

# Petitions Committee: The cost of living and financial support for disabled people

## Introduction

To inform the petition debate in Parliament on Monday 22 May 2023, the Petitions Committee ran an online survey asking respondents about their experiences of financial support for disabled people and the increase in the cost of living. The survey was available in both British Sign Language and Easy Read format.

The survey was shared with relevant organisations, including relevant [UK Parliament Partners](#) and promoted in the [UK Parliament Newsletter](#). The survey was also shared with signatories of the following e-petitions which triggered this debate.

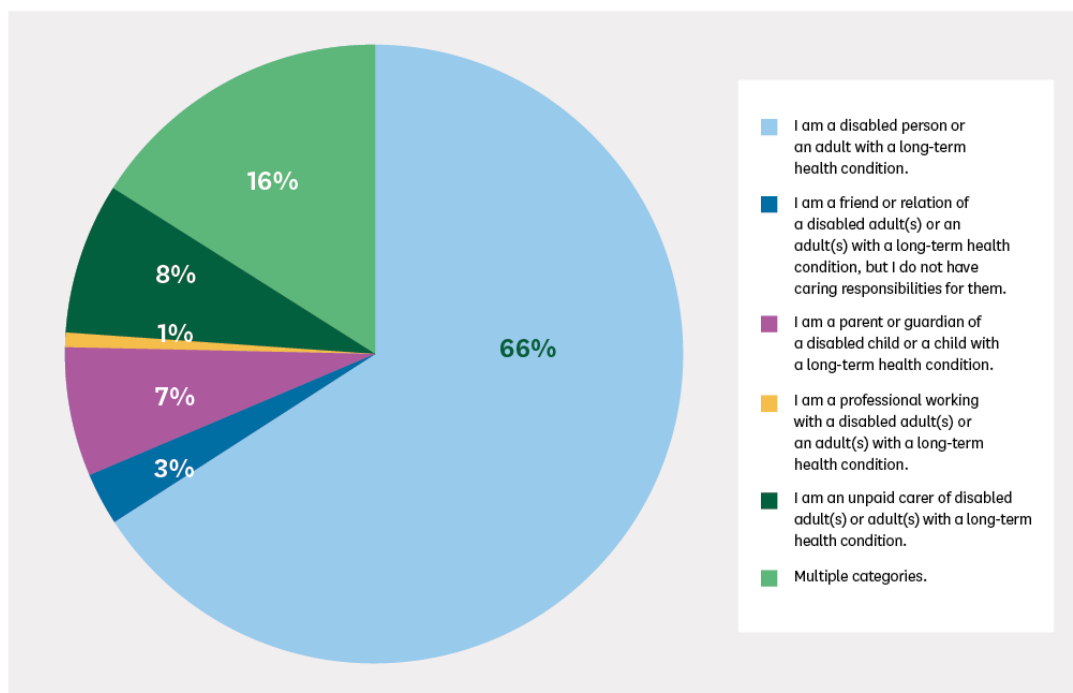
- e-petition [617425](#), 'Make people on disability benefits eligible for the £650 one off payment', closed December 2022.
- e-petition [610300](#), 'Provide an energy grant to people with a disability or serious medical condition', closed September 2022.

The contents of this brief are to be read as reflective only of the experiences of those who responded to the survey.

## Response

**10,854** survey responses.

**Table 1: Who responded to our survey?**



## About the respondents

The majority of people who responded to the survey said that they were a disabled person or had a long-term health condition.

In May 2022 the Government announced one-off cost of living payments for people getting certain benefits. These included a £650 payment in two instalments to recipients of certain means-tested benefits, and a £150 payment for those getting non-means tested disability benefits.

