Pressure points:

Experiences of the cost-of-living on disabled people and carers in Sussex

All survey comments

Are you affected by the cost-of-living?

112 comments

1. West Sussex County Council has not increased our care budgets since 2016 despite two increases in the national minimum wage and rising inflation. They have told us that it is our responsibility to make up the difference, and make sure we have the money in our accounts to pay for the extra costs and the extra we would have to pay for holiday pay because of the higher wages. And YET, since 2020 WSCC has increased the contribution we have to pay towards being able to receive care to 100% of our "disposable income". This means that the disabled have absolutely nothing left for the costs of disability any more. I only receive benefits and WSCC takes all of my PIP and a large chunk of my ESA for my care. I am left the very basics to live on. They have refused almost all Disability Related Expenditure DESPITE doctors letters confirming their necessity for maintenance of my illness. WSCC reasoning is that it should be prescribed (why would a dr be writing about something they can prescribe??) or its a 'lifestyle choice', despite NICE guidelines clearly specifying that these specific DRE ARE necessary, and this documentation being provided. I have no buffer for increased care costs, increased cost of living, for anything going wrong at home, my disability needs etc. When they increased care costs to 100% of income, they will not allow for any debt that you are repaying - so there is also no longer any way to pay any debt that you budgeted before - leaving you in a vicious cycle of arrears; making the most vulnerable have no choice but to get into a increasing spiral of debt if they are to receive the care that they desperately need. It is now basically a choice between care and living…. Do you have someone to wash you and prepare meals, or do you get your food and stay warm? The only income I have is from benefits. I did have savings but now I have absolutely none after the last 3 years.
2. Expensese of commodities increasing day by day and no solid job
3. Through fund of purchasing basic needs
4. Poor decision making by Local Authority and District Council about a variety of things that has been at the detriment of our household allegedly.
5. Not able to do so many things outside the home to entertain the person I care for. Petrol,bus fares,cafe prices all gone up tremendously and I have less money now for these things yet it is so important for my family members mental health that he gets out and about regularly. If we stay in, we cannot have the heating on much as the prices have increased so much for energy. Also, without the stimulation of going out and about as much, my family member becomes more isolated from social experiences which he needs to have, we all do, but because he is autistic he needs interactions on his level so he can keep up his limited communication else he will lose it. It is also very difficult for me if we can't go out somewhere as the day is more challenging and yet we can n9 longer afford to do simple things like go out for a coffee as often as we used to.
6. I care for my sick dad so I'm literally stuck up in the condition as well.
7. Can't afford to put heating on.
8. Everything has gone up. Gas, electric, rent, food, public transport to het to hospital appointments. Meaning difficulties in choosing priorities. I often eat less then the children and prioritise their appointments and needs
9. I am struggling with our, food costs and gas and electricity bills
10. Having to use my heating a lot less and being very careful with regards to food purchases.
11. Bills, groceries and rent cost are exhorbitant
12. Struggle to pay fuel bills and food
13. Shopping, bills,life is changing
14. Having to cut back on heating is the biggest impact but also my son has a very restrictive and expensive diet and he can no longer have all the food he loves.
15. Prices have gone up, my children are older so no longer eligible for tax credits and child benefit. My disabled son has been refused benefits several times, meaning a big loss of household income.
16. I had to stop work after my stroke, so money is lower but still need to pay for ever increasing bills/ food

17. struggling each month once rent is paid and bill left with £60 to do food shopping. worrying about bills constantly. worrying about my child's needs constantly. needing to borrow money but then struggles to pay back. unable to put heating on at home.
18. Cost of bills has increased. We are having to sell house to meet costs of supporting our daughter who has adhd.
19. I feel very scared and the fear is always there. I read articles in newspapers about how the government wants to reduce my benefits, and this is scary. I have had to cut back on some of my luxuries and just focus on affording the basics.
20. Unable to access as many private therapy providers, worried about paying bills, meal planning to the last penny.
21. I hardly meet up with my daily needs
22. My autistic child only eats specific food, so when food costs go up we can't switch to cheaper alternatives. I've had to reduce my hours at work to care for my child and it's only thanks to help from family that we've been okay.
23. Since benefits cut .have had to on a food bank . Not ideal as I have dietary issues.
24. Increase in my monthly bills to a huge extent
25. Unable to work due to caring duties, yet the cost of everything has massively increased. When you are home all day caring you are using more gas and electric too. My child has lights on 24/7 too due to their needs.
26. Finding everything so expensive. Husband DLL at care home, now in Princess Royal hospital recovering from surgery for fractured hip. I no longer have a car and finding visiting him difficult because 2 buses , which run in frequently and I have mobility issues. Physio bringing me a rollator in half an hour so hoping that helps. There is also the possibility that my husband may need rehab so I'm hoping he is not discharged to the Kleinwort where he spent 3 months last year as that's more difficult still to access. I live in Hove.
27. All costs have gone up - disabled /autistic son's favourite branded foods needing to be swapped for cheaper options which he's not happy with. Outings with PA for community engagement also have rising costs for transport, food, and where applicable ticket prices.
28. My husband is self-employed. We have a severely disabled son who is on a ventilator and is fully Mobility dependent. we have an excellent care package in place but when our son is very unwell my husband needs to take time off work. We also have a 4 year old daughter. As soon as he has just a few days off, our finances are affected Dramatically and then the cost of living becomes an issue for us . when our son was in hospital in June my husband was off work for a large period of time. At that point Our son was given a maximum of 2years to live. My husband needed to deal with this news but had to go back to work. family members had to help us out financially. there was a point where there was not enough money to pay for food and cover the cost of our bills. My weekly food shop has gone from £100 a week to £200 We do not receive help with energy prices even though our sons life relies on electricity, every plug socket in our house is being used. We are financially stable at present but that could change for us at any time.
29. Over drawn each month. Not putting on the heating Buying less food Saying no to invitations out with friends Trying to cut back on non essentials
30. Can't afford to keep the heating on as much as we need to really - particularly for my severely disabled daughter. We can't afford to go out very often as a family as it is too expensive.
31. price of everything - supporting a young person with a LD
32. I have limited mobility and rely on my car to get around, so I am impacted by the increase in petrol costs and maintenance of my vehicle. I feel the cold more than other people and it makes my chronic pain worse, but I can't wear extra clothes as it restricts my mobility too much, so I have to have the heating on more than I can afford to. I shop online with Tesco because I can't get around a physical store, and as well as all the prices going up and the product sizes going down, the minimum basket cost has gone up from £40 to £50 so I'm having to spend more than I want to and getting far less for my money. My autistic children have restricted eating, meaning that for some products I have to buy the branded items as they won't eat the supermarket own, or supermarket version doesn't exist, eg Hula Hoops (I'm aware that Aldi do an own version, but they don't offer online grocery delivery and I can't physically go to their store).
33. Energy, petrol and food. We are pensioners with an adult disabled son. Our house needs to be kept warm, our son has a restricted diet and he has to be driven to activities. Given his needs these are across west and into East Sussex but vital for his wellbeing and support.

34. All household bills are much more than they used to be, so now there is less money for fun and activities with the kids.
35. Unable to afford to put the electric heater on. Rented accommodation has no central heating, only night storage heaters which do not work. I get a lot more pain in my joints from feeling so cold.
36. I work full-time but I may have to give this up. I can't afford to heat my home and this is severely affecting two separate physical health disabilities, which is impacting on my ability to work. This is also affecting my mental health problems. I can't afford much food. I can't afford to take my car anywhere, which I need to get about, because I can't afford to run it, which means I'm not able to do anything socially. I can drive to work, drive home, and that's all I can afford. Public transport is so unreliable that I can't use it to get to work. I am having to space out and delay hospital appointments so I can ensure there will be enough money to put petrol in the car to be able to attend. I'm so tired as a result of all of this. The Government keeps telling us that "working is the way out of poverty", but as a Public Sector worker the same Government also sets my wages and they are too low for a non-disabled person to live on, never mind a disabled person. I've tried searching for other jobs but employers aren't keen on hiring disabled people, even if they can do the job, because they're scared of any reasonable adjustments they may have to make now or in the future.
37. Increase in the cost of services, food, utilities etc. I receive Carers allowance but I am also disabled myself.
38. Extra cost on bills, son is incontinent so lots of washing, electric bill high. He requires extra washing to keep clean, gas bill high for hot water. Clothing more costly, often have to replace clothes
39. Seen energy bills increase especially as we now have to use more electricity as my daughter requires more machines to keep her alive & heating is on as she is at home all day with additional carers in the house.
40. I have certainly been affected by the rising cost of living. In recent months, I have noticed that the prices of everyday essentials, such as groceries, gasoline, and utilities, have increased significantly. This has made it more difficult to make ends meet and has forced me to make some tough choices about my spending.
41. Its been much more expensive to biy healthy food to maintain good blood sugar levels. Its cheaper to eat ready meals bit these are often quite carb heavy and both fruit and veg have gone up in price
42. Everything is more expensive. When caring for a disabled person who has special dietary needs, uses more electricity etc this is more pronounced we have had to cut back on a lot of things.
43. I can't work full time, or find a job that fits with my disability and other family caring responsibilities so I work self-employed but still rely on benefits. Everything is a struggle to keep the family finances ok
44. My sons 1:1 carer had to resign his job as a very effective and skilled carer to work at a large retail shop as he was not getting paid enough to get by. This has had a direct impact on my sons ability to access the curriculum and has put the rest of the school staff under huge pressure.
45. The cost of food, heating, water, diesel and clothing have all increased. This has but a massive burden on our family expenses.
46. In every aspect of daily living! Most bills have increased including rent, gas, electricity. Food costs have increased and the weekly shop is far more than it was. Fuel for the car is expensive, as are the running costs. We live rurally and here is no train station or bus running from our village. My son has epilepsy and cannot drive. I have to drive him to either the location he needs to go to, or to a train station. The trains have all been on strike, so not reliable. Public transport is also not cheap! There are additional costs incurred as a carer for my son, eg additional travel costs to go and collect prescriptions, to attend hospital appointments etc. Some appointments are in London and we usually have to spend around £100 for such a day's visit. Sometimes my son needs to stay as an inpatient, and then due to his needs, we are looking at not only travel costs, but also accommodation and food etc t support him during his stay.
47. electricity and gas prices are becoming unmanageable,food costs have shot up and there seems to be less choice I very rarely use my tumble dryer cos of the expense and instead use an airer as i dont have a garden being in a first floor flat.. The dampness affects my bronchial asthma too
48. Really struggling to balance the books at the moment, constantly having to check my cashflow to manage the standard stuff let alone any extra stuff. I'm dreading my upcoming eye test, I know I need new glasses (and have to have the tinted ones which aren't covered by NHS vouchers) and am struggling to put aside any money as a buffer for things like this. I've no reserves left, whereas for years I've comfortably managed. There's not been much for extras, admittedly, but I haven't had to consider every single purchase down to the loaf of (gluten free, so further extra costs) bread.
49. Debt, can’t afford and behind with bills, often not enough money for buying food, missing meals, going hungry days, not eating as much fruit as used to, less able to afford household and personal care products,

can’t afford to buy and give family gifts, missed sleep, stress and anxiety, exhaustion, can’t afford things that council don’t cover in tenancy to do with fencing, gardens and disposal, home wear and tear upkeep, can’t afford extras such as vitamins etc that used to buy child with medical problems that doesn’t have DLA. Can’t afford new clothes when she needs them and shoes for youngest teenage daughter, she used to get low level DLA a few years ago before it got cut, lost appeal and both suffered ever since.

