

Out of Energy (Contact, November 2022)

Section 1: About the survey

In March 2022, Contact's research¹ with more than 5000 households with seriously ill and disabled children found they had average energy bills of £1,909 per year – £600 more than the typical household bill. Nearly half (42%) said they had gone without heating last winter.

Five months after the unprecedented rise in energy costs in April 2022 Contact asked households with seriously ill and disabled children about the cost of running lifesaving equipment and impact of increased bills on child health.

We also asked households what help they got from their energy companies with their extra costs due to disability and care.

Our survey ran online between 25 August and 5 September and was promoted to Contact's networks. There were 4118 responses (3893 qualifying and completed surveys) from UK families with disabled children.

A large majority of respondents (88%) use more energy because of their child's condition, disability, or care needs. Electrical equipment such as oxygen concentrators, ventilators, ceiling track hoists, wheelchair chargers and suction pumps are vital so cannot be turned off or rationed.

Section 2: Key findings

- Families are paying on average £1596 extra a year to run disability and lifesaving equipment – up almost £600 since April 2022. Even with the price guarantee introduced in October they are continue paying the extra amount.
- More than a third (39%) of surveyed families with disabled children have cut back or stopped using essential medical and disability equipment due to rising energy costs. That figure was 12% before April. That means three times as many families are now cutting back on vital equipment such as adjustable beds, ceiling track hoists, wheelchair chargers and suction pumps, since the April energy price hike.
- 40% of those going without this vital equipment say it is making their child's condition worse.
- For most cutting back on medical equipment like heart monitors, oxygen concentrators is not an option. As a result, we found a worrying trend of families cutting back on heating or getting into debt.

¹ [Out of Energy \(March 2022\)](#)



- Only 3% of surveyed families have managed to get help to run medical equipment via local NHS reimbursement schemes/ medical grants
- In the last 12 months, 79% of families with disabled children have reduced the amount of energy they use because they can't afford their bills and almost half (45%) say they have not been able to keep their home warm enough for their child's needs.

Dad Taran from Kent is a full-time carer to two-year-old Skye who has chronic lung disease, pulmonary hypertension and complex medical needs after being born four months premature. Taran says:

“Skye is non-verbal, tube fed and has heart and breathing problems. She needs a sterile environment. I haven't paid the electricity bill for two months now. I have no idea what to do. I can't take her off the ventilator. I can't not give her oxygen, but I can't afford to run the equipment that keeps her alive. It's scary. Skye can't be in a cold house. If she gets pneumonia, it will be life threatening.

“The extra costs of her ventilation and other medical equipment shouldn't penalise Skye and leave me unable to afford to keep her warm and therefore healthy. Choosing between breathing or freezing isn't a choice anyone should be made to do”

Section 3: Cutting back on using disability and health equipment

Before April, 12% of surveyed families had cut back or stopped using disability aids or equipment because they could not afford the energy costs to run them.

Since April, 39% have cut back or stopped using disability aids or equipment.

This means three times more families are now cutting back on vital disability equipment such as oxygen concentrators, ventilators, ceiling track hoists, wheelchair chargers and suction pumps, since the April energy price increase.

Impact of going without disability and health equipment

For those who have cut back on using disability equipment:

- 40% say it is making their child's condition worse
- 51% say it has increased the family's isolation as they can no longer go out
- 21% say it is affecting their child's education/learning
- 13% say it is affecting their ability to work.

Cost of running disability and health equipment has spiralled since April 2022

- Before April families were paying on average £84 extra per month (£1008 extra per year)
- Since April that went up to £133 extra per month (£1596 extra per year)



As a result

- 79% have reduced the amount of energy they use because they can't afford their bills
- 45% said they have not been able to keep their home warm enough for their child's needs
- 39% have cut back or stopped using disability aids and health equipment since April increase

Section 4: Thinking ahead to winter 2022

51% told us they think they will have to go without heating this winter (29% will go without daily).

When we surveyed families in March 2022, we asked how many had gone without heating last winter and 42% said they had gone without. So a rise of 10 percentage point (21% in percentage terms)

17% said they will go into debt rather than go without heating.

The price guarantee introduced on 1st October which saw prices increase again means the outlook for families with disabled children this winter looks extremely bleak as they continue to pay extra to cover the running costs of disability equipment alongside higher heating bills.

Section 5: Contact is calling on the government to:

- Offer an energy assistance payment for families of seriously ill and disabled children who are unable to access medical grants from local NHS services.
- Double the £150 disability payment and pay it next year
- Immediately uprate benefits in line with current inflation rates to help disabled household through this winter

The Energy Assistance Payment

The [NHS Service Specification](#) states that local NHS Trusts can reimburse running costs of certain equipment such as oxygen concentrator and home dialysis machines used at home. But reimbursement (sometimes called a medical grants) is inconsistent across the country and many patients receive none or very little financial support to pay for the additional energy costs of running medical equipment at home.

