

Together for Short Lives

Vulnerability and Carbon Monoxide Allowance

1 August 2023

SGN



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1 Description

Funding GDN(s)	SGN
For Collaborative VCMA Projects:	
Date of PEA submission:	01 June 2023
Project contact name:	Kerry Potter
Project contact number/email:	Kerry.potter@sgn.co.uk
Total cost (£k)	£500,149
Total VCMA funding required (£k)	£500,149

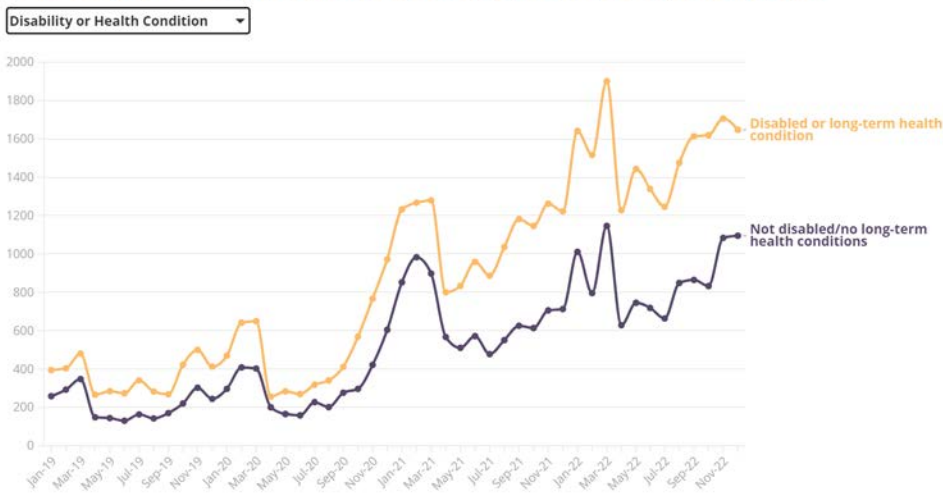
2 Problem statement

Against a backdrop of the UK’s energy prices doubling in the past 12 months it is currently estimated that there are over 6.7 million households living in fuel poverty in the UK.

Data shared by Citizens Advice as detailed in the February 2023 [Cost of Living Crisis dashboard](#), has demonstrated that it is disabled people and those living with a health condition that continue to be most likely in energy crisis and requiring tailored support, and that it’s this group who are disproportionately going into energy debt as the energy needs are greater and the impact of self-disconnection is more acute.

Extracts from the February 2023 [Cost of Living Crisis dashboard](#):

The number of people we’re helping with practical energy efficiency advice every month by demographic group



Together for Short Lives

Average energy debt held by the people we help with energy debt by health status



During this unprecedented time, Together for Short Lives is very aware that there are many families with children who are seriously ill, with a life-limiting or life-threatening condition, who are experiencing greater levels of stress as increased costs impact on household income. These are families who were already facing increased, hidden costs when looking after their child with complex needs at home. This cost-of-living crisis has exacerbated the situation even further, particularly for those families whose children rely on life saving technology for their everyday needs.

Many families depend on electrical equipment to maintain their child's health status, prevent further disability, and enhance their quality of life. For other families some equipment such as ventilators are used to sustain life. For all of these families, extra energy costs cannot be avoided. Essential equipment like ventilators, food pumps, hoists, warming blankets all add up to bigger bills. Families do not have a choice whether to use them less or switch them off. They are left with spiralling costs that they simply must meet if they want to keep this life-saving equipment switched on and helping their child.

Children who are technology dependent have been found to have a significantly lower health-related quality of life. Therefore, it is important to support these children to live at home and have as normal a life as possible. Providing support to a family to ensure they are able to remain at home and out of hospital is therefore paramount. Furthermore, seriously ill children are twice as likely to live in a home where, due to their caring responsibilities, there is no parent in paid work. Compared to 4% a decade ago, 33% of families with a seriously ill child have taken out a loan in order to pay for food. The situation for these families is pressing and escalating - 64% of families with a seriously ill child expect their financial situation to worsen over the next two years.