50. Energy high cost. High food cost for rubbish items cold damp flat
51. Less disposable income More worry about bills Feeling less like I can heat my home at the times I would like to
52. gas and electric have gone throught the roof and food bill is increasing every month
53. I have to ration food, fuel, power, water, look for bargains everywhere. I worry constantly about spending anything. My food bill has increased a lot. I have unplugged my small 2nd fridge, shop several times a week to save wastage, almost never eat out, have been selling off items to fund having an occasional takeaway. I joined a community pantry to lessen my shopping bill
54. Our gas & electric bills are huge! Need to keep the house reasonably warm as my husband is disabled.
55. Due to the rise in prices of my essentials like food and drugs, I have really been affected because I now ration my food and drugs, and most times I don't get the complete dose of my drugs and I eat lesser than I used to so as to save some money for other amenities.
56. Prices of many everyday goods have increased
57. The price of food has gone right up - this makes things extra difficult for me as I have a special diet. Fuel has gone up, which means that when my mum, who is my carer, drives us anywhere, we have to take petrol into consideration more than we used to.   The mortgage has massively increased - from £200 to £700, and we have a big mortgage and I'm scared we will ultimately be forced to move. We're managing right now, but we won't if it goes up any more.   We have been less affected by energy price hikes, because my mum got £5000 compensation for a car accident, and put it towards solar panels in March 2022. This has massively helped our monthly outgoings, and is why we can afford the mortgage.   We use a lot of energy in particular because we have an electric oven, and also because like many people with ADHD I have delayed sleep phase disorder and am nocturnal.
58. I’m overdrawn every month (even though I work) I’m showering and washing up less. I try not to put the heating on as I work from home. I’ve not had a break away from home since before covid. I’ve changed my food shopping habits and often eat toast or cereal.
59. Food shopping on some weeks and saying yes or no to what we can do with kids at weekends
60. Increased costs all round
61. Struggling with bills
62. fuel increases, using my vehicle for work is costly rent increases, worrying me as to how to afford accommodation in the future food costs higher, i am regularly using food bank Gas/electricity price high mean i am not putting heating on until it is 12 degree or colder in the home   i worry a lot more about how i will cope financially and this has an impact on my mental wellbeing.
63. Cutting down on electric, gas, fuel for car. Not having treats eg trips out, takeaways
64. I already live hand-to mouth with little spare due to high rent costs. The cost of the basics are going up, meaning I have less disposable income to save for my future or for when bigger things happen, like if something goes wrong with the car or if I lose my job. I would like to be able to save to buy a house of my own, but this doesn't seem possible.
65. Everytging is more expensive but I just about cope with my pension and attendance allowance.
66. I can't afford many essentials and I have to go without. I was not able to turn the heating off last year, and I very much doubt I will be able to this year either. I work and can't get ahead in any way. It's grinding, distressing and extremely discouraging - it's impossible to think things will ever get better.
67. No travelling except by local bus on my old geezer bus pass. Reduced to basic and cheaper lines of food. Some vitamins That's about where my money goes anything left on essential toiletries and a rare taxi to get me to medical appointments.
68. I suffer from pain from arthritis & vascular problems mainly in my legs leaving me with limited movement & using a relator to get about the house   The gas central heating is used for 1hour early morning & late afternoon ,I go to bed with a hot water bottle at 7.30pm as that is where I am warmest & most comfortable My diet is basic but good as my generation was taught food values & how to cook it,   If only I could have a warmer house

69. Private rent Part time hours Increasing bills
70. We struggle to get through each month. If we have anything breakdown or needs repairing we would then have to not pay a bill that month.
71. Rising costs without the ability to increase income to match mean cutting back on providing the best possible lifestyle for the disabled person.
72. I'm struggling to keep up with my bills and I can't afford to use all my heating, the cost of food is rising all the time and that to is a struggle.
73. Massive increase in food prices, I can only buy essentials now, no treats Struggling to pay electric Struggling to pay council tax
74. We have far less fresh fruit and veg to eat and don’t eat as much meat as it’s very expensive now. We do not go out to eat and are unable to put the heating on at the moment. We no longer have a streaming audio or visual subscription. I do not go swimming any more.
75. Unable to buy good food, pay for gym which helps manage my disability. Not even able to cover basic bills.
76. My son has SEND. He isn't in school and hasn't been since June. This means whilst he does attend some alternative provision, he is home far more so food bills are higher as is electricity and gas due to TV/Gaming/Sensory toys. And gas because he gets cold and uses baths and showers more to regulate. Fuel has increased and as he is out of school I am driving more taking him to therapy sessions and also taking him out and about to keep him active and occupied. Food prices have increased alpt over the last year. He is restrictive with what he eats due to sensory difficulties which means I'm restricted to buying the same items no matter the cost. I am behind with gas/electric. I am behind with council tax because I am unable to work longer hours and things have increased.
77. having to cut back on heating, treats, hair cuts, replacing old or worn clothing, shoes, household goods
78. Electric and gas have gone up. The cost of every day food items have gone up, our food shop has over doubled in cost and we aren't getting any non essential items now only enough for 3 meals a person each day. I used to spend around £60 a week on food shopping for 3 of us and now our food shopping is around £120 a week. Everything has gone up and benefits do not cover essential food and bill costs anymore. I'm unable to work due to being a full time carer and home schooling so I have no option but to rely on benefits which aren't enough to cover the currently cost of living. We can't afford new clothes and live on catalogue clothing which means getting into debt and having to pay back a huge amount in interest.
79. Affordability of food and household bills
80. Everything became so expensive. Energy prices gone up.
81. Prices rise but no extra help given to carers or disabled people
82. Unable to afford basic living amenities, food, travel and been unable to spend any real time with my children in 5 years.
83. Every week basic foods go up in price. Petrol and gas and electric. Cannot possibly afford to save
84. Food costs more affecting the amount of money we have especially since I gave up work to become a carer for my wife earlier this year
85. It is the choice between eating or putting the heating on. The constant badgering from companies that expect you to be able to pay the new rates e.g electricity and gas
86. Benefits went down, rent went up. Cost of goods has increased.
87. Prices gone up by much more than my salary. I work part time because of my disability but can't get PIP. there is little help as services are being cut back and mental health is decreasing. I use a community food shop, i go out very little and haven't got anything new for my self in a long time.
88. Rising costs have increased my anxiety.
89. The cost of living has affected me greatly. I am on a fixed income and although the additional payments received from the Government have helped we definitely continue to "feel the squueze". We do not put the heating on even though my condition means I am a wheelchair user and need a comfortable living temperature. I now use a heated blanket which costs less to run to keep warm. The cost of shopping has incresed. Nearly every item that I buy has increased by at least 20p. If you add that together for a basket/trolley of shopping that is a massive increase. We try to only use the car for essential journeys and I catch the bus rather than using the car. We can no longer afford any treats or luxuries.
90. Food and bills
91. Everything has increased in price by a big percentage. the cost of energy to heat our home has become a very high percentage of our outgoings. We have made cuts to how we heat our home ie turned the

thermostat down, reduced the time the heating is on. We use our woodburner more so that we do not need to use the gas heating. Food has increased massively. We shop at Aldi as it is the cheapest supermarket. I cook from scratch. But I would make an approximate guess that our weekly food bill has increased by 20 to 30%

92. Gas and electricity and food bills
93. Fuel Bills and Food inflation through the roof. General inflation high
94. Heating and food bills have almost doubled, but we need to have the heating on for the person I care for. He is not mobile like other peers, so gets colder quicker. He has to have a shower every night as he wears pads and this obviously takes longer than an able bodied person showering.
95. Energy bills keep rising, I work part time but I my salary is to high for me to be able to claim careers allowance.
96. Since having to move onto Income Support when my son's extensive care needs and my marriage breakdown meant I could no longer work. 13 years ago. And then this chronic impact has been hugely heightened over the last 2 years especially with the rising cost of living
97. Firstly, I am answering as a disabled person and as a carer of a disabled person. The cost of my mortgage has tripled, we are not switching on the heating when we need it, and we are putting on extra jumpers, but this is causing mould as the house is cold, and the washing isn't drying. I have cut back on food shopping, and paying for costs (such as vet bills for our dog) is putting financial strain on myself, my disabled child who lives with me and the support I can give to my other son who is also disabled and at university. I work one full time job, an evening job one day a week and a saturday job, and it's still financially challenging.
98. I can barely afford to heat my home to 17c. My car insurance has almost doubled.
99. my wife and I are both disabled and care for each other and have to use our PIP for food and bills as everything is so expensive including putting heating on.
100. Having adult son at home with multiple health needs requiring additional costs. Stydent but cannot afford to live anywhere but home Tiring taxing stressful.   Living in rented accommodation we can't afford Managing utility bills when home 24/7
101. Although I work full time and earn a good salary, the cost of living crisis has had a detrimental affect on everyone but disproportionately those of us that are disabled. I am particularly concerned about the impact of rising mortgage rates when my fixed term mortgage comes to an end. Being disabled costs more money, you need more support, you require adaptations and adjustments and finding employers who can/will accommodate disabilities is incredibly hard.
102. I have a young family, so the cost of living and the prices of every day household items, shopping, food ect has had a huge impact on how we budget and plan on a monthly basis
103. Mortgage increases to double what they were
104. Spending more on everything, gas, electric, food, etc all.has gone up in price
105. Rising costs for everyday items make it difficult to budget and prioritise...... it means that I have to make decisions each month on which things I cannot afford to cover.
106. bills are up and food costs are up and so is housing costs
107. Can't afford petrol to drive to work, tuff paying bills, rent is high
108. Everything has gone up over night . Leaving me with nothing after bills paid
109. energy, food, fuel prices have limited our options and I have had to resume working to make ends meet, when I had hoped at age 68 to have more leisure time to maintain my health and wellbeing
110. The cost of gas and electric has been one of the main issues as my condition flares when i am cold. Our gas and electric bill has tripled in the last year so has caused some massive financial strain. Our rent has also increased by £250 per month in the last year as well. Shopping for food each week has increased by about £50
111. Utilities and the genal cost of everything has risen although the COL payments from the government do help. My biggest issue in Disability Related Expenses (DREs) have dramatically increased and the benefits used to cover these have not increased. On top of this other organisations and business are ignorant to the realistic daily costs for people with disabilities. For example I get free prescriptions but various items I need on a regular basis like creams to treat a skin condition, or vitamins to treat deficiencies' I still need but can no longer get on prescription and 'other people' assume that every cost is already covered by another benefit. Or they think I get both of my wheelchairs on the NHS when I don't qualify for an electric

on the NHS so have to buy it; people think it will cost about £2,000 when in reality a new chair will cost upwards of £7,000 and there's no point buying second hand unlike a car.

112. More financial outgoings than incomings. It is worrying as I don't know when this situation will change.

Please rate the impact the cost-of-living has had on your physical health, mental health and quality of life.