Information and awareness of grants and local reimbursement schemes is also poor among families, disabled people, advice charities and NHS providers themselves.

We found only 3% of surveyed families had received help from local NHS trusts or councils towards the costs of running lifesaving medical equipment. Those that had managed to get



a medical grant, usually after a long battle, said not all equipment is included, and grants rarely cover true running costs.

With families now paying on average £1600 extra a year just to run medical equipment (before heating costs and running household appliances), while others have been forced to cut back on running medical equipment due to energy costs.

Therefore, we are calling on the Government to create a national energy assistance payment to replace or supplement the inconsistent access to local NHS medical grants and reimbursement schemes. The energy assistance payment could be administered by DWP to households in receipt of DLA or PIP. There is a similar payment in Scotland for disabled children in the winter

Section 6: Help from energy companies

In the last year, more than quarter (28%) of surveyed households have fallen behind with energy bills.

17%² had contacting their energy company because they have been unable to pay their energy bills.

Sadly, the response from energy companies was poor, with most (80%) of the responses saying no help was offered. A minority had their monthly payment reduced, were offered fixed rates or some form of credit.

Comments from parents of seriously ill and disabled children from the survey
Nothing was done when I contacted my energy company. Said everyone was in the same boat. I can't even submit meter readings anymore because I'm too scared to see how much debt we are in

No real help: was offered to go back to pre-payment meter but that's not really a help as its more expensive

Some of our debt was written off but our monthly payments are still £350

Challenging monthly payment

- Just one in five families (20%) have contacted their energy company to challenge proposed direct debit amounts they have been asked to pay. More than a quarter (28%) say they didn't know they could challenge the direct debit amount. (15% don't pay by direct debit)

However, 42% of those that did contact their energy company were successful in getting their direct debit reduced.

² 20% for households on Universal Credit



- 28% said energy companies refused to change direct debit
- 8% stopped direct debit and agreed to pay bill on receipt
- 1% moved onto a prepaid meter

Help for extra costs and the Priority Service Register

- Less than a third (30%) have told their energy company of their extra energy needs due to their child's condition or disability (19% not sure)

We asked families what their energy company did as a result. Based on 928 responses, 54% said nothing was done

- 39% were put on the priority services register
- 7% were offered help such as a reduced direct debit, signposted to charities for help, given the warm home discount. Some responses indicate that they applied for help but did not qualify.

Positive comments from parents of seriously ill and disabled children about the help offered from energy companies from the survey included:

Added us to Priority Services Register. Allowed us to change the proposed direct debit to just cover what we were using (still a £75 increase to the direct debit) to be reviewed in 3 months.

Put me on the register said to phone back to help me fill out warm home grant for this coming year but it is a drop in ocean

Note: If you live in England, Scotland or Wales, families with disabled children should contact your energy supplier to register as a vulnerable customer on their Priority Service Register. Families should also contact their [local electricity network operator](#) to join their priority register.

Prepaid meters and being cut off from an energy supply

17% of surveyed households are on a pre-paid meter or card (which are the more expensive per unit of energy than most other tariffs)

5% (212 responses) have been threatened with being cut off or where the company has a pre-payment meter installed. Of these, 22% said their energy supply has been cut off this year.

What do surveyed families want from energy companies

Overall responses covered three broad categories:

- Reduced tariffs/cap amounts for households with higher energy costs due to disability or health needs



- More proactive in offering help to disabled households on reducing their bills such as reducing direct debit for those on priority register, grants/credits to households on DLA/PIP (not just low-income household)
- Lobby government for better support for disabled households with higher energy costs

Comments from parents of seriously ill and disabled children from the survey

Protect vulnerable families by capping at a lower rate for those whose health and lives depend on using energy

Make sure I am on a tariff that is affordable for my budget and inform me of any support that I may be entitled to

The standing charge increases are what is crippling us as a family. I can cut back on usage but it's costing us nearly £2.50 a day just to be connected. That's before I've used the washing machine and shower/bath as my child is incontinent

Section 7: Contact is calling on energy companies to:

- Be more proactive in offering help to disabled households on reducing their bills such as reducing direct debit for those on the priority register and to households on disability benefits.
- Integrate their priority registers with similar registers run by network providers and set what support there is for families using disability equipment ahead of potential energy rationing or blackouts this winter.
- Offer grants to help disabled households struggling to pay their energy bills (currently the criteria for some of these grants does not include those on disability benefits)
- Energy companies should stop moving disabled people in arrears to pre-payment meters as these is more expensive.
- Work with government to introduce social tariffs for disabled households.

For more information please contact:

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Full breakdown of survey results by UK nation and region are available on request