

Rt Hon Rishi Sunak MP and
Rt Hon Liz Truss MP

26 August 2022

Dear Mr Sunak and Ms Truss

Urgent financial support for families of seriously ill children

As a group of charities that represent and work with seriously ill and disabled children and their families, we ask you both to agree a package of financial support for these families. This is needed now, before the Conservative leadership election concludes.

Like many, these families are alarmed that the energy price cap will rise by 80% in October, with a further rise predicted in January.

However, families of disabled children will incur even higher energy costs. Research shows that families with seriously ill and disabled children are already paying almost double that of an average UK household on their energy bills. This might be due to life-saving equipment powered by electricity or extra washing due to continence issues. Some disabled children are less mobile and get colder quicker. Others have health conditions that mean they can't regulate their body temperature.

Elisa from Bournemouth is one of the thousands of children across the UK for whom families need to pay even higher energy bills just to keep them alive. In May, the Daily Express delivered a letter from Elisa's Dad, Dan McEvoy, to 10 Downing Street asking for urgent help from ministers. We welcomed the UK Government's cost of living support package that followed, which is helping families of disabled children and recognises their unique situation. While one-off payments are having an impact, we are very concerned that they are not enough to address the additional challenges that disabled children and their families will face this winter.

We are therefore calling on the government to go further by providing an energy assistance payment for families of seriously ill children who are unable to access medical grants from the NHS, and to double the £150 disability payment when it is paid in September to reflect their higher household and energy costs.

We support calls for an emergency uprating of benefits in line with current inflation rates, which should come into effect in Autumn. We would also be interested in exploring the idea of social tariffs as a long-term solution to reducing energy bills for household with high energy usage due to disability.

Time is short for these children, some of whom are seriously ill and unlikely to reach adulthood. Their families cannot wait long for the government to act.

Yours sincerely

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Matt James, Chief Executive, Wellchild

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Caroline Stevens, Chief Executive, National Autistic Society

Jolanta Lasota, Chief Executive, Ambitious about Autism

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Helen Hewitt, CEO, Chailey Heritage Foundation

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Maria Timon Samra, Chief Executive, Tŷ Hafan Children's Hospice

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Rami Okasha, Chief Executive, Children's Hospices Across Scotland

David Webster, Chief Executive, Douglas Macmillan Hospice

Lavinia Jarrett, Chief Executive, Demelza Hospice Care for Children

Tracy Johnstone, Chair, Charlie House

Heather Weir, Chief Executive, Northern Ireland Hospice

Luen Thompson, CEO, Forget Me Not Children's Hospice

Chris Baker, CEO, Richard House Children's Hospice

Martin Edwards, Chief Executive, Julia's House Dorset and Wiltshire Children's Hospices

Jan Hall, Chair of Trustees and Co-founder of the Charity, Thomas's Fund

Toni Mathieson, CEO, Niemann-Pick UK

Michael McGrath, Founder & CEO, Muscle Help Foundation

Sarah Dearman, Chair and Trustee, The Children's Hyperinsulinism Charity

Lisa Hopkins, Chief Executive, SeeAbility

Carol Boys, Chief Executive, Down's Syndrome Association

Lesleigh Bounds, Chief Executive Officer, White Lodge

Mark Arnold, Additional Needs Ministry Director, Urban Saints

Sally Polanski, CEO, Amaze