85 comments

1. There is the struggle of trying to make ends meet. There is the struggle of your care hours being reduced because you can't have the same amount, because the budget hasn't increased inline with the minimum wage cost of living. Due to inflation and 100% of disposable income being taken you cannot buy the food, heating and necessities you need. My illness has increased in severity as I cannot afford the DRE that are necessary. I don't have family or friends to rely on. Only my carers. They are the access I have to do anything and my hours are continually decreasing. I now have no care hours to go out, to get to appointments, or to socialise. We just had to have a meeting where I had to reduce their hours further, and we had to carefully plan each minute of their week hours to make sure I had the food prepared, medication and treatment managed, shopping done. it left 30 mins a week for either one shower or cleaning the house. Not having my DREs makes everything take longer. Since becoming seriously ill my close friends have moved away from the area or country, but I do not have the means to get out to meet new ones. I have to choose between the house being clean or me being clean, and have contracted bad allergies. I don't have a choice to go outside or have hobbies now. It takes me a lot of energy to communicate or process information, and this year WSCC has shut down my advocacy service so I do not even have the means to be heard. WSCC say they will dealing with the advocacy themselves which is a clear breach of interest and I have heard nothing since. Every appeal takes years and so much energy to get the most basic of what they are providing. It took a year to be provided the care I was assessed as needing. I have to use the care hours I so badly need to fight for my rights, or just get a reply from the service that provides them. They have lost my files and document evidence multiple times, and closed my cases without informing me on more than one occasion. This repeatedly drains the care hours I desparately need.
2. Less or no money to use
3. It affects positively
4. It wears you down which is unnecessary.
5. I cannot see friends etc so much as cannot afford to go out as much. Hearing what other people are still doing and enjoying negatively impacts my mental health as I would like to do simple things like go to the cinema once in a while but my first thought is always, always, how much will that cost, can I afford it? I belong to a gym run by the council so I get a carers discount but I am cancelling it as £38 pm is too much, I have to just go for walks instead which is a shame as I enjoyed it, as going to the gym I feel safe and it helps my mental health positively and 8t helped me to lose weight, i am overweight
6. We struggle to go by the day. We can barely afford proper health care and decent meals.
7. Constantly monitoring electricity use, putting me on edge. Living in cold and damp affecting breathing
8. We can't afford to do treats such as going out for a few hours or having a weekend away. We don't have a garden to play in neither.
9. I have to rethink our daily meals that can be extended for the next day or think of batch cooking and freezing. We only put our heating on for a hour a day. Now I only use our microwave and airfrier to cook. We switch all our appliances off when we are not using them. We use our washing machine after 8pm to help with our electricity bill. We shower for under 5 minutes. My older son only uses his car for the basic reasons like work. Sometimes my children will eat and I would eat toast or leftovers.
10. I tend to have increased blood pressure
11. Often cold which affects arthritis and breathing constant stress regarding payment of bills
12. With my mental health everything is a struggle
13. Can no longer afford to go to the gym which has impacted on my mental health and quality of life
14. I am having to fight the DWP to get my son benefits. As I am autistic myself I find this hard so keep putting it off, meaning we have less money and can't afford food, bills and activities for my son. He may have to leave college if I can't sort it, so this is affecting my mental health greatly.

15. literary work and stay home, Don't make plans as cant afford to. Work is the only time I spend with others anymore, as we are all struggling. I used to go to the gym but no longer I cant afford to so this has impacted me as I'm no longer active and just sit at a desk most of my time. Mentally struggling a lot.
16. The fear never goes away. I have always been anxious and it feel like things are going to get worse.
17. Worries about money have added to my stress levels which were already high as a carer.
18. Have issues getting motivated and mental health is worsening .causing a knok on affect on my physical health
19. Have had 3 falls in the last year and 2 Hip Replacement's. Constant worry about increased bills has made me distracted and nit noticing where I walk in the flat and outside. Hence the falls. When I can't get up without help. Sometimes have had to wait hours for best cone and help me.made me terrified of falling again.
20. Being unable to afford to do anything, as money has to go on essential bills, does impact. Being unable to get out, even for such things as a walk, can also impact.
21. My health is deteriorating despite the rise in living costs!
22. We are lucky that daily living routines and diet mostly ok - but monthly outings (2-3 / month) will be cut back from now as the financial / personal contributions have finally been assessed 10 months late and benefits income is now going to be less by approx £50 due to needing to make contributions and service debt accrued by not having this done earlier in the year. A hope to do a once a year longer trip / short break just with my son also now uncertain as we wait to see what funds are left by summer.
23. When we are doing okay financially we are able to afford healthy food and to pay for activities for our children. We are trying to complete a bucket list with our son but have had to raise money in order to complete the activities on it.
24. Doing less activities with my children Trying to make food last longer, shopping around for better prizes House is colder as only putting on heating in the evening
25. Worry about money all the time and can't afford to do very much.
26. worries about how our daughter will cope when she has to manage independently.
27. I am more worried about money, I am going out less, I am not able to afford the usual things I use for self-care for my mental health and I am in pain because I am cold.
28. Petrol costs have been a big concern. We haven't wanted to get out as much as everything is so expensive. Then the heating costs of staying in. We have to prioritise a warm house. It's the future that is concerning as we don't see much hope of things improving. Also the constant criticism of disabled people and pensioners it's very demoralising.
29. Lack of opportunity to do much, heating is a considerable problem for me. My mental health can get quite low, when #i'm trying to prioritise where money goes.
30. I can't afford to heat my home, despite having a full-time job. My asthma is triggered by breathing very cold (or very hot) air, which means I am having much more frequent asthma attacks. I also have Reynaud's syndrome and I can't feel my hands and feet during the winter at home, because I can't afford to put the heating on, which means I have been experiencing more injuries as I can't feel what my hands or feet are doing. I am slowly losing sensation in several fingers and this was made worse last winter when I couldn't warm them up at all, and I'm dreading this winter.
31. Caring is expensive and has negatively affected my income and health. The constant fight for services and being treated as an inconvenience. I live on my occupational pensions and carers allowance. I have some meals at a pay as you can Junk Food project.
32. Struggle to cover essentials, nothing left for leisure activities
33. The rising cost of living has had a significant impact on my physical and mental health, as well as my overall quality of life. Physical health: The stress of financial hardship has taken a toll on my physical health. I have been experiencing more headaches, muscle tension, and fatigue. I have also been less motivated to exercise and eat healthy, which has led to weight gain and other health problems. Mental health: The rising cost of living has caused me a great deal of anxiety and depression. I worry constantly about money and my ability to make ends meet. I also feel guilty about not being able to provide more for my family. This stress has made it difficult to concentrate and sleep, and it has worsened my mood. Quality of life: The rising cost of living has made it difficult to enjoy life. I have had to cut back on activities that I enjoy, such as going out to eat and seeing friends. I also feel like I am constantly on edge, waiting for the next bill to come in. This has made it difficult to relax and enjoy the present moment.
34. I can no longer afford to do the little things that I enjoyed

35. My wife is dislexic and our eldest son has a severe learning disability plus we have an 8 year old. Everything falls to me to organise and look after the family finances. It's very very stressful!
36. An increase to the cost of all essentials has meant that we have had to pick and choose which come as a priority over others. Such as not having regular baths, decommissioning the hot tub which we used to help our daughters movement disorders. Less travel as we cannot afford to keep filling up our WAV which uses a lot of diesel, meaning less outings for the children.
37. As I have already mentioned, I feel the cost of living is having an impact on all areas of my life as a carer. It is also having an impact on my son who is disabled.
38. i do have mental health diffieculties anyway so trying to make decisions on what i can and cant do financially is really hard
39. I've given up on some daily activities as I couldn't justify the cost, including inclusive exercise that I was doing to try to build up some strength. I've reduced my private health costs, like physio and specialist movement help. It's really stressful worrying whether I can afford heating now we're in the colder months, I'm mentally dreading my bills each month. And being at a bad temperature effects my physical health too.
40. We've all suffered with mental health needing help from Gp and well-being, medication, two of us felt suicidal feelings at different times, too much stress, can't afford to go into town or travel or socialise sometimes etc
41. Cold and worried about the constant battle of keeping up with bills . As we are not on pension credit or universal credit. We pay our own rent and rates .
42. Thankfully physical health has not changed, but the increased anxiety about spending and the decreased ability to spend on 'treats' makes life feel less happy.
43. I worry about money usage, and have to justify every spend. I can't join clubs, go out to eat regularly, go to the seaside or on holiday as I fear for the future. My family members live an hour's drive away so I see them rarely. I used to give them fuel money to help them, or drive to see them, but am now unable to do it most of the time. This has led to a feeling of isolation
44. Regarding my mental health I have really been affected by the cost of living because I now work more only to be paid lesser than expected and with income that cannot solve my needs
45. We have had to make some changes to our daily lives to try to save energy and money, but it has not really negatively impacted me because it's something I would like to do anyway and I think being frugal and energy efficient is a good thing. However, I know it is only getting worse, and this makes me really concerned that ultimately we will not be able to afford our house, or food, especially my special diet.
46. I can't afford to go out and only go shopping with a friend once a week. Fuel costs also impact this. I have a PA once a week and apparently I'm lucky to have this agreed. I can't afford the adaptions I need on my house and sleep/work in the same chair.
47. My Mum is worrying about how she will afford the cost of care
48. Having to think twice about putting the heating on, and having to be very careful about my energy consumption
49. I can no longer afford a gym membership, am eating less fruit & veg and socialising less.
50. I have to rely on cheaper, processed food to eat. I am missing full food groups because I can't afford them. I am miserable because I feel trapped and lacking options to get ahead. I have to be so careful using as little electricity as I can, and also not turning the heating on when it's cold, it's absolutely miserable and all the work feels pointless. I can't afford to do any fun things and feel burned out.
51. I suffered a stroke in March, The blood thinning drug I'm now on mean I have to take great care not to cut or graze myself as the bleeding is hard and slow to stop. It has left me suffering badly from the cold. I have since had a heart scan and been told I have a valve problem. That was some weeks ago as an urgent scan on a doctor's advice and direction. Sadly I haven't heard back from the hospital on treatment or timescale. I'm constantly cold but can't heat my house to make it warm enough and afford the bill and food. I get a reduced pension because I missed stamp payments at times when I was caring for one or the other of my parents years ago. My total income is £110 a week Approx. My partner subsidises my expenses but can't continue after she retires soon. I applied for a share of my wife's pension after she died (we had not divorced) I sent a copy of my marriage certificate which they demanded but have heard nothing after more than a year. Stress you bet.
52. Physical health I sit with warm rugs around me as my legs shoulder &back are more painful when cold Mental health although I live with my 90 year old husband who has hearing problems he wants to sleep a lot of the day ,very little interaction there Daily activities I don't / find difficulties moving around because my joint pain is worse when cold

53. Both my husband and I are disabled we don’t go out unless we really have to.
54. Ever rising costs are a constant concern with the ability to cope being extremely limited.
55. We can no longer go on fun trips and days out, I live on my credit cards now
56. I worry about money all the time, this then causes me physical problems like headaches and fatigue I used to enjoy days out with my daughter like going to the swimming pool or cinema, I can no longer afford to do these things Every month I have to budget my income to the penny, it’s rare now days that I can afford anything as ‘treat’ despite working and claiming UC
57. Things are worse for us as a couple of years ago, I could go swimming, take taxis and do more. Now my DLA is being used for bill and grocery payments, which has effected all of the above negatively.
58. Stressing about money is causing a decline in mental health. Not being able to afford food or snacks air being able to work out makes my health decline. Can afford to live to working more than I should. Body unable to recover properly after birth as I’ve had to return to work so quickly
59. I'm exhausted all the time. I am suffering with stress headaches and migraines.
60. without our age bus pass we would not be able to go out beyond the locality we struggle to keep warm and are sick of wearing so mnay bloody layers. do not like having to wear a hat in bed for instance but needs must
61. We can't afford the basis things, let alone days out and new clothes or other essential things in a families lives.
62. With my ADHD, I can only work a limited amount of hours, which does not cover everything for my daughter and me.
63. I have severe pain in my spine, legs and hands... Have had a number of mental breakdowns which have resulted in serious personal injuries due to not being able to live with basic human dignity..
64. Can't afford many taxis now to help my own mobility Have had to go without heating sometimes which my wife needs
65. My children miss out on trips, clubs and other opportunities to be social with children their age as there is always a cost to it which I cannot afford
66. I can't afford treats or to meet my friends as often - some of whom are still going out and enjoying activities.
67. My physical condition remains unaffected as such. However, the anxiety of managing financially on an every day basis is awful. We are unable to save any money to give us stability or security. Our existence really is 'hand to mouth'. We are feeling desperate about what will happen when the government support ends.
68. My husband is 66, gets a state pension and an NHS pension, but this is not enough to cover our costs so he is working part time at a charity. I also get carers allowance and a very small NHS pension, and I work very occasional shifts at the charity. We make ends meet by doing this extra work, as well as caring responsibilities.
69. I suffer chronic pain and feel the cold so I have to have the heating on for a long time. But as I can't afford the bills I don't.
70. Cannot do as much as I used too as things expensive. Need to assist my daughter, (Adult Learning Disability, living on her own) with her finance which gets tighter due to MIG not increasing with inflation.
71. Its a worry when the heating goes on, and how to cook healthy, cheaper meals
72. Activities I enjoy are sometimes difficult to afford, I asked for some money towards photography course through WSCC Carers support well being fund which they kindly gave me.
73. I wake up worrying and go to bed worrying, I feel sick and anxious when I look at my bank account. I have family bailing me out every month which is humiliating. I limit our outings as I can’t afford to keep filling the tank, and have to keep reminding my teenage children that we need to be really careful with our money when we shop. They ask me not to keep saying it as it makes them feel worried too.
74. I have an injury on my ankle (long term issue) but I can't afford to rest and not work as I will lose money and can't afford it (evening job is zero hours and Saturday job is self employed), so I have been working which has made it worse, and now I had to take some time off which caused anxiety financially. The cost of living crisis has made everything more expensive, and wage increases have not matched this so it is a challenge.
75. It’s expensive to stay home due to electricity and gas and food costs. And it’s expensive to go out. I spend a lot of time looking for coupons just to get out. Like buy one get one free on coffee so I can get out the house to a cafe.