Whilst the government and charities have announced some support for cost of living across all four nations of the UK, many families are excluded from help as they don't meet the eligibility criteria.

Contact, a leading charity for families with disabled children, has recently surveyed families about their energy costs:

- Families say they are paying on average £1,596 extra a year to run disability equipment – up almost £600 since April 2022, set again to rise later in 2023
- More than a third (39%) have cut back or stopped using disability equipment due to rising energy costs, three times higher than before the higher energy price cap rose in April 2022
- 40% of those going without this vital equipment say it is making their child's condition worse
- In the last 12 months, 79% of families with disabled children have reduced the amount of energy they use because they cannot afford their bills
- Almost half (45%) say they have not been able to keep their home warm enough for their child's needs

Calls to the national helpline at Together for Short Lives (TfSL), and discussion threads in their private Facebook group, demonstrate that these issues are having considerable impact on the families they support. Many families are having to make impossible decisions about protecting the health of their child versus protecting financial

security. To keep equipment running, families are making choices between heating their home and putting food on the table.

Furthermore, families report that they are worried about what will happen if the power goes off, for other families there are concerns about pre-payment meters and escalating debt. As all equipment relies on energy, this means that children who are dependent on such technology would be at risk from serious deterioration in their health, possibly choking and dying. These families are constantly living in survival mode. Many of them are unaware of the Priority Services Register (PSR) and we must ensure that their utility companies are aware of the additional and critical requirements, and the impact of a supply interruption on health and wellbeing – especially for those on life support equipment.

Over the past six months TfSL has seen families face unbearable decisions where they are unable to continue to care for their child at home or transfer them to hospital or the hospice as they have found energy bills unaffordable rendering them unable to provide adequate care at home.

3 Scope and objectives

The objective of the initiative is to minimise the health and wellbeing impacts on families who are caring for others ensuring they have the required energy safeguards in place.

SGN and Together for Short Lives are delivering a partnership running from August 2023 to April 2026.

The scope of the initiative provided by Together for Short Lives will support families who are providing palliative care to a child within their family by:

- Promoting the importance of getting signed up to the Priority Services Register delivered in a multi-channel approach including social media, community workshops and with case worker support where needed
- Providing access to a dedicated energy advice service for families that understands what support is available to help them address energy issues including providing emergency fuel vouchers where households are reliant on assisted technology and are unable to afford the energy for their homes; delivered in a multi-channel approach including social media, community workshops with case worker support where needed
- Where it is assessed that the households are unable to afford to heat their home to a satisfactory temperature, the partnership led by the dedicated caseworkers will then look at other ways to support them such as a crisis fund which can help with 'heat the person' assets such as electric throw blankets, a low cost to run alternative that will increase wellbeing
- Provide a targeted campaign to reach the BAME community and marginalised communities (particularly prevalent in SGNs Southern area) delivered through a specialist marketing agency
- Provide onward support to families in need via a network of partners that are able to tailor their services to help families with children with terminal illness including but not limited to Turn2us and Evie's Gift

4 Why the project is being funded through the VCMA

This project will provide support to those most vulnerable, those providing in home support for young people with life limiting illness providing access to energy safeguards including simple access to the Priority Services Register and help that addresses fuel poverty tailored to the needs of families. This project will provide support for households that are extremely vulnerable whilst delivering a positive Social Return on Investment.

5 Evidence of Stakeholder Support

5.1. Citizens Advice – Cost of Living Dashboard

Citizens Advice are collating the data from the support they're providing in our communities, this data is significant and has highlighted not just the increase in need for households throughout the last few years, but

more recently the challenges faced by customer groups most impacted by the cost-of-living crisis. Key insights from the research highlights that there has been a significant increase of households in energy crisis, those unable to afford to top up prepayment meters or going into energy debt. All indicators on cost of living and energy crisis highlight that disabled people and those with health conditions have more adversely impacted than non-disabled people due to their increased energy needs and the impact of inflation on benefits.

