not me who is unreliable, it's my health.

I've had terrible experiences at the hands of the DWP when I've applied for benefits. The health services are not much better. I've had to become my own advocate because the one thing I'm sure of is that I wouldn't be here now if I'd just agreed with what they said with regards to treatment etc.

Work

I think a lot of companies could offer something to people who struggle for whatever reason with the normal 9-5 routine.

I do have periods where I could do something if help was given with regards to home help but there are periods where I can't do anything at all. A lot of the time it takes all my energy to shower and dress. Some days I can do a little housework and cooking. If I'm completely honest, after working for nearly 40 years before becoming sick, I would rather use my limited energy to do something nice for myself.

I have looked for things outside of work and do attend a mental health peer support group meeting once a week.

I've come to realise that it's okay to be selfish. I've done a lot for others in the past to the detriment of my own health (and purse). Where are those people now? They are nowhere to be seen.

When I was well, I used to think that work was a means to an end i.e. you earn money to buy the lifestyle you want, but when I became chronically ill and became quite isolated, I realised it was about much more than that. For me, work was about status (in a way) and my place in the world and my sense of belonging and wellbeing as a useful member of society. I do believe work is beneficial to most people's health but is detrimental to someone's physical health if they don't have the physical strength or stamina to do a job.

I believe that most chronically ill people do want to work, as I do. But I think we would all feel better about ourselves if it was universally accepted that we cannot work so should have other services available like clubs and social things so that we can be included in society.

The government and employers are a long, long way away from understanding what chronic illness does to a person. For a lot of chronically sick people, even with all sorts of help and adaptations they still wouldn't be able to work.

Isolation

Most of my friends and family have fallen away now and I rarely hear from them. This really upsets me, but I understand that people are busy... I don't make plans anymore as I've had to cancel so many in the past and it upsets me to let people down.

I feel that I no longer participate in society as a whole, mostly my participation is online as I don't leave the house very often. I don't feel very loved anymore and that makes me feel incredibly sad. I feel invisible and pushed to one side and that my views and membership of society are no longer valid or wanted.

I would love to have friends and family who really understood what my illness has taken away from me. The biggest improvement for me would be that there were places to go where I could be included in society and not judged as not valuable because of my limitations and that I could have friends that would include me.

I would like to do something to feel useful to society as all my former positions revolved around helping people in NHS and advocacy charities. I'm often better in the evening so could maybe do something phone or online based.

On the odd occasion I do feel like trying to go out and do something I live in fear that if I'm seen to be 'having a life' then they will declare me fit for work and my benefits will stop. I don't think about the future as it is too overwhelming and just makes me feel more anxious.

Benefits

You have to jump through so many hoops it makes you want to crawl away and die in a dark hole. I don't receive enough in benefits to live and if it wasn't for my partner I'd probably be living under a bridge in a cardboard box.

I think on reflection that most of my mental distress now comes from the uncertainty of the benefits system as I have no control over the outcome of any assessments. I had to wait 14 months for a PIP Tribunal which I won but because my award was only for 2 years it means I will be reassessed very soon. I've just sent back my ESA reassessment form so I'm worrying about that now. I fear for the future because I don't know what will happen to me.

ABOUT THE EDITOR

Catherine Hale is lead researcher and project manager on the *Chronic Illness Inclusion Project* and has worked as a policy researcher with Mind, Action for M.E., the Spartacus Network and Inclusion London. She has a keen interest in researching service users' experiences of government policies as a tool for campaigning for change.

Catherine was previously involved in running a local peer support group for people with M.E. All her work to date has convinced her that people with certain forms of chronic illness are among the most excluded and overlooked groups in society. This is how the *Chronic Illness Inclusion Project* came about.

To find out more about the *Chronic Illness Inclusion Project* visit: www.inclusionproject.org.uk

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You may also be interested in:

Reclaiming 'Chronic Illness'

In this paper Catherine Hale argues that, 'chronic illness' is a self-ascribed identity which implies both a distinctive form of impairment (in our case, bodily malfunction) and a shared experience of disability or disablism (social oppression).

This paper is available to read [here](#).

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The Centre for Welfare Reform is an independent research and development network. Its aim is to transform the current welfare state so that it supports citizenship, family and community. It works by developing and sharing social innovations and influencing government and society to achieve necessary reforms.

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