76. My wife and I as I said are both disabled and both carers. The stress of financial struggles aggravates both our health conditions and makes life harder and makes us feel low because we have our own health struggles but adding how to afford things and enjoy life so much harder.
77. Nil social life   Can’t afford exercise classes   Worry about every bill
78. I have to be much more conscious of what I spend and am more limited in the activities that I would have previously enjoyed which improved my physical and mental health.
79. Have had to cut back on leisure activities and days out ect,
80. Worrying about where I will find the money to pay the added costs of the mortgage
81. I used to meet friends out in the community for coffee or lunch a few times a month, to support my mobility and mental health. These trips have had to take a back seat due to cost of fuel and transport, as well as unjustifiable food costs.   I have been unable to access my regular swimming (hydrotherapy) due to increased costs.
82. It is hard to enjoy life, when life is currently only about working enough to stay off the streets
83. Instead of spending my retirment doing the activities I like such as biking and hiking and a bit of volunteerinmg, I have mostly had to occupy my time working for remuneration of one kind or another. the impact on my partner has been even more severe, which has also affected me
84. I am currently refusing to put or heating o due to the cost and the fact that the only person in my house that feels the cold is me. That has affected my Ehlers Danlos syndrome and i am struggling with more dislocations every day. We no longer go on family days out at the weekend because we cannot afford to so i feel that my children are missing out on elements. I have panic disorder and general anxiety anyway so money troubles to make these worse as my brain spirals. We are having to budget each week to ensure we can afford food as well as affording travel to get to work and bills
85. I can only afford to food shop once every 2-4 weeks, rather than once a week I can rarely afford fresh ingredients so rely on frozen or donations from friends. I used to go out socially at least once a week now its once every 2-3 months, for special occasions. One of my volunteer roles I no longer get travel expenses (their budget's been cut) so instead of working 2-3 times a week I can only afford 2-3 times a month. I haven't had a holiday or been to a hair salon since Dec' 2019. since the rise in living costs my world has got a lot smaller and isolated. I check my bank balance on a daily basis rather than monthly, if at all. I used to know without checking that I could the kind of life I wanted only checking when I was about to make a large purchase. My contribution towards my care is my highest single outgoing and I don't have any choice, it used to cover 20 hours per week support plus running costs, now the same budget only pays for 7 hours a week and I have to pay the running costs, and I can't appeal because the advocacy service has had its funding cut. Not being able to get out either because I can't afford it or the friend I want to meet is working every hour just to afford their utilities let alone go out or be able to do some of the things and need to do for my mental health has left me depressed and anxious with no hope for the future.

Have you had to make any changes to your budgeting or lifestyle due to the cost-of-living? If yes, how? Have you had to go without anything, or make substitutes?

102 comments

1. 100% of my 'disposable income' from benefits is taken to pay WSCC for my care contribution - I have less than the ordinary person to deal with cost of living crisis. No buffer for increased care costs, increased cost of living, for anything going wrong at home, my disability needs etc. It is now basically a choice between care and living…. Do you have someone to wash you and prepare meals, or do you get your food and stay warm? The only income I have is from benefits. I did have savings but now I have absolutely none after the last 3 years. I have no way to pay for Disabilty related expenditures as they were refused by WSCC despite detailed Dr's letters and NICE guidelines saying it was needed. This has made life and illness a lot worse. My consultants were axed in the NHS, and the LHA has little provision to deal with my illness once it reaches this severity. I have had to forgo getting outside the house as I no longer have the care hours to do so. We have had to reduce my bathing to once a week, and alternate it with cleaning the house. I do not have the care hours or money to socialise anymore, or do my hobbies. It is is the very basics of living that is left. Since becoming seriously ill my close friends have moved away from the area or country, but I do not have the means to get out to meet new ones. I have to choose between the house being clean or me being clean. When WSCC increased care costs to 100% of income in 2020, they will not allow for any debt that you were repaying - so there is also no longer any way to pay any debt that you budgeted for before - leaving you in a vicious cycle of arrears. It has made the most vulnerable have no choice but to get into a increasing spiral of debt if they are to receive the care that they desperately need. They have also axed my advocacy service this year so I no longer have a voice. I do not have the care hours to supplement this, so my now my ability to be heard has gone as well.
2. Buying in small quantity, reducing and even cancelling some.
3. To guide me proper on how to spent
4. More so.
5. Basic evening meals like beans on toast instead 9f a proper dinner of meat, veg, potatoes. Less meat as so dear. Not putting heating on very much at all Own brand items at supermarket only. Always looking for reduced food items near sell by date. Not seeing friends as much as even meeting up for coffee is expensive. Using charity shops more. Cutting down on sending Christmas, birthday cards which I always liked to send. Going without things so my children can still have a treat now and again, like a cake.
6. Not currently but I am concerned when my contribution towards my care goes up.
7. A lot of times, we forgo meals in-between. We sacrifice a lot of comfort to afford medical care. We live in an uncomfortable home.
8. Applied for various grants and funding to ease the costs
9. I've had to miss mportant appointments because of means not being there for me or the children. I also have gone plenty a day without a meal so the children are well fed. Same with clothes.
10. I only buy food that are shop brand cheap names and from the reduced section. We can’t treat ourselves to takeaways anymore. I use my deodorant sparingly, shampoos, no hair extensions, no new makeup , no top brand perfumes (now the from the chemist) , clothes , bras and shoes from the charity shop (Barnados)
11. Reduced heating
12. I cut down on expenses
13. Cut down on food and heating.
14. Stopped spending, stopped eating
15. Gym membership Special food for my son My son's multi room sky subscription

16. Buying less meat, eating more vegetarian food as it's cheaper. Buying value products. Not buying snacks or biscuits. Not being able to buy new clothes/shoes. Not putting the heating on. Skipping bills to pay for food.

17. I have cancelled my mobile phone contract that iv had for 15+ yrs. I have cancelled gym membership that iv had for the last 8+yrs. I do not put my heating on at home as I need the gas for hot water, I have 2 electric heaters to warm us up, we live in our bedrooms as to keep them warm. unfortunaly I don't have double glazed windows in the living room. we have to plan and budget food shopping and I have to tell my child to be mindful regarding money and wasted food. My child is constantly worrying about money and doesn't want to ask for basic things that are needed.

18. Going without more expensive food.

19. I have had to ask my support worker to help me send less money. I bulk buy things now, to find bargains. I am not able to keep my heating on for long and I have damp in my flat and it is cold.

20. Not having any kind of treats, not going out to places we have to pay for entry, substituting food for lower cost options.

21. Yes. I've had to go with meat and eggs

22. Substituting Heather foods for any that I can get from food bank . Desid weather to put heating on or put washing mashean on . Keep to one room for most of the time . Stay in bed to keep warm .

23. Going out for a hot meal is no longer something I can do more than two or three times a week. Worried in case I have further increase in Bills then don’t have enough to pay.

24. I have had to scale down, swap brands, not buy some items etc.

25. No longer use dishwasher, keep heat low. Bought air fryer as apparently cheaper than oven. Now rarely use oven. Don’t buy many treats or go out much.

26. Substituting branded goods for unbranded - assuming they will be lower quality in some cases.

27. I plan out our meals for the week meticulously and make sure I cover lunches as well. I look after our money well

28. Go out alot less Eating out is a treat just for special occasions Trying to make food last longer Buying less clothes for myself and children

29. Don't go out as often as we did. Try and buy cheaper brands. Wear more jumpers.

30. cut down on everything and be more careful in shopping at the supermarket

31. I am buying more out of date food from surplus stores, using the oven less, eating less and buying less.

32. Less going out and about. Prioritising energy costs (came off a fixed price plan in June so really seeing an increase). Don't spend on luxury foods e.g Christmas is going to be more basic. None of us drink or smoke anyway.

33. Have gone from daily baths/ showers to weekly for the kids.

34. I have had to reduce my energy usage in order to save money and use coal and wood fires rather than central heating. Also changed to basic range items when shopping

35. Budgeting is harder, as cost of most things has increased. I generally sit in one room only on my days off, and try to keep as warm as possible with blankets, but without using electricity, eg heat blankets, as I worry about the cost. Food shop wise, I have been able to buy less and less for the budget I have, but still manage just about.

36. Forget heating, it doesn't happen. And I definitely can't afford three meals a day either.

37. I try and bulk cook simple meals. Less eating out. Buying cheaper supermarket products.

38. Cut everything i can, got rid of any tv packages and home phone just pay for Internet. Use budget lines on everything at the supermarket. Boil kettle once a day and fill flask for tea

39. Only buying what is required, only occasionally buying a treat. Only buying some things when they are on offer

40. Yes, I have had to make significant changes to my budgeting due to the rising cost of living. Here are some of the ways I have adjusted my spending: I have cut back on non-essential expenses. This includes things like dining out, entertainment, and travel. I have also started looking for more affordable options for groceries and other household items. I have created a detailed budget and track my spending closely. This helps me to see where my money is going and identify areas where I can cut back. I have started saving money in an emergency fund. This will help me to cover unexpected expenses and avoid going into debt.

41. Eaten less fresh produce and more tinned veg
42. Cancelled subscriptions, eat less healthily because it is cheaper, try to eat less, try not to put the heating or lights on.
43. As previously described. With the addition of less food on the weekly shops, being unable to buy new clothes as needed
44. Cutting back on things that we could have afforded previously eg treats like takeaways or a meal out. Not having holidays that we may have been able to save up for previously. Looking at all the things we spend money on and working out if any savings can be made in any areas. Not going out as often as we may have done before as a family eg if we have time off, we are not able to visit places we may have done before where you have to spend money (most of these places have also increased in cost to meet their own demands). We have also had to start paying for provate dental care which for the household is a lot of money, however I feel so important to be able to access. There are no NHS dentist spaces available in our area.
45. Being diabetic i have to make sure i eat regularly,so i try and eat little and often Its not always possible to find the right foodstuffs and diabetic foods are just too ridiculously high
46. I'm going without simple things like new compression stockings, because I can't justify the cost. And I've been cutting down my self-funded physio, exercise etc. I've tried to do more bulk food shopping but that's difficult without much money in the bank account to manage that, and without the energy or mobility to get things back from the supermarket. I'm highly vulnerable to COVID so I'm still having to take measures for that, which are expensive (taxis instead of buses, buying my own testing kits and masks etc)
47. Heating in the home is a big thing drying clothes indoors.
48. Buying cheaper food, travelling further to go to shops with cheaper food Not putting heating on as much Not going to events with friends as much
49. turned heating down ans cut back on food shop
50. I have pets and I have tried to reduce their cost as much as possible. All insurances are the cheapest available, I have changed power tariff to the cheapest available, I shop carefully and use a community pantry. I try to not put my heating on, I make sure I am using appliances in the most economic ways
51. We go out and enjoy ourselves less
52. Yes, I have made a lot of changes to my lifestyle due to the cost of living. One, I ration my food now and I usually skip lunch. Two, I do not get the complete dosage of my drugs again.
53. We are very mindful of when we use electricity and try to plan things with the weather and time of day (when our solar panels are making electricity or when we have a good battery store). I avoid having the heating on, even though I'm always cold! I wear a lot of layers and thick clothes around the house. I have simplified my diet and have expensive treats less. I have a free bus pass and try to use this rather than my mum driving me.
54. I’ve substituted usual brands, eaten cheaper foods or not proper meals as I can only do ready meals. I go without social activities.
55. Reigned spend in
56. More careful with shopping budget and gas and electricity
57. stopped buying much meat/dairy going out to eat or socialise has stopped not buying new clothes no holiday plans
58. Cheaper versions of items on list. Not having extras biscuits crisos
59. I have had to cut back on buying fresh meat, vegetables and fruit. I don't think I get close enough to my protein or 5 a day anymore. I also don't go out and socialise with friends in social settings.
60. I had to take a CAP budgeting course. I can't for the most part eat fresh produce or meat unless it's heavily reduced and past its best by date. I worry constantly about anything breaking as I'm unable to save for big expenses. So far I have avoided being in debt by careful budgeting, but I feel like it's only a matter of time.
61. Oh sorry I think I put that above. I have simply stopped buying most of the things I would have in the past. I grew up poor so belt tightening is not an unknown hardship.
62. I use hot water bottles to keep warm during the day Heating when used turned down low Curtains shut to keep out the cold risk of falling
63. Therapy

