

Cost of living crisis

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Cost of living and rare disease

The cost of living is rising across the UK at its fastest rate in 30 years. Price increases are forecast to peak at 8.7% in autumn and the energy price cap is set to increase by 54% in April. Household incomes are predicted to see the largest drop since records began.

Chancellor Rishi Sunak's Spring Statement set out measures to tackle this crisis. This includes cutting fuel duty of 5p a litre, an increase in the rate at which National Insurance is paid and a pledge for a further £500m into the Household Support Fund to extend it beyond March. This fund allows councils to help the lowest-income and most vulnerable families in their local area.

"We are already struggling.... It's getting very scary now... I'm not sure what we will do in April."

Parent to child living with a Urea Cycle Disorder

Living with an inherited metabolic disorder can be expensive and involve significant additional costs in order to manage a condition. The cost of living crisis is likely to compound the financial uncertainty and hardship that many in our community face. There is presently little statistical evidence on the financial burden for families with a rare disorder. However, research into a small number of disorders have identified serious implications with a call for further work to be carried out (Angelis et al, 2015).

This burden has also been documented in The Hidden Costs of Rare Diseases: A Feasibility Study (2016) by Genetic Alliance UK which provides qualitative data on the challenges. These include the costs arising from attending multiple appointments and associated travel and acknowledges increased costs due to accessibility needs, overnight accommodation and childcare arrangements finding all costs were exacerbated by ineffective or absent co-ordination of care.

Key stats

Families with disabled children face an average extra cost of £581 per month (Scope, 2019).

Families with disabled children are already paying £600 per year more for energy than other households, before the energy price rises coming in April 2022 (Contact, 2022).

Shire's Rare Disease Impact Report (2013) showed that almost all UK clinicians felt that patients needed to attend more hospital appointments to diagnose and manage a rare disorder than a more common condition. On average, people with Inherited Metabolic Disorders travel 72 miles to attend their appointments (MSUK Annual Survey 2021) which emphasises the burden on finances.

"It's very worrying. The cost to go to hospital was already expensive as it's an hour and a half away, the cost has just about doubled and that's before getting a coffee. If we have no prescription bread, it's now £2.70 for a loaf for our son. It's going to make an unhappy, expensive situation worse and raise stress".

Parent to child living with Homocystinuria

We know that:

46% of respondents to our MSUK Annual Survey 2021 said they are in receipt of some form of financial aid. Most, if not all, of such aid will not see increases that are in line with the rising cost of living.

"The cost of fuel is a big worry. Our fear is with the rising costs of living, but not a rise in the Disability Living Allowance that we receive to help us cope with the extra spends related to the condition and is barely going to cover our basic needs"

Parent to child living with a Urea Cycle Disorder

69% of parents/carers for someone living with an IMD have had to give up employment or reduce their working hours as a result of their caring responsibilities.

What can you do?

Check to see what financial aid you may be entitled to

There are a number of resources available online to help you find out what you might be able to claim. Enter your details into one of these calculators and you'll receive an estimate of your entitlement to benefits, tax credits and Universal Credit.

- **Turn 2 Us** <https://benefits-calculator.turn2us.org.uk/AboutYou>
- **UK Government:** <https://www.gov.uk/benefits-calculators>
- **Entitledto:** <https://www.entitledto.co.uk/benefits-calculator>



When it comes to applying for benefits, we recommend visiting the following organisations:

Citizens Advice offers information on each benefit available and advice and assistance in completing forms and any actions you need to take whilst on the benefit and guidance on appeal processes. <https://www.citizensadvice.org.uk/benefits/help-if-on-a-low-income/>

AdviceNow provides step by step guides to completing forms and offers guidance and tools should a decision lead to appeals <https://www.advicenow.org.uk/help-deal-benefit-problems>

Turn 2 us offers guidance and practical support on claiming benefits including help finding a local adviser. The site also links to grant giving organisations or charities for additional support if needed. <https://www.turn2us.org.uk/>

More information is available on our website: <https://www.metabolicsupportuk.org/benefits/>

Top tip

When claiming benefits, gather as much evidence as possible. This is particularly important for rare disorders as the reviewer will be unlikely to know the condition. We recommend beginning a diary to capture insight into the symptoms, how the condition is managed, and the level of care you need daily. A supporting letter from your consultant will help and can be used towards evidence and you may also wish to consider reaching out to other healthcare professionals involved in yours or the claimants care who may be able to provide a letter of support.

Talk to your local council about the Household Support Fund

The Household Support Fund was announced by the UK government in September 2021. It is funding that will be given to local councils to support the households who need it most with the costs of living.

In the Chancellor's Spring Statement, it was announced that the Household Support Fund would be doubling from £500m to £1 billion to help vulnerable households.



Who is eligible for the Household Support Fund will vary from one council to another. You will need to contact your local council to find out more about the eligibility criteria and how to apply. To find your local council, enter your postcode on GOV.UK.

Receive support with your travel costs for medical appointments

Check to see if you are eligible to be reimbursed for your travel costs to hospital appointments. If you're referred to hospital or other NHS premises for specialist NHS treatment or diagnostic tests by a doctor, dentist or another primary care health professional, you may be able to claim a refund of your travel costs under the Healthcare Travel Costs Scheme (HTCS):

<https://www.nhs.uk/nhs-services/help-with-health-costs/healthcare-travel-costs-scheme-htcs/>



Local hospitals may also have their own support measures. For example, if you travel by public transport to Great Ormond Street Hospital, you may be able to be reimbursed for your travel costs providing you meet certain eligibility criteria:

<https://www.gosh.nhs.uk/your-hospital-visit/travelling-gosh/travel-reimbursement/>

Understand your household budget and explore ways to reduce costs.

This might seem obvious. However, there are many tools available to help you plan the incomings and outgoings in your household. It is important to review this especially considering many expenses increasing or set to increase further.

<https://www.moneyhelper.org.uk/en/everyday-money/budgeting/budget-planner>



<https://www.moneysavingexpert.com/banking/budget-planning/>

Get help if you are struggling to pay.

It is always a good idea to contact your suppliers as soon as possible and inform them of the situation as they are often able to provide a short term solution or reduction in costs. For additional help and support, the following organisations offer dedicated support:

<https://www.nationaldebtline.org/>

<https://www.citizensadvice.org.uk/>

www.turn2us.org.uk

For further help read the Martin Lewis "Cost of living survival kit":

<https://www.moneysavingexpert.com/family/cost-of-living-survival-kit/>



For further information ring 0845 241 2173 or email contact@metabolicsupportuk.org

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