**36%** of respondents said that they or the disabled person they care for or know received the £650 Cost of Living Payment

**30%** said that they only received the £150 Disability Cost of Living Payment.

In addition, respondents said that they or the disabled person they care for or know received the following benefits:

- **82%** Personal Independence Payments (PIP), Disability Living Allowance, Attendance Allowance, Adult of Child Disability Payment (in Scotland), Armed Forces Independence Payment, or War Pension Mobility Supplement
- **30%** Housing benefit
- **26%** Income-related Employment and Support Allowance, Income Allowance
- **26%** Universal Credit
- **18%** Carers Allowance
- **15%** State Pension
- **11%** Contributory Employment and Support Allowance
- **8%** Child Tax Credit and/or Working Tax Credit
- **2%** Income-based Jobseeker's Allowance, or Pension Credit

## Overall tone

The general tone of text responses was negative. Many spoke about how they felt that disabled people had been "ignored"—that the additional expenses they face have never been reflected in financial support. They felt that this had been a particular issue during the covid pandemic and the current increase in the cost of living. Anger and frustration was expressed towards the Government and society in general for "leaving them behind", "ignoring them", and "abandoning them". Some described feelings of despair, saying that they were worried whether they could "survive much longer". Some said that they had considered suicide.

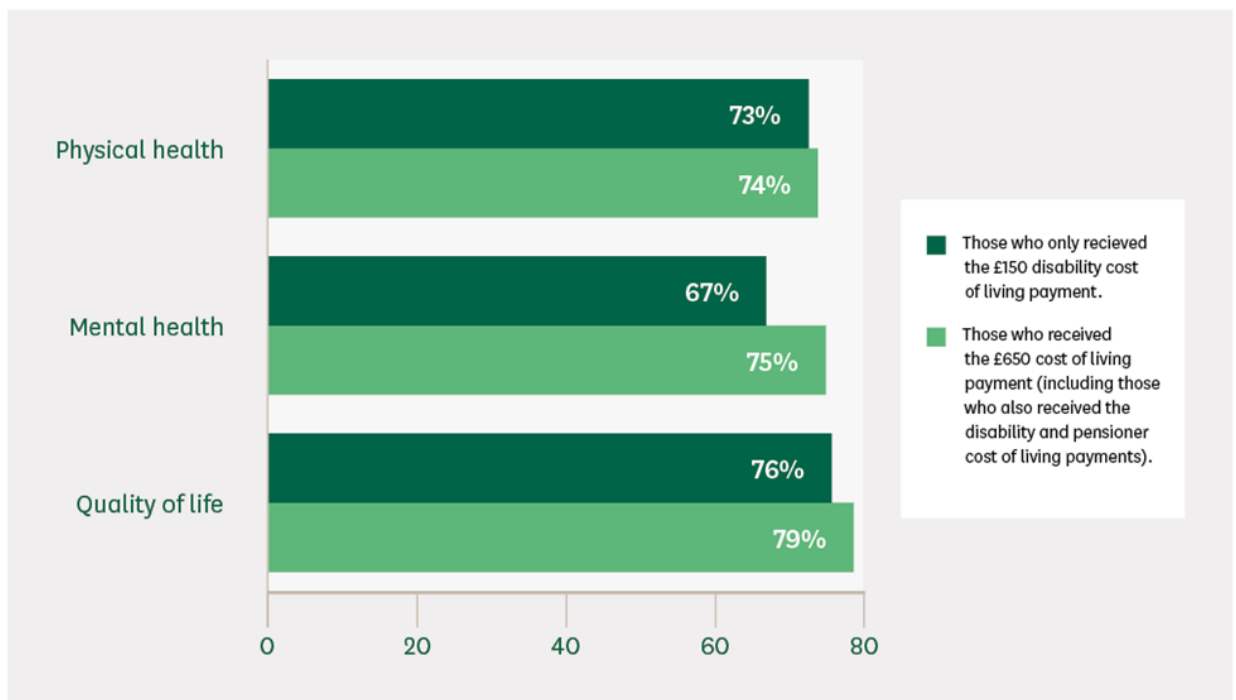
## Statistics

Most respondents said that they were “extremely concerned” about the impact of the increase in the cost of living on their physical and mental health and quality of life, or that of the disabled person they know or care for.