Many of the children supported by TfSL depend on a variety of equipment to maintain their health status and prevent further disability or to sustain their life. Life-saving and non-medical equipment and consumables such as wheelchairs, special mattresses and hoists are all dependent on electricity to work - without them children's quality of life would be seriously compromised.

5.2. Together for Short Lives

As the national charity for children's palliative care, Together for Short Lives works with families who have a child with a life-limiting condition and the professionals involved in their care/professionals who care for them. Their expertise is in this very specific area of care and have both the networks and brand relevance to deliver this project to families. The charity is a recognised brand, known as a children's palliative care organisation - meaning that families can access this service feeling reassured that they are being supported by an organisation that truly understands the sensitive issues that affect them.

Together for Short Lives also has a large network of professional relationships, working with over 1000 professionals and organisations such as children's hospices. This will provide a means to reach families who need the support. In addition, the reach via social media channels with over 26k followers on Twitter, will provide another direct route to share advice and to promote the Priority Services Register directly with families and the charities who support them. Through their family support hub, accessed by the national Helpline, the team are able to direct families and professionals caring for them to a wealth of resources, relevant information and support. The Helpline is delivered remotely and is free to call from UK landlines and UK mobiles and currently operates Monday to Friday from 9am - 4pm. The helpline team is available to respond to calls, Live Chat and email.

Together for Short Lives, also recognises the clear benefit of working with service users to co-design and inform their work. They use parent volunteers as experts, an advisory board and as trustees, as research participants, for media purposes and as moderators for the Family Facebook group. They recognise that a family's voice is a powerful tool for Together for Short Lives' campaigns and lobbying. It can also be beneficial to families to feel that they are giving something back and improving the experience of other families in their situation. They also recognise the need for peer support and host three private Facebook groups and provide regular online 'informational' workshops, with invited speakers, to enable families to have time to reflect and evaluate and to share experiences with others. These provide reassurance to other families that they are not alone on their journeys.

Below are two case studies of families who are supported by Together for Short Lives to highlight the challenges faced by families caring for young people with terminal illnesses.

Case Study – Kerry, Daniel & Louie

For Kerry and Daniel, the cost of running their home and caring for Louie has doubled in the last year. Louie, who will be three in October, needs life-saving equipment including a ventilator, saturations monitor, and a baby monitor; these machines all have to run 24 hours a day. Louie who is incontinent, does not qualify for nappies until he is five and so the family also need to cover the cost of incontinence nappies. In addition, Louie can get through three outfits a day, so the washing machine is constantly in use. Louie can have as many as five hospital appointments a week in three different locations. Kerry's monthly fuel cost is between £300-£400. It costs £1000 to care for Louie alone and they are in receipt of the higher DLA payment of £350. Louie is one of three children in the family, there are tough decisions made daily so that they can make ends meet.

Kerry said: “This cost-of-living crisis is affecting everyone, but some of us more than others. Daniel and I are dreading how we are going to get through it. We are also parents to two other small children, and we feel through no fault of our own that we are often left with no choice but to let them down, to ask them to go without simple things like a day out. Parents with seriously ill children don’t know how long they have with them, every moment is precious, and we want to make our time together as joyous as possible, not constantly fighting for survival.”

Case Study – Sophie & Isabel

Sophie is mum to Isabel, age 11, who has Batten disease: “Isabel is bed-bound and palliative. She isn’t able to leave our home and is completely dependent on another person for all of her care.” Isabel relies on a magnitude of equipment to keep her comfortable and alive, we are running a mini-intensive care unit in our home” says Sophie. She requires regular suction day and night to stop her from choking and high flow oxygen therapy to help her breathe. Isabel isn’t able to control her own temperature and so heated blankets keep her warm, and the heating in the house must run to keep her temperature at a safe level.

