

Jeremy Hunt MP
Chancellor of the Exchequer
HM Treasury
1 Horse Guards Road
London, SW1A 2HQ

Wednesday 7 February 2024

Dear Chancellor,

Support for disabled children in the Budget

My name is Samantha and I am writing to you on behalf of families with disabled children and young people across the country.

I am writing to demand extra financial support for families like mine.

I am writing to ask you to commit to a social tariff for disabled households where children, young people and adults are reliant on electrical equipment to keep them alive.

I am writing to highlight the very real difficulties and cuts to financial support families like mine are experiencing when moving onto Universal Credit.

I was absolutely devastated to hear that plans for a social tariff had been shelved. I am literally terrified and too afraid to think about how we are going to cope financially when our financial support drops at the end of this month when we are due to move over to Universal Credit.

My son Lewis, God willing, turns 20 at the end of February. At his diagnosis I was told he might reach the age of 10 – he is a miracle every day. Lewis has a terminal disease called batten disease of which he has the variant CLN14 – the most recently discovered and rarest type. Any form of batten disease is devastating. A seemingly healthy and normal baby, child or young person unknowingly born with this disease will begin to deteriorate until they are barely able to function physically. Mentally and cognitively batten disease devastates families with the horrific onset of childhood dementia and neurological regression coupled with progressive epilepsy and seizures.



There is no cure for batten disease and it is terminal. A family given a diagnosis of batten disease for their child knows their child will die.

Lewis was a healthy and completely typical baby and young toddler. The first sign we had of something wrong was a slight limp at age 2. After this, the deterioration was extreme and within six months my son could not move or speak or eat. After an extended period in critical care in 2013, Lewis was given a tracheostomy in order to help him clear the secretions drowning his lungs and a ventilator to keep his lungs from closing up and collapsing. This machinery, this equipment, this LIFE SUPPORT is how my son Lewis is still here with us at the age of almost 20.

And through all this, he smiles and he laughs and he enjoys every day. Lewis has regular seizures, I have to do everything I can to protect him from everyday coughs and colds, I am his 24 hours a day 7 days a week 365 days a year carer, nurse and personal physician with all the massive responsibility this holds. I never get a break from being this 24/7 mummy to my son – like most mums, my children are everything and I have given my life over to keeping Lewis happy and safe for as long as he chooses to be here. Everyone who meets Lewis can see his sparkly personality and how much he wants to be here. That is why I do what I do – like all mums.

Lewis loves giraffes and being outside in the fresh air. He has been electively home educated since he left hospital in 2013. I ensure that we get out every day, often to our local wildlife park or the nearby woods. Lewis requires round the clock care which I provide with the help of a team of carers and nurses. I get to go to bed at night, but with an emergency buzzer that the night nurse can press if they need me.

The list of equipment Lewis needs to have plugged in and running at all times includes two ventilators, an oxygen concentrator, two feeding pumps, a SATS monitor, 2 suction machines and camera monitors for the nurses and carers to watch over Lewis as they care for him overnight. We must have two pieces of each equipment so that if one piece fails, then we always have a backup.

I currently pay £500 a month for electricity and gas. My bills were around £300 a month before the price increase two years ago and I was lucky to get onto a fixed rate of £500. I say lucky, but only because I was faced with fixed rate offers of £800+ which was terrifying. As a result of the jump in costs, it has been a desperate situation and I struggle financially. The only reason



that Lewis is alive is because of this electrical equipment, I can't turn it off and I can't turn it down.

Sadly it's not just the cost of energy which is so scary - everything has gone up in price. I don't go out socially, I'm here 24/7 with Lewis. We have pets at home as they bring Lewis and myself joy and they are a great way to attempt de-stress, but that's it. The time I get to myself is when I have a bath and read my book (but I still have the emergency buzzer).

Once Lewis turns 20, at the end of the month, our benefits will go down. At the age of 20, Lewis is no longer considered a child, and he will have to apply for Universal Credit. The Child Tax Credits I receive for Lewis (our largest benefit income) will stop and be replaced by Universal Credit, which will be considerably less than the Child Tax Credits I have received. This is truly frightening for me as we already struggle with what we do receive. I am a single parent and Lewis has a terminal disease. It's not possible for me to go out and get a job as I am a carer 24/7. There is nowhere else we can get money from.

In addition, the system is unbearably complicated for young disabled people in education transferring over to Universal Credit. Lewis is clearly unable to ever work and yet we have to go through processes including an interview for fitness to work. It feels cruel for families already under enormous pressure to try to work out how to claim these benefits, and to try and pull together all the information and 'evidence' required.

Without charities like Contact, families would be left alone to navigate the benefits minefield, and it IS a minefield. I was lucky enough to come across Contact's Facebook page and their extensive website. It was the only place I learned just how drastically the benefits system changes for children transitioning into adulthood, despite their care needs staying the same or increasing. It was only through a telephone conversation with Contact's listening ear service and later their helpline that I found out what I needed to do to ensure that our financial losses are kept to a minimum. Had I relied on information from the benefits system itself, Lewis and I would have been left destitute, as all of Lewis' childhood benefits would have stopped for a minimum of five weeks. As it is we are still going to be worse off, but not by as much as could have happened without Contact's advice.

Contact's research has found that 40% of families with disabled children and young people are worse off since claiming Universal Credit, despite



assurances from government that no one would be worse off. Close to two thirds of families say that caring responsibilities mean they or their partner had to given up paid work, losing on average £21,270 from their family income.

On behalf of all the families living this life, the families stepping up and being the parents their children need, please, urgently, let us see:

- the swift introduction of an energy social tariff for families like mine where there is a person reliant on life-saving electrical equipment in the household.
- steps taken to ensure families with disabled children are not worse off under Universal Credit, including a simplified route for young disabled people in education to claim Universal Credit.
- a series of cost-of-living payments for disabled households to help us cover extra costs.

I am urging you to take steps to ensure families with disabled children and young people are not financially disadvantaged during this cost of living crisis. We did not choose to live this way. We are doing the absolute best we can for our children. Lewis may not be classed as a child anymore in years, but he is a child, a child in need, he is my precious little boy.

My heartfelt thanks for taking the time to read this letter and for taking the time to consider us and all we do. Please help us to help ourselves better.

Yours sincerely,
Samantha from Doncaster

My letter is also backed by almost 3000 families with disabled children who have signed up to support my letter. It is also supported by more than 100 disability charities from the campaign group Disabled Children's Partnership which is led by Anna Bird from the charity Contact.