- **97%** of respondents were concerned about the impact on physical health. **72%** were “extremely concerned”.
- **94%** were concerned about the impact on mental health. **69%** were “extremely concerned”.
- **97%** were concerned about the impact on quality of life. **77%** were “extremely concerned”.

There was little difference in the level of concern expressed by those who had received the full £650 cost of living payment and those who hadn't.

**Table 2: Proportion of respondents who expressed ‘extreme’ concern about the impact of the cost of living, by cost of living payment received**



## Quotes

"I'm freezing, I'm hungry and I don't receive the amount of care I need to live a dignified equitable life. A shower is a treat for me now; that's the stage I have got to. I have to spend about an hour in the shower as it takes me a long time to wash (even with support) so I have had to limit the amount of showers I have. I used to shower every other day, now its every 10 days on average. I'm smelly, I'm so cold, my pain levels have increased due to the cold so my mobility has reduced and I am stuck in doors, in bed to try to stay warm. I am isolated as I can't afford to leave the house to meet friends or do social things like go to the cinema. [...] I am now in debt for the first time in my life. I always used to be able to just about live on my benefits but even then I had to be very careful on where my money went and I hardly had the money to do something fun with friends. Now I sit in a dark cold flat that is mouldy due to the condensation. My life is hard. I survived childhood cancer to become a disabled adult. I had so many hopes for my life but now each day I regret not dying of cancer. My life is not dignified."

"The price of everything has increased by far more than disability benefits cover. Most of us live from hand to mouth and don't have excess income to save. Lockdown depleted what little emergency funds we had on food deliveries and the increased cost of food—the government food parcels didn't support special diets. The cost of living crisis has hit us very hard as the illnesses suffered are exacerbated by not being able to get timely treatment and not being able to afford the special dietary requirements. Also not being able to keep warm enough seriously affects my husband's COPD [chronic obstructive pulmonary disease] also chemotherapy aftereffects and my autoimmune conditions including Raynauds. I now have injuries to deal with because the circulation problems caused have impaired my mobility and caused falls. Things were bad enough before, sadly now we feel that there's no quality of life."

"Due to ill-health, age, and disability, I spend all my time at home. So it is more important to heat my home adequately. But that's not possible on my state pension. So I've stayed in bed much more, to keep warm. I sleep fully clothed to keep warm. When I am in my lounge, I have 3 blankets around me, folded double, to keep warm but that has restricted my movement around the home and I've been unable to do my hospital physiotherapy exercises. I've noticed my physical health has deteriorated. It's too cold to take off clothes to get washed. My mental health has been affected, partly because I've not had money to go out anywhere so I am alone at home. My asthma is worse. I've had to change the food I buy and cut out fruit and veg because I can't afford them now. [...] Life has gone from tolerable to just existing. My food bill has gone up hugely despite me choosing cheap things. And my energy bill is about a third of my state pension. I don't know what to do to make ends meet. It's worrying and has affected my mental health. In April the energy bills will rise even further, it's worrying because I have no more I could cut out, to pay the extra. I've applied 3 times for Pension Credit and been refused because my weekly income is £9 too much. [...] I'm just existing and it's endless & miserable."

"I have cut back so much there is nothing left to cut back on. I cannot afford care to help me, my daughter helps with no pay which is completely unfair; I have to either eat or heat my home. I cannot afford to buy items for my home or clothes and no socialising and no holidays, I do not drink or smoke. I'm existing I stay at home as I cannot afford to do anything. I so wish I was well enough to go to work. I loved and so miss my job [...] but I have 9 physical health conditions/disabilities and I'm unable to work. I did not choose to live like this. It affects my mental health the frustration of being unable to work when you loved your job and living in such conditions on such a low income compared to the cost of living is so high. I just exist and the loneliness that comes with this it's very hard. Unable to afford travel to see my family [...] Hospital appointments and therapy have been hard to juggle with paying for fuel. I worry very much if I will be able to afford to live past April 2023 as everything is due to go up again. It's so frightening and this is definitely impacting my health."