64. We go without things and have to make substitutes for really cheap brands. We struggle as my husband is celiac so his food is more expensive
65. Less breaks and trips out for leisure with the patient.
66. I'm always having to switch my brands of food and have smaller meals, my son is Autistic and struggles with food at the beast of times, he needs the same thing every day.
67. I budget every month, I know always buy to food that is on offer or promotion or cheaper supermarket brands. I've changed energy supplier
68. Primarily it has been the rise of energy bills. We used to have some credit, achieved or the summer, going into the winter months. For the first time this year we are in the red and not planning to turn the heating on this winter. Cost of groceries has also risen, with quality being lower from most supermarkets. Or, shrinkflation, where we are getting less and paying more on nearly everything.
69. I eat 1 meal at most 4/5 days a week so my children can eat. Unable to put heating on due to the debt I'm in. Unable to travel to food bank due to not having money for buses
70. I've reduced what I eat to allow me to still take My son out and to allow me to continue buying the foods he will eat.
71. we google food prices and make numerous bus trips across the city to chase the pennies off. we've made it a game because it's so bloody depressing otherwise don't have people round for meals anymore and we can't heat the house to be sociable one coffee a week now when it used to be regular meet up treat
72. I have changed where I shop to aldi so I can get more for my money but its still just not enough.
73. Changing supermarkets, only buy savers option products.
74. Go without items or billed paid late, used food banks and community places
75. I've had to cut out everything that makes this terrible existence tolerable... And the fact that I don't get to spend any real time with my children because the government look at men like we don't matter.... I don't have TV or a computer to keep myself occupied.. I don't have any friends anymore either.
76. Gone without heating Not eaten so well Social life is virtually non existent
77. No extras whatsoever Christmas isn't happening this year
78. Have to balance my money more and often rely on overdraft
79. i don't go to cinema or out for meals any more. I don't buy alchol and haven't got any new clothes in months. I have gone from a comfortable life style to one where i have to make cuts all the time. Cut back on heating, eating and going out.
80. I have had to go without.
81. We look at making savings in everything which is feasibly possible. e.g. home hair cuts rather than visiting hairdresser No physio therapy for my health condition or chiropractor which really helps No treats..e.g. meals out-replaced by car picnics No drives out in the car except for essential journeys No heat-use heated blankets Do not use 'big' oven-use microwave, slow cooker or airfyer.
82. Cut down on food and bills not good for my diabetes
83. I shop at Aldi as it is cheaper. We do not heat the home as much to try and reduce our gas\electric bills Cycle whenever possible to reduce car fuel usage (although this is healthy and good for the environment!) I buy clothes from charity shops (recycling and cheaper)
84. Food
85. We bought an air fryer to avoid using the over as much. I limit cooking with things like fresh fish as its expensive, meal planning is now way harder
86. Had to look at how I budget my money, look at cheaper energy suppliers, look at ways to save on money in the home and my weekly shop.
87. Lots of changes in food shopping, I rarely buy meat as I can't afford it and don't want to buy poorly reared meat. Being ethical is harder with less money. I don't get my hair cut more than once a year or buy new clothes unless I have to. I ration our heating, I go to visit my elderly mum in her care home less because it costs so much fuel to get there. She gives me 'diesel money' so we can visit and I'm 53. I don't meet friends if invited out for a meal because I can't afford it (they're able to work and they all have partners also in work) and don't want to sit there feeling anxious or say I can't split the bill. I very rarely drink. We don't do 'family outings' like cinema or bowling as I can't afford it.
88. Shopping - reduced the amount of food I'm buying, and buying cheaper brands Not planning a holiday for next year (I always save for a holiday but finances are too tight) Weekend activities with myself and my son - tend to look for cheaper options (for example, he likes going to Brighton but has sensory issues on the

train and bus, so we drive, but parking has gone up severely at Brighton , can be around £17 approx for 6 hours in Churchill Square) so we have stopped doing this. Clothes shopping - not currently buying anything new if at all possible School uniform - my son is in year 11 so we didn't buy new this year, instead hoping his year 10 uniform lasts

89. Smaller meals. No new clothing even though some of mine is thread bear. Keep the house cooler.
90. we cut down as many bills as possible. We prioritise our child and the essentials and dont focus on clothes with holes in as that is not the most important thing to life.
91. Reduction in food for me to allow son to eat well as physical problems Do not go out to eat or gave coffees with friends
92. I am very careful when spending money, making choices as to what I can substitute but I am one of the lucky ones as I have a good salary, if I was relying on benefits as I did in the past due to my disability I would be entirely segregated from society and would not have the means to have my physical and mental health needs met.
93. As mentioned previously, had to cut back on things like days out, eating out, gym memberships ect
94. Ensuring I only get what is needed and not overspending on things where possible
95. Substitutes, putting heating on less
96. As previously mentioned. Unable to justify social trips and hydrotherapy/swimming. Also seeing family and friends less frequently due to fuel/ travel costs which impacts on feelings of isolation and loneliness
97. All my money has to go on bills, utilities, rent. Very little left over to spend on hobbies or treats
98. Yes all the time. The kids cone 1st
99. We are very frugal regarding heating. We rarely eat out or buy pre-cooked meals and I do all the cooking. We have reduced our entertainment package. I am highly dependent on bgroadband quality for social and professional contact (beacuse I have profound hearing loss). I have had to buy a new computer to ensure quality of transmission and reception and I have applied for grants
100. I no longer see an osteopath and chiropractor for my disability as we cannot afford it. My children are unable to do certain afterschool clubs as the cost is too high. I take on extra work at the weekends to try and get some more money in so feel that i am not spending much time with the children either.
101. I can't afford the cheapest food brands because of food allergies and intolerances. I used to buy my clothes in M&S now I shop in Peacocks or the pound shop I used to buy a takeaway or 'nice' meal from the supermarket every week or 2, I've had about 5 takeaways in the last 5 years, and I make it last 2 meals. I used to eat 3 meals a day, now I can only afford 1 or 2 I no longer have a social life because I can't afford it or don't have the transport or budget to get there!
102. Improvements to house delayed. Shop less frequently as before and only online or by using retail stores who are known to be good value for money.

Do you feel the cost-of-living has had an effect on the level and quality of care you receive from the NHS? If yes, how has it had an effect on the level and quality of care you receive from the NHS?

70 comments

1. It is a battle between the LHA and WSCC on who pays for my illness and I am stuck in the middle receiving no treatment or care. I have no way to pay for Disability related expenditures as they were refused by WSCC despite Dr's letters and NICE guidelines saying they are necessary. WSCC said they should be prescribed, the Dr says they are not items available on the NHS and their need is covered in the NICE guidelines. I am the one who ends up without the ability to deal with my disability. This has made life and illness a lot worse. The GP is powerless to intervene with social services, and their words seem to carry little weight. I do not understand how social services accountants are more qualified on my illness and its requirements than a medical professional. My consultants were axed in this region of the NHS, and the LHA has little provision to deal with my illness once it reaches this severity. The NICE guidelines on the very basics of what my illness should receive has not happened for over 10 years. When I raise this with my GP and ask if I found a national consultant myself if I could be referred to them, I was told the referral was possible but it was up the LHA as to whether to fund it and it was not likely at present. So I am left in limbo again with noone to turn to with specialisation, for maintenance or management of my illness; with the WSCC and me picking up the care tab of an unmanaged serious health condition. Instead I am referred to different departments to manage specific symptoms of the illness. I have been on waiting lists for over 1 year on 5 different referrals. My symptoms have get progressive worse during this time without treatment or management. This happens every time I need something reviewed, as there is no one point of contact/consultant I can go to anymore. West Sussex LHA only provides services for mild to moderate cases of my illness, once you reach severe or bed bound capacity you fall through the cracks as the service has been removed, despite very strong NICE guidelines that it should be the opposite. I was discharged from a 6 month inpatient stay to no consultant or provisions for my illness and subsequently deteriorated rapidly, requiring the care that WSCC now has to provide. It all seems very shortsighted financially - and being the person who has to live through it is maddening and heartbreaking. I just want to be given a chance at being well and independent, why is that too much to ask?
2. Some benefits have been reduced
3. Quality of care determine cost of living
4. Not from Front Line staff.
5. Very difficult to get a GP appointment within reasonable time. Was told a skin lesion wouldn't be done because it was deemed cosmetic even though it affected me mentally, told no budget for that.
6. Appointments are difficult to get to meaning I haven't been able to have scans etc
7. Very difficult to get a reasonable time scale appointment from my GP
8. Waiting longer for referrals
9. I pay less for less service
10. Nhs are too busy
11. Requested a repeat prescription of melatonin over two weeks ago - still not been actioned
12. I'm waiting for results for brain scan , body scan lung function test it's been nearly 5 months this is impacting my mental health
13. I have been unable to make an appointment and see a doctor/ nurse for the last 18months but keep getting letters to make an appointment?! in the last 6 months I have had 4 trips to A&E to wait a minimum of 13hrs being the shortest time waited to be triaged at Worthing hospital with my elderly grandmother, total time waited minimum of 18hrs before a doctor has been spoken to.
14. No face to face assessments Difficult to see health professionals