Sophie has to regularly run the washing machine due to incontinence. Due to stiff and painful muscles, the family bought a special hot-tub to provide at-home hydrotherapy to ease Isabel’s pain: “We can no longer meet the rising costs of running this, and so we will have to switch it off. Which means that Isabel will no longer be getting the relief she needs from stiff and tight muscles. Every part of Isabel’s life relies on the use of machinery, which obviously runs on electricity. Our bills are rocketing and we can’t manage for much longer. It’s terrifying and it just feels out of control. The reality is that Isabel will only live for a few months, or a year or two more if we are really lucky. And what will we be left with? Overwhelming grief and debt.”

5.3. SGNs Vulnerable Steering Group

Our Vulnerable Steering Group has helped us shape our vulnerability strategy and our priorities for GD2 from strategy into delivery. With their guidance we intend to prioritise key initiatives to support our most vulnerable customers.

With a data driven approach to identify communities most likely to suffer detriment from living in a cold and unhealthy home it was identified that we should prioritise programmes that help those with critical medical needs especially those at end of life. In 2021 our strategic steering group re-iterated the vital impact we could have by co-ordinating our activities with others to identify and support those most in need, those most impacted by the cost of living and energy cost crisis.

6 Outcomes, associated actions and success criteria

6.1. Outcomes

Working together the three year partnership will enable SGN and Together for Short Lives to:

- Improve the ability of existing staff and professionals/hospice staff to identify fuel poverty in homes and provide appropriate information and resources to the most vulnerable families
- Support families who are caring for a terminally ill young person at home with access to the Priority Services Register helping them achieve greater resilience and peace of mind should they experience a supply interruption or need extra help from their utility companies
- Train existing helpline and outreach teams to be able to handle enquiries with greater knowledge about utility companies, energy questions and fuel poverty
- Provide a support service via the TfSL helpline and established outreach services to help families who are having difficulties with their energy bills or facing energy debt helping them to stay safe, warm and at home
- Provide a targeted engagement campaign for the BAME community via a pilot in the south-east SGN network

- Ensure families have more choice and access to a range of information and correct financial support to cope with issues of poverty via a network of experienced partners who are familiar with the needs of families managing terminal illness including but not limited to Turn2us, Evie's Gift and Rosie's Rainbow Pantry
- Increase reach across areas of highest need and the most vulnerable families
- Increase awareness and uptake of the core services and support offered by the Together for Short Lives Family Hub
- Increased insights to support the Together for Short Lives policy team to provide an evidence base to identify issues which require systemic change in policy and practice in order to reduce fuel poverty for families of children with life-limiting condition

6.2. Success Criteria

Working together, SGN and Together for Short Lives will be looking to support families caring for young people with a life limiting condition, to stay safe and warm at home for as long as they wish. Over the duration of the partnership, we are aiming to deliver the following customer outcomes, which has formed the basis of our social return on investment modelling.

Total customer reach of the programme is targeted to reach **27,000** vulnerable households and **1,000** professionals working in the children's palliative care sector. To break down as:

- 1,000 professionals across the Together for Short Lives network including hospices provided with energy safeguarding training inclusive of PSR and Fuel Poverty support via the network of palliative care and hospice networks
- 24,000 vulnerable households nationally, provided with information on the Priority Services Register and given energy efficiency and energy scheme benefits information (including information on carbon monoxide awareness) through our social media channels, media campaign and promotion, with a success rate of at least 2,500 new PSR registrations. These households additionally supported to access onward support via embedded referral networks to address poverty and debt including but not limited to Turn2Us and Evie's Gift (TfSL partners)
- 3,000 families to be offered (via hospices), targeted support via an energy support officer with potential for this to be escalated to a caseworker. (south-east only). Of this number:
 - 650 to receive fuel vouchers. south-east only
 - 330 to attend workshops. south-east only
 - 200 households provided with a carbon monoxide alarm where required

In addition to the above specific success criteria, we believe that the partnership will ensure further impact by:

- Decreasing anxiety and worry regarding rising energy costs for those looking after children with a terminal illness
- Reducing the number of difficult decisions families need to make between having their heating on or feeding their family
- Enabling families to continue to power and use their vital electric medical equipment so children can stay and be cared for at home, rather than transferring them to hospital / hospice care thus reducing the impact on the NHS
- Increasing the quality of life for children with terminal illness by enabling them to continue to enjoy therapeutic benefits from powered equipment and promoting a sense of normality in their homes
- Helping to inform policy and influence decision makers thereby benefitting the position for families in the future through awareness raising and an increase in funding

7 Project partners and third parties involved

- **Together for Short Lives** – to deliver the campaigns, training, workshops and support via energy support officers embedded within the TfSL team. To identify and provide support services to eligible vulnerable households. Delivering support via unique access to a network of professionals (15 palliative care networks) and hospices (54 children’s services) across the country to cascade information
- Onward support provided via the network of partners working with TfSL including but not limited to:
 - **Turn2Us** – a national charity providing practical help to people who are struggling financially
 - **Evie’s Gift** – offering immediate financial assistance to parents whose children have been admitted to hospital with a life threatening or life limiting condition, this charity will aim to pay for 2 nights’ accommodation locally and help meet other costs associated with being near their child while they are in hospital
 - **BBC Children in Need Emergency Essentials** - the fund provides essential items such as washing machines, fridges etc, for families facing poverty. Currently paused as oversubscribed but anticipating that it will reopen later in 2023
 - **Rosie’s Rainbow Pantry** - providing food and provisions for families whose children are receiving palliative care
- **SGN** – provide funding and ongoing support to deliver successful outcomes for the programme including funding for training, fuel vouchers, heat the person resources and carbon monoxide alarms
- **National Energy Action** – providing energy advisory training where required for energy support officers
- **Think CO** – providing training specifically for carbon monoxide awareness
- **Hospice network** – identifying families in need of support the network will include the following local hospices and support groups:
 - Chestnut Tree House
 - Naomi House & Jacks Place
 - Helen and Douglas House
 - Rennie Grove
 - Julia’s House, Dorset
 - Demelza, Demelza Kent and Demelza South East London
 - Shooting Star
 - Ellenor

8 Potential for new learning

Monitoring and evaluation

Evaluation and measuring impact will be vital to the success of the project and in ensuring that we remain up to date and accessible to all families who need our support. It will also be crucial in determining the success of the pilot project and will help to inform expansion of the initiative to other regions of the UK (subject to further funding from other GDNs).

Monitoring will include:

- Capture data on the awareness / promotion to identify how many people the campaign reaches
- Capture numbers of callers to the helpline who are referred to the Energy Support Officer including demographics, vulnerabilities, and needs
- Capture numbers who are referred on to a dedicated Caseworker
- Record number of fuel vouchers / heat the person assets allocated
- Capture numbers and demographic information about those receiving enhanced support (referred on to other services or partners)

- Offer families an opportunity to complete a survey or to be interviewed about their experience of the service provided through the Helpline
- Record number of workshops held and any feedback from the workshop attendees
- Record number of families and professionals who attend training and any feedback from attendees

Learning

The outcomes of the project will be shared at a minimum across our partnership network and with other energy network / energy supplier organisations via the Utilities Customer Safeguarding working groups and other key stakeholder groups linked to supporting vulnerable customers.

9 Scale of VCMA Project and SROI Calculations

We worked with leading social impact research consultancy SIA Partners to carry out an assessment of the financial and wellbeing outcomes applicable to our services for vulnerable customers incorporated in this partnership. Carrying out an in-depth assessment of the predicted outcomes we forecast a positive net social return of £2.42.

Social Value Measurement

Total cost*	£482,196.80
Total gross present value	£1,650,715.31
Net Present Value (NPV)	£1,168,518.51
SROI	£2.42

**Accounting for inflationary factors over the term of the project.*

10 VCMA Project start and end date

The project will run from August 2023 until April 2026

11 Geographic area

SGNs network areas

12 Approval

Rob Gray - Director of Stakeholder Relations and Communications