"I have had to cut down on my oxygen use due to the cost of electricity to use it; my breathing is affected from breathing in cold air but I can't afford the heating on. I have a number of debilitating conditions which require me to be warm and require warm air. I have an electric throw which keeps the body warm but that doesn't warm the air. The cold also increases my pain which is not controlled as pain meds don't work fully. I am unable to regulate my body temperature. I am over £800 in arrears due to not being able to afford what energy I use which is only going to keep rising. This is affecting my mental health [...] It is disgusting that we are having to suffer and be in poverty like this. [...]. The vulnerable and low-income families deserve a standard of living that does not involve having to choose to eat or heat."

"I became disabled with constant chronic lower back pain and neuropathy caused by my physically demanding work as a nurse, helping to care for the sick people in this country. During my work as a district nurse I witnessed older, sick and disabled people freezing and starving in their homes because of low income. I never dreamed that my reward for helping them would be to end up living in the same poverty."

## Cutting back on essentials

The majority of respondents said that they, or the disabled person they know or care for, have had to cut back on things that are essential for their health and wellbeing.

### Statistics

- **93%** have had to limit their use of energy (such as heating or hot water)
- **76%** have had to limit their use of transport
- **70%** have had to limit access to medical appointments
- **60%** have had to limit the use of specialist equipment (for example home oxygen, dialysis machine, electric wheelchairs, hoists, or sensory equipment)
- **60%** have had to limit their use of personal care products (for example incontinence pads, dressings, specialist toiletries or cleaning products)
- **59%** said that they or the people that they care for or know have had to limit access to mental health support
- **53%** have had to limit specialist food needed for dietary requirements
- **51%** have had to limit access to medication
- **44%** have had to limit access to therapies (such as speech and language, physiotherapy, or hydrotherapy)
- **44%** have had to limit access to specialist clothes and/or shoes
- **43%** have had to limit access to carers

### Quotes

“I’m disabled and a powered wheelchair user, with 7 long-term medical conditions, all of which have been worsening due to the cost of living crisis. I cannot afford to run my central heating for more than 2 hours per day, I cannot afford to fully use my many disabled aids, and I cannot afford to stick to my medically advised diet—2 gastro-enteric conditions—due to ever-rising food costs. The government payments are only a drop in the energy ocean, as I am having to find £300 per month to pay my energy bills. Thankfully, in Scotland we receive free prescriptions, or I could not afford the 21 medications I have to take. Without independent transport, I cannot afford to go anywhere, and the only times I have left my home in the past 3 years are for outpatient appointments, for which I have to use Patient Transport. If I make it alive through this winter I shall count myself fortunate.”

“I have had to reduce how much I use my electric wheelchair—it is the only way I can access my home and the outside world so I rarely get to go out now. This has caused profound loneliness and very poor mental health. I also have an electric bed and I have to ration using it which has had a bad effect on my physical health. The same goes for other electric medical devices I own. We can’t even adequately heat

our home and this has also had a really [bad] effect on both physical and mental health, especially my pain and breathing difficulties have deteriorated. I also have to follow a special diet for my health conditions and buy a lot of medication that the NHS no longer covers (e.g. vitamins, food, joint braces, medication recommended by NHS specialists that the NHS won't cover – it totals well over £150 per month) – I can't afford it all so I simply don't have the things I need anymore, again leading to worse health for me. I cannot work due to severe illness and disability; my benefits barely make a dent in the increased costs we face. My wife has a well-paid job and still we can't afford these basic things. We are suffering greatly.”

“Have cut back on heating, electric use, food, washing and even bum shuffling upstairs rather than using my stairlift and eating half a meal or snack per day and heating on 16 degrees. I'm living alone isolated from community; can't afford support or transport to other venues or go for other help. I pay privately for few hours' cleaning a week and am so reliant on other tasks being done by them but want a personal support worker to enable me to get fresh air and not be housebound every day to enable my independence. I feel suffocated with claustrophobia [...] I have less life than any group I can think of. I can't afford clothes, basic medical required essentials, haircut, hygiene products, carpets, home basics, most food shopping and paying higher for food delivery doesn't give me the choice of shopping around without the health to go where I need in the community.”