15. My child has received the same level of care, which isn't fit for purpose.
16. Much harder to book GP appointments. Consultant and GP intervention has enabled me to receive physio appointments. NHS staff always go the extra mile to be helpful but they have to spread themselves thinly. Had to cash in some savings recently to help pay care home fees and rent.
17. Accessing gp requires longer waiting on phone lines, and more frustrating experience as they've moved to an automated phone tree. Family members are not seeking gp advice as quickly either if feeling unwell as the trade off for advice versus wait times puts us off.
18. I feel that paediatric care remains excellent but feel the issues lay more in adult care. Nurses are under appreciated and this can be reflected in their practice
19. Can't get a doctors appointment so put off going when need to
20. Everything seems to 'cut back' - less of everything really. Funds don't seem to be available for trips, extra carers - everything is stripped to a minimum.
21. Services are obviously reduced
22. More staff are leaving because they can't live on the salary the government gives them, which reduces continuity of care, staff satisfaction, waiting lists and service.
23. It's all about the money. We don't have confidence that the NHS is there for us anymore. Pensioners and disabled are the bottom of the pile.
24. Less money in the NHS leading to Dr and Nurses striking leading to waiting times increasing which impacts on patients which directly impacts on me
25. There seem to be fewer staff now, and they don't stay in their posts long. When I ask where the previous staff member went, I used to be told they'd transfered to another NHS post but now I am being told they have left to work in supermarkets for better money.
26. Yes. Everything is such a fight. No automatic referral to services. In some cases I have to do my own research and go back to GP pointing out eligibility to get referrals.
27. Some of the medical supplies & medicines used for my daughter have been in short supply, & sometimes unavailable.
28. I feel like the rising cost of living has put a strain on the NHS, leading to longer waiting times, fewer resources, and increased stress for staff. This can impact the quality of care that patients receive in several ways:
29. A lot of the nurses and therapists I know have gone to private practise as they can't afford to work for the nhs any longer. There have been cut backs on the products we receive such as incontinence pads, dressings etc.
30. My experience is still very good. I think we're just lucky where we live in this regard
31. Our GP practice has collapsed. We cannot get appointments, if you need urgently to see someone you get told to go to the A&E at Redhill. My son will soon be transitioning to adult care and he does not have a memes GP which will detrimentally affect him. The GP practice says that they cannot recruit doctors
32. Products used by the NHS have been reducing in quality as they are having their own budgets squeezed. Such as PPE gloves, syringes etc
33. A recent example is that I took my son to A&E on Saturday after he dislocated his knee and it went back in again but was very painful and swollen and we needed to see a Dr. We waited for 8 hours. I am not sure you need more of an example than that to highlight the impact of many things on our NHS.
34. Everything within the NHS feels so squeezed that care is really difficult at the moment. And it's not the fault of the workers who are trying their best. I've had really unsatisfactory care this year and nothing is resolved, I'm waiting on scan results that should have been immediate but we're now at 10 weeks afterwards and still waiting. My GP tries to get it prioritised but gets nowhere.
35. hard to get an appointment
36. The level of care from the NHS has been reduced by so much more than the cost of living! It is frankly frightening to think of how vulnerable we all are to poor emergency medicine, how hard it is to see a G.P., how many hoops it takes to get referred to a specialist, how many patients are covered by one member of staff if admitted to a hospital etc. It is poor funding and policies rather than cost of living
37. Don't get much help from NHS anyway?
38. Ambulances take a long time to turn up, which I have both witnessed and experienced, but I think Covid had a bigger effect.
39. I only get calls now and the services I need don't have the resources.

40. NhS is broken. 6 month, 18 month waits for appointments. Doctors do not answer phones or put phone down
41. Dental treatment costs make me avoid some aspects of dental care such as replacing dentures.
42. Sorry guys I can't face writing all that again. However, a doctor told me both the stroke and the heart condition is most likely caused by rotten teeth, Which I was told when young would be free all my life if I paid tax and insurance.
43. Understaffed and overworked
44. I’m not sure if it’s the cost of living or the changes which have occurred since 2020. It is now almost impossible to get an appointment with my GP, see a GP and obviously impacts any referrals you may need.
45. The NHS has been a mess since brexit and worsened by covid. The quality of care is appalling. I feel for those working for the nhs as they are suffering from lack of resources and staff and are not able to provide the correct level of care
46. Long waiting lists Unavailability of an nhs dentist in my locality
47. I have recently received very poor service from the NHS.
48. Appointments cancelled and no arranged after. No help given for lock down or after
49. Had to wait years for a basic appointment about my back... Which held up my PIP claim for two years due to "lack of evidence"
50. Trouble getting doctors appointments
51. waiting lists of years for neurodiversity assessments and no support for those who then go private as don't want to / can't wait 10 years for assessment Everyone's mental health is being challenged and work loads increasing which impacts on quality of care
52. Poor care,no support
53. I know that there are long waiting lists for hospital appointments (my husband has been waiting over one year for a cardiology appointment, despite an earlier diagnosis of a heart condition) My husband is also waiting for a Neurology appointment and is in constant pain. This has an adverse effect on our family life. I do not blame the NHS staff, I blame the government for Real Term cuts in pay to nurses, doctors, consultants and all the other staff. I fear this present government is not fully supportive of the NHS or it's ideals.
54. In some respect yes
55. Poor staffing levels due to below inflation pay rises making it harder to recruit.
56. I have some health issues and the waiting list is very long, I've been waiting months to see the ENT and I'm on the waiting list to have an injection in my spine and been told I may be waiting for over four months.
57. I think the stress of COVID has led to huge backlogs and that’s had a major impact. My daughter waited over a year for a hearing assessment . We should visit the dentist more but I can’t afford it and there aren’t enough dentists offering NHS places. Staff are leaving the nhs because their salaries haven’t increased with inflation and the stress is too much, which creates more backlog and that has the impact on everyone’s health with much longer waiting times and criteria being changed. GPs seem less willing to prescribe as medicine costs have increased off the scale
58. My son has regular visits to hospital as he also has a chronic health issue which requires regular and ongoing interventions. We have been at hospital during strikes, the staff do an amazing job to keep procedures happening and care to patients, but it's a huge strain on the staff and you can see the pressure they are under.
59. Anybody working for the NHS is not paid enough to afford to live in Brighton and Hove meaning lots of good staff are moving out of the city.
60. ADHD meds availability due to shortages Long waiting times due to lack of funded trained staff
61. Access to health care is very challenging. There are no NHS dentists locally, GP surgeries put barriers in place to access in person care and I constantly have cancellations of appointments with consultants. Mental Health care is non-existant.
62. Not directly
63. GP surgery’s reluctant to see you
64. Greater challenges in accessing appts due to travel/fuel/parking costs
65. waiting times have changed

66. Yes 100% I have been suffering from gallstones and waiting for an op to have gallbladder removed
67. Although I have had conditions that would have required clinical attention the chances of getting that attention are so small I have had to use home remedies, for example extracting my own teeth or loose fillings. I should have blood tests twice per year but this has not been possible since COVID. However, NHS Futures now presnets this opportunity which I am currently taking up
68. I am unsure if this is because of the cost of living, however, getting an appointment is near on impossible. Hospital appointments take forever and GP appointments are never available. I visited the doctor with my daughter recently and the doctor stated that 80% of her day is supporting people with their mental health which i feel says a lot about society at the moment and how much of a struggle it is for people.
69. Even though I get free prescriptions what I can get on prescription has dramatically decreased - see example on question 5. Also because GPs are so busy it's impossible to get an appointment; when you do its never with the same person so their no continuity. I don't think I've ever met my GP she's just a name on a piece of paper that's supposed to co-ordinate my care. I also feel that they more reluctant than ever to properly investigate or diagnose a problem because it cost too much.... if they don't find a 'reason or label for a cough' they don't have to spend money on treating it
70. There are too few doctors and nurses, especially since Brexit. Those who remain are stressed and overworked.

As a disabled person or carer, do you feel more affected by the cost-of-living?

87 comments

1. The cost of my care contribution has increased 375% in 7 years, despite my situation remaining unchanged. My benefits have not increased to offset this. This isn't a volutary charge I can opt out of. This is to keep clean and eat. We have no bargining power to withdraw. And yet, West Sussex County Council has not increased our care budgets since 2016 despite two increases in the national minimum wage and rising inflation. They have told us that it is our responsibility to make up the difference, and make sure we have the money in our accounts to pay for the extra costs and the extra we would have to pay for holiday pay because of the higher wages. And YET, since 2020 WSCC has increased the contribution we have to pay towards being able to receive care to 100% of our "disposable income". This means that the disabled have absolutely nothing left for the costs of disability any more. I only receive benefits and WSCC takes all of my PIP and a large chunk of my ESA for my care. I am left the very basics to live on. I have no buffer for increased care costs, increased cost of living, for anything going wrong at home, my disability needs etc. 100% of my 'disposable income' from benefits is taken to pay WSCC for my care contribution - I have less than the ordinary person to deal with cost of living crisis. It is now basically a choice between care and living…. Do you have someone to wash you and prepare meals, but then you don't have the food or ability to stay warm? Its a Catch-22 I don't know the answer to. The only income I have is from benefits. I did have savings but after the last 3 years I have absolutely none, and I'm in debt. I have no way to pay for Disabilty related expenditures as they were refused by WSCC despite detailed Dr's letters and NICE guidelines saying it was needed. This has made life and illness a lot worse. My consultants were axed in the NHS, and the LHA has cut the provision to deal with my illness once it reaches this severity, against NICE guidelines. When WSCC increased care costs to 100% of income in 2020, they will not allow for any debt that you were repaying - so there is also no longer any way to pay any debt that you budgeted for before - leaving you in a vicious cycle of arrears. It has made the most vulnerable have no choice but to get into a increasing spiral of debt if they are to receive the care that they desperately need. I don’t have family or friends to rely on. Only my carers. They are the access I have to do anything and my hours are continually decreasing. I now have no care hours to go out, to get to appointments, or to socialise. This month I had call a meeting where I had to reduce their hours further, and we had to carefully plan each minute of their week hours to make sure I had the food prepared, medication and treatment managed, shopping done. It left 30 mins for either one shower or cleaning the house once a week. I have to choose between the house being clean or me being clean. I have contracted bad allergies leading to breathing difficulties. Not having my DREs makes everything harder and take longer. Since becoming seriously ill my close friends have moved away from the area or country, but I do not have the means to get out to meet new ones. I do not have a choice to go outside, socialise or have hobbies now. It takes me a lot of energy to communicate or process information, and this year WSCC axed my advocacy service - so my abilty to be heard has been taken as well. WSCC say they will dealing with the advocacy themselves - which is a clear breach of interest - and I have been given nothing as a replacement since. I have to use the care hours I so badly need for basic necessities to fight for my rights - or just get a reply from the service that is supposed to provide them. They have lost my files and document evidence many times, and closed my cases without informing me on multiple occasions. It has taken years to fight for basic backpayments owed. Months for care hours that have signed off, to be paid. I have had my care threatened to be removed for months because of their mistakes. It can take months for to even recieve a reply from someone, and yet days to charge you thousands of pounds in backcharges because they didn't provide the right forms. I have no point of contact, no social worker who has access to my case. Accountants know my illness better than medical professionals, and have more power over care and treatment. I do not have the care hours to counteract this, so my now my ability to voice my rights is gone as well. Social services have made me iller, worse off, and taken up more of my care hours than any other input in my life. How ironic and counterproductive. It is is the very basics of living that is left. Very little of the Care Act is reality. Care is in no way affordable now . Much I want it to be different, I have no way to supplement my income. Wages wouldn't be considered 'disposable', unlike my benefits, and I could keep the extra money. But unfortuately my condition has progressed to much for that option. It is the most vunerable, who have no options and struggle with enough, who are bearing the brunt of these

changes - and their small voices have now been silenced. And with no support from the LHA or NHS or WSCC, there is no way for my condition to be managed or improve. All I desperately want is to be given a chance. A chance to manage my illness, a chance to use my care to get better and give back, a chance to be seen as human who can contribute and not a problem thats a number. I have a Physics degree, my illness can go into remission. But how can I be heard or seen?