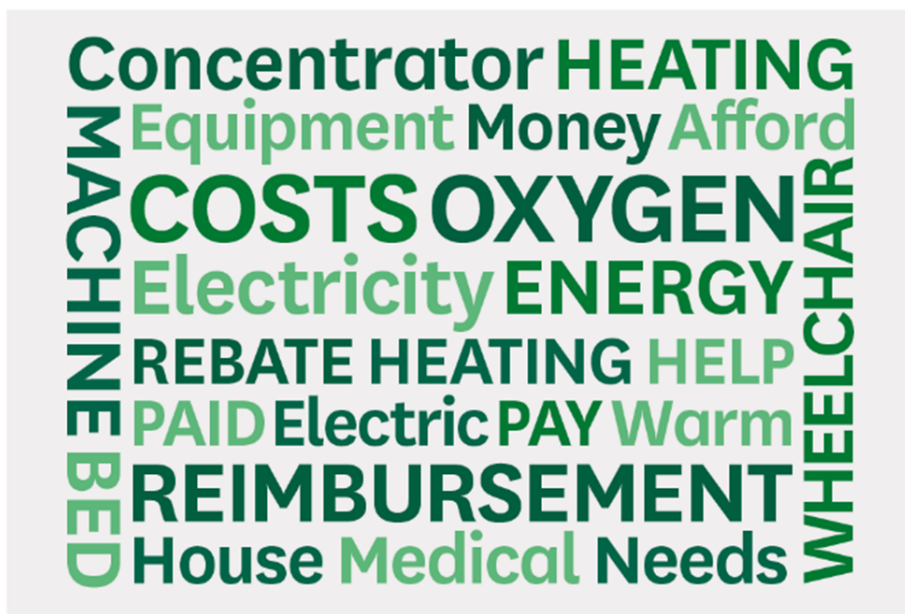
“We only get the figures others get too, nothing to compensate for equipment needed because we are disabled. We've reduced down to just the most important essentials such as the bath seat, our rise and recline chairs we sleep in too, landline phone and pc for ordering food and contact advice and the security cameras/lights because we cannot move around quickly and the area has had break ins. [...] Everything else has been side-lined, including mobile phones, tablet, kindle, mobility scooters, heat pads etc and cut down to one shower a week the rest is strip washes, filling a flask with hot water to save the kettle, one electric heater is not on now at all and we just heat the bathroom with small fan heater when personal care is happening, wash loads cut down on because we cannot hang clothes out they have to be in the drier. As we no longer sleep in bed that's cut a couple of loads out completely. I'm dreading needing oxygen at home, needing a profiling bed or anything more for mobility needs.”

## Specialist equipment

Many respondents spoke about the specialist equipment that they had to run at home. A small number of respondents received reimbursements for home oxygen concentrators, but not for other equipment. Some of those who did receive reimbursements said that it was not sufficient, or that because this was paid in arrears it was still challenging to afford to use this equipment. Many said that they were limiting the use of their specialist equipment due to energy costs.

## Statistics

- **48%** said that they, or the disabled person they care for or know, have extra energy costs due to the use of specialist equipment
- **4%** said that they received some reimbursement for the energy costs of running specialist equipment at home
- **3%** said that they have had to go into hospital or care because they cannot afford to run specialist equipment at home
- **9%** said that they were thinking about going into hospital or care because of the cost of running specialist equipment at home





## Quotes

"We receive reimbursement towards the electricity costs for my son's oxygen concentrator machine, but do not receive any reimbursement for the electricity cost for his pulse oximeter which monitors his oxygen levels in his blood and his heart rate, for his feed pump, which delivers fluids and nourishment to his body, for his profiling bed which means he can lay as comfortably as possible which his body requires as he is quadriplegic, and his ceiling track hoist, which is the only way we can move our son in and out of his wheelchair and his bed. All of these things are vitally important for his daily life."

"For baby Airvo and oxygen (both electric) we receive £50 every quarter of a year. It does not help much—our electricity is 400 a month at the moment before the next increase. Why is a child's breathing equipment not covered as a prescription?"

"The disabled people I support receive a rebate for their home oxygen usage, however this is given 6 monthly based on meter readings from their equipment, which means they can end up in debt before they receive this. Patients have also reported that the amount they receive does not match the costs of using their oxygen. Two separate patients on prepayment meters have told me their electricity has cut out because they can't afford to top up the meter since starting oxygen - this could be life threatening as the oxygen delivery stops, especially if during the night when they are asleep. One patient has stopped using their stair lift as they can't afford the running costs and they are not reimbursed for this."

"The way things happen with [the company] who supply the oxygen is that I pay it for 3 months and they reimburse me 3 months later. This is paid to me in arrears. I understand why its paid in arrears but when you start paying £10 a day you worry if you'll have enough money to get you to your next pay day. Then there was an increase on the electric and now my oxygen got increased I worry even more. I can't live without the oxygen but I still need to pay bills and eat and it's getting to the stage where the oxygen stays on and I'll have a snack instead of a full meal. [...] my weight goes up and down [...] so I'll turn the oxygen generator off and use the outdoor cylinders just so I can try and save enough money to buy a larger size in clothes. I worry constantly and most days I'm usually crying."

## Heating

In addition to specialist medical equipment, a large number of respondents spoke about the importance of heating for their health. Many described medical conditions that were exacerbated by the cold. For example, they needed heating to help control their pain, help with their breathing, or regulate their body temperature. Some also spoke about needing to pay for air conditioning and fans in the summer for the similar reasons. Others spoke about how their mobility issues meant they were less able to create body heat through movement and so were more reliant on heating, which increased bills.

## Quotes

"My son has cold urticaria he is allergic to the cold he has EPI pens and I have had to use them this winter as I can't afford the heating on all the time or I can't afford special clothing for him. I feel like a failed mother."

"I have had to cut down on my oxygen use due to the cost of electricity to use it, my breathing is affected from breathing in cold air but I can't afford the heating on. I have a number of debilitating conditions which require me to be warm and require warm air. I have an electric throw which keeps the body warm but that doesn't warm the air. The cold also increases my pain [...]. I am unable to regulate my body temperature. I am over £800 in arrears due to not being able to afford what energy I use which is only going to keep rising. This is affecting my mental health [...] due to the worry of being in debt and not being able to afford to heat my home adequately and having to skip on meals and my oxygen use which is severely detrimental to my health."

"Being a disabled person with limited mobility I feel cold even with heating on. So there is no way I can reduce the temperature. Also, I am home all day and night so must run the heating 24hrs. As a consequence my heating bills are huge and PIP alone is insufficient to cover the extra cost."

"It's not just the winter that is expensive. It's the summer too. Too cold cannot move. Too hot cannot breathe. Keeping the balance costs not just heat in the winter but AC in the summer. The extra money helped. But it barely scratched the bill."

## Mental health

Many respondents spoke about feelings of isolation as a result of having to make cutbacks. Many also spoke about the impact of the increased cost of living on their mental health, due to money worries. Some described having suicidal thoughts.

## Quotes

"The inadequate financial support from PIP and the impact of the cost of living crisis means I have cut back in multiple areas including personal hygiene/ laundry, paid-for medical care (NHS and private), specialist food that would help improve my condition (as advised by specialists), and heating at home which helps alleviate various pain and breathing symptoms. I am unable to socialise as I used to due to costs and my worsened condition arising from cutbacks I've been forced to make. This leaves me more isolated and vulnerable and worsens my mental health further."