2. Spend alot on the person you are taking care of
3. Bcos of my cost of living
4. Not taken seriously by Local Authorities allegedly.
5. Only receive carers allowance which is a limited amount yet caring for someone with special needs is more expensive generally. They use more personal items such as toilet rolls, need accompanying out, need to keep connections made and yet the money t9 support us both to do simple everyday things 8s more limited than ever as everyth8ng has gone up, food, petrol, energy, insurance and yet you cannot explain this to someone autistic as these are hidden costs, not tangible things and anyway, they'd feel burdened and upset by this and thin' it's their fault
6. Cos I suffer to provide for myself and my sick dad as well. My comfort goes in the way.
7. My son is very particular about what he eats, making it difficult as to what to cook for him which is affecting his weight. He is upset about our very cold house and the quality of the food I can afford to buy
8. Reduced income and increased expenditure
9. Disabled people really feel the cold. And need more heating not less
10. Because everything costs more and the children are getting bigger not smaller, they eat more. Clothes cost more to
11. See above
12. The DWP won't give my son the benefits I feel he needs, thus impacting on out household income.
13. I'm stuck with out my daughter who works and is 21.
14. In order to meet costs of supporting our disabled child we are having to sell house
15. Everything has gone up in price.
16. I am unable to work, so when I see big bills it is very worrying. All my bills are going up and shopping bills are getting more expensive. I rely on benefits because of my disability, so I don't get any extra money even though things are getting more expensive.
17. I can't work because of my caring commitment so no opportunity to earn more to cope with rising prices.
18. My child needs some specific food, clothing and equipment. We can't switch to anything cheaper. They're at home most days as they can't go to school due to their mental health. The cost of them being at home all adds up with bills as we're all at home more.
19. Having to chose between health living in debt . Or unhealthy out of debt .
20. Would have to have the heating on more often then witty and the increase in psyments
21. Because you don't have the opportunity to work more hours to boost your income. Being at home 24/7 is also more costly.
22. Weekly shop and delivery costs much more. Increase in pension doesn't match rise in cost of living. Most people on fixed income would agree.
23. Yes - as an unpaid carer my carer benefit disappears into my own health therapies so I can stay well to look after son and his benefits are used up in contributing to family electricity, oil/heating, grocery, and other living costs with less left over for the outings he enjoys most.
24. Our electricity usage is way over the norm in order to meet our sons needs
25. Need to work more to earn more money but can't because of being a carer.
26. My daughter needs to go out for her mental health but we can't afford it very often - car fuel is also expensive so you have to factor every cost in. We should not have a cold house but we do quite often. We have night carers and I worry the house is too cold for them.
27. My disable daughter has an EHCP which means she can stay in education for longer which is a good and necessary thing but that means as her parents we have to step up to pay for her to remain at home and pay for all that that involves - PIP really does not cover her needs
28. I can't walk, cycle or take public transport instead of the car, I can't shower more quickly, I can't leave the heating off and wear more clothes, I'm not able to work and benefits haven't gone up in line with inflation.

29. We don't have a mortgage or rent to worry about. I feel for families struggling.
30. Because being disabled is expensive! I pay for all splints and wraps for my limbs for the RA I have. I fund my own equipment if needed, as the waiting lists for OT are long. I haven't had much of a budget for health needs this year.
31. I need my home to be warm so I don't suffer worse problems from two separate physical health disabilities. I can't afford to heat my home despite working full-time. A non-disabled person might be able to survive a winter without heating, albeit with some discomfort, but I literally can't breathe without the heating on and I spend my nights buried under a pile of blankets and duvets and just trying to catch a decent breath.
32. Less opportunity to increase kncome.
33. Somethings can't cut back on, not a choice, due to incontinence issues HAVE to use a lot of electric and gas
34. As a person with a disability, I have found that the rising cost of living has had a significant impact on my life. I have additional expenses related to my disability, such as the cost of medication, assistive technology, and transportation. I am also more likely to have a lower income than non-disabled people, making it harder to make ends meet. This has made it difficult for me to afford basic necessities, such as food and energy. I have also had to cut back on activities that I enjoy, such as going out to eat and seeing friends. This has made me feel isolated and lonely.
35. Because I have to eat and cant miss meals and its harder to eat healthily
36. I think everything is magnified for us We are less able to take on work outside the home or additional hours. We are at home more so need to use the heating etc more - especially as my loved one can't move so gets cold more easily.
37. When you rely on benefits, you get stressed by the politics of a government that really don't seem to understand (given those making the decisions are all multi millionaires!)
38. Outings and trips are very expensive, having a meal out is becoming prohibitively expensive
39. The costs of things are more for anything with the disability association. Our daughter requires more expensive foods due to her conditions. We use far more electricity due to medical equipment in the home.
40. Already described some of the ways above. More costs are incurred, for sure. Disabled people tend to spend more time at home, so keeping warm through winter is another factor. My son has various sensory needs. There are only certain foods he will eat, and certain clothing I can buy for him to wear. All of these things make a difference to our costs. He needs certain things to help him feel comfortable, eg a fan running overnight to sleep. This all has a cost that non-disabled people do not have to think about.
41. in both ways
42. My essentials cost. And I can't safely scrimp and save as others might be able to. Everything costs more as a disabled person and so with everything going up due to COL I'm even more stuck.
43. Being a disabled person and retired what else can I say.
44. I have to use sugary foods/drinks to treat hypos, which cost more and more due to sugar tax and supermarket price increases
45. fix income so cannot earn more
46.
47. As a carer I can't go and earn more money? I need to be with my husband 24/7
48. Because I work more and get less pay compared to able persons
49. Because I have extra needs I need to pay for, including extra heating and my diet, and because I do not have the ability or freedom to make money. I feel at the mercy of the benefits system.
50. I am not getting the cost of living payment other than the £150 when others get £900 and yet I'm cold, I need to shower longer, it takes me at least half an hour. Equipment is not free and I have to charge my scooter battery (I only have a scooter as I was given it)! I can't use it as it doesn't go over my threshold and I can't lift it out the car unless someone is with me is physically able to. Hoist for car is too expensive, even through motability and I won't be eligible for a grant because I work.
51. As there seams to be more help as a carer
52. There are so many other things that need to be purchased; incontinence pads, equipment, special foods - such all to make life more comfortable/ bearable.
53. Can't have the heating on as I need for my medical condition
54. I am unable to find a better job as to do so I need a car, and I can't afford to get a driving licence or a car, so I am trapped working part time locally.

55. I don't know how other people are affected so it's impossible for me to say.
56. I need therapy to help with my mental health and this is only available privately
57. My income is limited and this is the problem, i can't earn any more with out losing support
58. Because I can only work part time, I have to rely a lot on my UC and PIP income, which isn’t very much, compared to if I could work full time
59. Everything for me has changed.
60. Because daily costs are higher due to needing extra support with disabilities. The use of aids, transport and specific diets costs more and the money isn’t there to cover the basics least of all the additional costs.
61. Because as a carer I am unable to work longer/more hours. I am unable to pick up second jobs etc. I have to have the small hours of work I do (8 a week term time only) because my sons not in full time or long term education/provision. I'm stuck and have no way out to enable me to earn more. Carers get carers allowance but realistically this is nothing.
62. keeping warm and well fed is very expensive and both are essential to keep my partner functioning at a reasonable level
63. During covid we didn't receive the uplift that people on uc received and just let everyone else sat at home we had to pay extra for deliveries, special taxis, food shopping to be delivered to our front door however no extra money to help with this. This has had a knock on affect over the cost of living too where we have no extra help despite being unable to work
64. Unable to work due to caring role
65. Not struggling to heat my home ,cuting on food and supplement not having petrol to get to work or others appoitments.
66. The amount of money the government expects us to live on is not enough
67. As a carer I cannot do a full time job but I get penalised by UC because I don't work enough
68. Less in benefits means less leisure activities
69. it costs more being disabled and if you can't get support or PIP it comes out of your own pocket
70. I think that because we are on a fixed income we cannot improve our circumstances, my husband is my full time carer. As a disabled person, I feel that my security and peace of mind is in someone else's hands.
71. It's harder to live of shopping
72. Carers do not have as much time/freedom to work. The carers allowance is abysmal (approx £70 a week), and carers are very limited to amount of paid work allowed. The carers allowance should increase!
73. Because I cannot afford to live. I live hand to mouth every day. Some days are worse than others
74. Heating costs are much higher than 18 months ago
75. Yes, we do not have the same options as people without a disabled young person as mentioned above. He is in the house more, less mobile - so needs teh heating on. He has to shower for hygiene purposes as he wears pads and showering takes much longer
76. As carer I have to work part time to care for my elderly disabled mum, and I need to reduce my hours again in the new year to full fill my caring role.
77. My son has dietary allergies - his food is now 3 times more expensive for gluten dairy and soya free alternatives. Personal Assistants (PAs) understandably want a better hourly rate than the Local Authority will give in their social care direct payments package. So families who can afford to, will ‘top up’ PA pay, but families like us can’t afford to do that. So we either can’t attract and keep a PA or we have to spend 4 hrs of DP hourly rate to only receive 3 hrs of care
78. Loss of earnings if you can't work as need to attend a medical appointment, petrol costs and parking to attend hospitals (for us, and example is Haywards Heath Princess Royal, and we also attend the Royal Alex in Brighton), loss of earnings when my son is in hospital and I've taken unpaid leave as I stay with him on the ward due to his age, difficulties in reaching full potential as under employed for large parts of my life reduces earning capabilities
79. My disability prevents me from working so I’m not able to find more money for the increasing costs. Causing me to get into debt.
80. We have greater needs and reasons to not always be able to go to supermarkets like lidl and aldi meaning online delivery shops cost so much more and heating our room to keep health okay means we have to cut back on other things that we enjoy.

81. Disabled people have greater costs and less means of increasing income. Certain costs have to be met and you do not have a choice if you require support to complete normal day to day activities. Constant insecurity in terms of access to PIP makes being disabled even more challenging.
82. Disability related expenses means that it costs me more to live independently than a non-disabled person. It is harder for me to get about, so my travel/fuel/parking costs can be high.
83. More pressure keep things the same. More equipment needed
84. I am both a disabled person and a carer. I cannot use public transport because of the unacceptably crowded conditions and lack of support for people who are deafened and have mental health conditions and neurological conditions. I have cut back on mileage from around 12000 to around 2000 per year. We have not had any holidays away for years. I have been to London once in the past 4 years by train, which was such a bad experience I shall never travel by rail again. I have travelled into london once by car in that time, which required me to pay congestion charges and ULEZ charges. Therefore vents in London are pretty much ruled out for any leisure activity. I think the system is very inequitable. If you are wealthy and travel tens of thousands of miles you can drive what you like regardless of high emission levels. If you drive a frugal car such as the one we bought in 2012 intending it to last us for the rest of our lives, and only drive on essential journeys, less than 2000 miles per year, you still have to pay the same as the gas guzzler whose emissions are 10 or 20 times greater. the state of roads is another hazard. We have had to replace two sets of shock absorbers. There is no selectivity about policy in many areas. It is all a broad brush that imposes the same burden on everyone, rich or poor, able or not, regardless of individual impact on environment. Anyone thinking for even a few minutes about this would see that road charging schemes could easily be related to mileage per year and could be monitored via MOT. For new cars, emissions should be low anyway. Any car that emits more than a certain level should be fixed or withdrawn. Public transport is a joke almost everywhere. It is a hazard to health and wellbeing in urban areas and an absence in suburban and rural areas. policy makeres are very centred on London. There are better systems elsewhere
85. As a disabled person, we usually on average have to spend around £500 more per month on disability related expenses. This makes me wonder why cost of living payments are not given to people with disabilities? Disabled people have received around £500 less than others entitled even though we are more likely to spend more on every day living in order to make things accessible to us.
86. As a disabled person there is an assumption that the cost for this or that will come from someone else's budget in reality the disabled person ends up paying out of their own pocket and not just financially.
87. Limited hours of availability to work

Is there any support you would like to see offered to ease the impact of the cost-of-living on disabled people and carers?

100 comments

1. Cap the care contribution to below 100% disposable income/the PIP care componant. Non PIP benefits MUST be ringfenced for daily living costs and not be taken for care. Keep care contribution increases in line with inflation. Mandate that the WSCC care contribution must increase in line with the minimum wage. Allow Drs opinions to have more weight than an accountants or social workers. Do not allow the WSCC to advocate or deal with appeals within themselves. Set up an independant body to deal with this. Have a named point of contact for social service clients and NHS patients Make Advocacy a basic right UPHOLD THE CARE ACT, especially that care must be affordable. How is 100% of disposable income affordable?
2. Provide more health services easy for them to afford
3. Rehabilitation center services and family services support
4. Council Tax Reduction implemented when you're still caring but have underlying entitlement to Carers Allowance and E.S.A. combined.
5. Discounts on things like cinema, free use of buses, days out, eating out. Coffee vouchers, exemption from MOT costs, food vouchers for any carer or PIP claimant
6. Not sure at present
7. Yes, maybe a proper accomodation. Food stamps or items.
8. Additional cost of living payment
9. More government sort (financially. Help stop the war in Ukraine and stop supermarkets shrinking our foods and still charging us even more for the products. Let the water companies be made accountable for polluting our water and charging us to fix what they are responsible for. The government has to take control of the prices at the petrol stations
10. Social support
11. Social tariff for fuel bill s
12. More money, his disability should be high rate now
13. Lower monthly pay roll fees for direct payments? Which would save money which could be put into other things that would benefit disabled children/young adults.
14. I used to get a warm home discount on my heating bills, but no longer receive this.
15. Help with cost of heating
16. Help with things like petrol, essential items such as dietary specific foods. These things were already so expensive and now it is even worse. My child's school is an hour away, he gets transport however he regularly has meltdowns or appointments where I have to collect and it costs me £25 per trip in fuel. There's barely any SEND days out, no compass card anymore. We're just getting from one day to the next currently
17. Lower bills
18. Food bank vouchers.
19. Increased DLA / PIP / Carers allowance
20. Yes, financial support
21. Carers allowance is insulting it is so low. This needs to be increased to pay carers the minimum wage at least for the hours they spend caring.
22. Easy to get help with public transport
23. Advice on how to keep my home warmer.
24. Capped gas and electric prices for those who have to stay home caring. Being a carer is a much cheaper option to the Government, yet the impact on the family in every aspect is huge. More financial support should be offered.
25. I'm not sure what else could be done. The country appears to be on its knees.

26. I’d like government to stop cutting benefits and adding ever more hurdles to jump through in order to access them. West Sussex county council services could be more user friendly - trying to budget, meal plan, arrange PA outings, and all other life admin for the month, does not need to be complicated by WSCC putting the wrong phone number into a letter and everyone sign posting to correct sept /service on first request. As a carer my stress is ramped up by every element from consumer price rises to the admin that goes along with being my son’s financial, personal, entertainment, etc manager.
27. For us it would be automatic assistance for self employed parents and caps or financial assistance with electricity bills
28. Don't know
29. Financial support towards trips and heating costs.
30. funding for respite and for longer term support from organisations such as My Network Plus
31. Increase to disability benefits (including legacy) and carer's allowance, increase to tax allowance
32. Firstly stop bashing them in the press, government etc. also everyone who lives law abiding lives should be valued why are we all reduced to monetary value? What happened to mutual respect, society, community, kindness and doing what's right?
33. Help with energy costs
34. Anything would help at this point, either a slightly reduced energy tarriff, or an increase on benefits, or a discount for buying disability equipment.
35. Full-time wages being enough for people to be able to afford to eat AND heat their home, because at the moment I can do neither. Then I'd like for there to be enough money left over for me to be able to afford something approximating a social life.
36. Increase in carers allowance as we are financially penalised for caring.
37. More help with essential bills
38. Discounts for energy bills for those using life saving machines like ventilators, feeding pumps etc.
39. Healthy Start vouchers for adults with long term health conditions
40. increase Pip and carers allowance
41. Lobby the government better! Be better than the politicians!!!
42. Yes, but I don’t have the energy to even think what kind of help we need
43. More payments to families who are affected like us.
44. more support groups for respite time
45. Raising the PIP/ESA rates
46. Reinstate DLA to children who had it before and increase benefits to single lone parents with mental health and physical disabilities, stop the pressure put on by sanctions!
47. Please be fair when thinking about the disabled and the elderly and their caregivers
48. Higher benefits rates More tailored advice for managing e.g. necessarily higher energy costs More FREE respite care so carers can take time to themselves, not only for essential medical appointments etc but also to socialise, undertake wellbeing activities Concurrent provision of activities for carers and cared-for people so they have somewhere to go that is low cost and can be used as a warm space
49. Those with medical equipment need a reduced power tariff to allow for the running of electrical equipment and sterilising etc
50. Give us a decent carers allowance!
51. Yes, the government should pay attention to disabled people by giving them a lot of incentives
52. To extend the grants for solar panels - having them has helped us so much. The government are sitting on millions and millions but only for houses without gas central heating, and they are having trouble finding eligible recipients; they should just extend this to other people.
53. I would like a COL payment and recognition and support to have the equipment I need, to be able to go on holiday (it costs more when disabled).
54. No
55. Better acknowledgement of these costs. A nominal payment towards them. Easier processes to gain free incontinence products.
56. Don't know

57. I think everyone is affected, no different. Being a carer of 12 year old disabled boy.....everything's expensive!!
58. Support with mobility costs when not entitled to Motability allowance owing to mobility being impared after retirement.
59. I could have claimed years ago but I thought circumstances would change.
60. Yes
61. Help with costs of living food etc
62. The equivalent of the pension triple lock.
63. My benefits need to go up
64. Extra or higher cost of living payments from the government
65. The only thing I can think of would be financial help.
66. More help to claim pip and obtaining the necessary evidence. Running the healthy start initiative until the child is of income earning age. Increasing the health start allowance. Increasing the minimum threshold to claim healthy start, Creating a similar concept to healthy start cards but for those with disabilities to ensure we can all afford basic essentials to aid our disabilities
67. More support from government/councils to support carers who are unpaid. A realistic carers allowance to those who clearly cannot work due to their caring role.
68. use all avenues , social media, bus stop adverts, surgery posters bla bla to advertise what help there is and then make sure it's easy to apply hahahaha, is it ever
69. Extra money longterm
70. Food vouchers
71. Free transport
72. More financial help given to cover the costs
73. I would definitely love to see some travel support, I'm unable to walk like I used too so I rely on public transport.. But even then am unable to go places and attend appointments due to being unable to afford the travel costs
74. Yes
75. More money even if shopping vouchers
76. Higher threshold for those who do work so what little money you do get is actually kept
77. Fairer benefits system,
78. supermarket vouchers given to different community groups to distribute
79. Financial targeted support that goes direct to e.g. electric supplier
80. Just more support
81. My daughter has a learning disability. She lives in a flat and is supported by carers. Every month she pays WSCC over £415.76 out of her benefits towards her care package. She also has to pay gas and electric, food etc. With our help and a strict budget she just about manages. If she was allowed to keep a bit more of her money her life would be easier. Carers allowance should be increased!!
82. Universal credit increase
83. Ignore the MIG and restore the discretion of the council to charge contributions. I am aware that the central government squeezes on local government funding has caused the need for this.
84. Financial support for people who are the shared carers....discounts/grants
85. Yes I think the government should look at the threshold of the amount carers can earn before they can claim carers allowance. In my opinion the threshold is to low, many unpaid carers still have to work to make ends meet and we save the government millions of pounds every year in care costs.
86. A proper Carers Allowance payment based on the Living Wage would be a good start. My son is at home full time and I provide around 18 hrs of care - for £76 Weekly CA. That's about 60p an hour (see photo)
87. Cost of living emergency grants for individuals
88. I was out of the country for a few years and upon my return I was told I had to wait 2 years to apply for PIP despite my disability. As a British citizen and with the cost of living, this is crushing.

89. recognition for disabled people and understanding that 2 disabled people can date and should not be punished financially and be worse off than if we were not together.

90. Lower cost exercise and podiatry   Help with transport if not eligible for notability

91. Yes - financial support, increase in disability benefits, caps on energy price increases and housing cost increases

92. Discounts for those in the key workers groups and sick pay entitlement when off with covid

93. Wage increase

94. Free accessible transport/fuel concessions/parking fee waiver for disabled people

95. more help

96. We seem to work harder than nurses in some instances, a significant raise would be nice

97. I have received a grant this year which helped me to license some software to aid my online interaction for business and leisure. That sort of scheme should be more widely available

98. It's the little things. When i have to travel to a different Doctor surgery because my current one cannot offer me an appointment downstairs and has no lift, i would like for that travel to be compensated to me. What would be a very short taxi ride or bus rise and cost less than £5, now costs around £12-£15 per journey. Any financial support in general would be appreciated to cover things like heating. I think we get a £10 payment from PIP for heating per year but currently that does not even cover 1 day.

99. I am very grateful for the extra money I already get in COL payments but some needs to be done to address the disparity between benefits and DREs including contributions to care

100. Increase the rate of Carers Allowance.   More general subsidies for carers, similar to those already received by pensioners and the disabled.

Is there any else you would like to say?

50 comments

1. No
2. Not yet
3. Because my family member relies on me so much, when I take him out I have to pay for both of us as I am supporting him. I am now just drinking water which is when we go to coffee shop and he has a hot drink. This seems minor but a coffee is about £3.50 so that's a lot of money when you have to buy two all the time
4. No
5. No
6. None
7. No
8. The DWP need to sort out Universal Credit for disabled people still in education as adults.
9. It is very hard indeed
10. No
11. We are so lucky to have family who can help us financially. Without their help we were at risk of defaulting on our mortgage. We are in serious debt after years of trying to cope paying for everything from our own pockets before we managed to get DLA for our child. We expect to be paying off our debts for years to come. The financial impact of having a disabled child are not considered by Government and they don't care about disabled people.
12. Would be good to have someone to talk to about these issues.
13. Not really.
14. I am glad this survey is being done I hope it helps
15. No
16. It feels like disabled people have been forgotten with any extra help offered...my daughter also has lots of equipment needing power and no consideration or help offered in the cost of keeping all these things running.
17. It took us a year to get a needs assessment from WSCC and then a year to be referred to My Network Plus - we feel that because our daughter is ok at home and we are very happy for her to be here our support needs were not addressed quickly enough - probably because adult services are working in a crisis situation and our was not a crisis... does it have to get to crisis situation before people who are struggling on a day to day basis and saving the state millions of pounds get the support they need?
18. I think I've said enough!
19. Resolve PIP issue
20. I think carers are treated very badly by services. I have had to postpone my own medical care as a carer as there us nobody to look after me.
21. No
22. No
23. No
24. Don't think it will make a difference sadly.
25. As in so many situations our families are often forgotten about and left to struggle. It is so wrong.
26. its very hard yo do the right things for both myself and my hubby who is registered disabled
27. No
28. no
29. No
30. No

31. The government need to invest more in private solar and wind energy, and they need to invest more in arable farming: you get exponentially more food per acre by farming plants rather than animals (because the animals need to be fed planst), yet the government has given £300 billion to animal agriculture. They also keep building on arable land. Both of these factors threaten our future food security as a nation because we are over-crowded and currently do not have enough land to feed people without importing. This is because the land is mismanaged and too much is devoted to livestock grazing.
32. I am penalised for trying to keep working and benefits do not cover my extra support needs.
33. No
34. No
35. Loads but I'm not sure I have time.
36. Sorry I'm very muddled & not to coherent now
37. No
38. No
39. No
40. No
41. The nhs is absolutely shocking, wait times are too long, quality of care is rubbish and it's all the governments fault. I fear to use the services provided for me or my children and I feel sorry for those working within the system. There needs to be a redistribution of funds within the nhs too. No reason anyone in the nhs should be paid hundreds of thousands annually when nurses and student doctors are using food banks to survive and services can't run due to lack of funding.
42. thank you for doing this questionaire...it's importnat and i think people in this demographic have very little opportunity to speak out. let's hope we are heard and change will come.
43. No
44. in work povety is real
45. The Government are talking about reducing benefits for sick/disabled. this causes huge anxiety for us as a family as our daughter cannot read, understand money, is incredibly vulnerable. She needs her disabled benefits to survive.
46. This Cost of Living crisis is caused by central government and the local government should be more open in making this known to the electorate!
47. It can be very difficult and stressful caring for a family member and it does have an effect on your own well being and health, especially as carers themselves begin to age and develop health issues. Due to my own financial situation there will come a time when I will need to look at paid carers for my mum.
48. Something's got to give because so many of us are on our knees with the failing services on top of the cost of living crisis
49. No
50. The government is really horrible for ignoring the people at the bottom of the hierarchy