"I have never had my energy usage lowered because of my dependence of use of gas and electricity even though I'm on the health register with my energy suppliers and in a lot of debt due to my usage of my oxygen and other electrical medical appliances that I rely on an everyday basis. I'm in so much debt with my gas and electric [...] we didn't ask to be disabled and I hope we are going to get some real help from the government. As it stands right now not just for myself but for every disabled person we need help and support in these harsh times"

"I am having to pay more from money set aside for other bills meaning I'm going into debt [...]. I'm bipolar, and suffer from two types of PTSD. I need help. Desperately. I have no one to help no family. Because of my disabilities and no finance I'm not able to go into sociable situations. My already dark mental health is going to get worse."

"I currently receive around £500pm due to having £126pm taken as payment for my mobility wheelchair. This reduced payment and the so called 'cost of living crisis', has meant that after I have paid bills, bought food and personal hygiene products, I am left with nothing within 24 hours of receiving my 'benefits'. I cannot cope with this. My mental health is at an all time low, with no access to support. My physical health has worsened due to pain and stress. [...] My incontinence is awful and not having the ability to keep my clothes clean, is absolutely debilitating. My husband is not a well man either so I am having to do everything, in a great deal of pain and low mental health. I honestly don't know if I want to carry on, but I fight every day [...] I haven't been out for a meal, to the cinema or had any type of social interaction for years, everything I do is for my family."

## Carers

Respondents felt that carers had been “forgotten” in the cost of living payments. Many spoke about not being able to work, or being unable to work additional hours to increase their income, due to their caring responsibilities.

## Quotes

“As a couple with no ability to increase our income, my husband is on PIP and I receive Carers Allowance, it’s extremely concerning. We received £150 from government. I don’t work as I provide full-time care for my husband with motor neurone disease. It’s a drop in the ocean as all of our costs are rising. Our fuel, our food bills, our council tax has just gone up. Everything is increasing and being disabled adds to these costs and whilst the government recognises that disabled people have higher costs they don’t take into account the carers of those living in disabled households. I can’t work extra hours or get a better paid job as my unpaid job of supporting my husband 24/7 is what I do. So our only option is to cut back on everything else. Things that keep us happy and socialised - the odd coffee out with a piece of cake is an absolute luxury. There are specialist foods we have to get for my husband which cost more. We can’t cut back on these. He’s recently lost 1/2 stone due to covid, so we need to buy more calorie dense foods again to supplement drinks we are prescribed. This costs. If you have a muscle wasting disease, you feel the cold. You can’t have your home cold. If we put another layer on it doesn’t work for us, the house has to be warm or he is unable to function, to move, to walk, to use his hands (even with gloves on indoors) so you see £150 for our family is a drop in the ocean. And it makes you more vulnerable than you should be. More vulnerable mentally, physically and socially. And whilst I appreciate the cost of supporting families like mine, not supporting us means possible trips to hospital, greater costs in the long run on other services we will have to use.”

“My daughter has extremely complex medical needs and profound learning and physical disabilities. I have been unable to return to my highly paid career since she was born 32 years ago. I give her ICU nursing-level care, having higher clinical skills than the average nurse, and higher than district nurses and hospital-to-home teams. [...] My daughter is too clinically complex to receive respite and I have to accompany her 24/7 when she is in hospital. I receive reimbursement for the oxygen concentrator only. This is slightly less than the energy company charges me. I do not receive reimbursement for the hourly use of nebulisers, colomycin machine, 2 suction machines (one on charge while other in use), oximeter, electric bed, hoist and adjustable electric bath, electric wheelchair which charges overnight, HEPA filter, keeping the room warm in winter and air conditioner in summer due to very fragile respiratory conditions triggered by temperature fluctuations, sensory equipment and lighting, fridge to keep medications in, wi-fi and tv which are necessary to keep my daughter entertained when confined to her room due to illness – this is often.”

“As an unpaid carer who has to work (18 hours a week) I do not qualify for universal credit, carers allowance or any other financial support because my job pays very slightly more than the qualifying amount. I am unable to work more hours due to my caring responsibilities and my own long term health condition so I have had to try to absorb all the increases. I am at risk of losing my home as my mortgage has more than doubled, I don't use the heating in my home to avoid a bill I can't pay. Food choices which impact on my health have had to be ignored for cheaper or in many cases no other options. My physiotherapy treatments which support my own health condition have had to be cut to save money. Unpaid carers are propping up the health and social care system. There should be a FAIR reward and support for this.”

## **Government support**

Respondents said that the Government's support was not enough and did not reflect the particular costs and energy needs facing disabled people. Many said that the eligibility criteria for the Cost of Living Payments was “unfair”, with many disabled people “missing out” on extra support. Some said that they had lost their Warm Home discount, a £150 rebate on electricity bills for low-income households, which offset additional cost of living support.

## **Statistics**

- **77%** said that they did not agree that the Government's financial support for disabled people in receipt of benefits was adequate.

## **Quotes**

“Anyone claiming contributions-based ESA [Employment Support Allowance] was excluded from the larger cost of living payments. [...] Many of those receiving contributions-based ESA are so poorly due to their disability that they are unable to work despite wanting to, otherwise their health deteriorates (as confirmed by their doctors). Many of these people rely (spend money on) electrical based aids, carers, heating due to inability to regulate body temperature, more expensive food such as pre chopped or pre prepared options as they cannot prepare it themselves etc. It's not just a case of being 'hit hard' by the cost of living crisis as an abled bodied person would have been—our health is literally deteriorating, not simply our quality of life. The fact that vulnerable people have been excluded from various cost of living payments seemingly because they are not working is outright disability discrimination.”

"I have to limit the heating because of the cost. Because of that my mobility is worse, not just walking but using my hands which has a knock on to my depression and anxiety. My husband is my carer but he has to work extra shifts just so we can live, that means I have to spend more time on my own in a cold house wrapped in blankets to keep warm. I can't work due to my problems both physical and mental. Claiming PIP is a nightmare process, the money isn't enough and why should we only be allowed £150 when other groups get more? Because my husband works I can't claim any other benefits. My husband is a proud veteran and 60yrs old, we shouldn't have to constantly worry about money and what food we can afford this week. I thought food and heating were basic human rights [...]."

"I used to get the 150 warm home discount for the last 4 years but this year was told i was not eligible due to living in a new build even though it's a disabled flat with electric doors, windows emergency buttons etc which all cost more and using more electricity than a normal flat and now I'm not eligible!"

"I received only the help given to every household – which I am truly grateful for. But, the same Government decided to cut my usual winter help through Warm Home Discount of £140 for reasons unknown to myself. So I am worse off this year due to the decisions of the Government. Still disabled, in the same house, living alone on the same benefits, but now slightly worse off as my body aged and I developed further health problems, and I am now substantially worse off financially as my heating costs in winter amounted to over 30% of my income."

"I and my disabled friends all used to get the Warm Home Discount, which offset some of the costs of charging chairs and using equipment but most of us became ineligible when the rules were changed for the most recent year."

## **Have you been affected by this issue?**

Information about help and support with:

Your mental health: <https://www.nhs.uk/nhs-services/mental-health-services/where-to-get-urgent-help-for-mental-health/>

Day-to-day living because of illness or disability: <https://www.nhs.uk/conditions/social-care-and-support-guide/>

Benefits you can claim if you're sick or disabled: <https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/benefits-for-people-who-are-sick-or-disabled/>

Government support to help with the cost of living: <https://www.gov.uk/cost-of-living>

Other support organisations: <https://www.gov.uk/cost-of-living/finding-things-difficult>

## **Methodology**

NVivo Pro 12 (a data analysis software) was used to identify and contextualise the most common words and phrases in responses to open questions in the survey. This allowed us to group and summarise recurring themes which were threaded throughout much of the responses.

In addition to this analysis of the data, Committee staff manually reviewed hundreds of individual comments and answers, using both subject searches and randomised selection.