

Supporting Families Together with CHAS and BGET

Vulnerability and Carbon Monoxide Allowance

April 2024
SGN



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1 Description

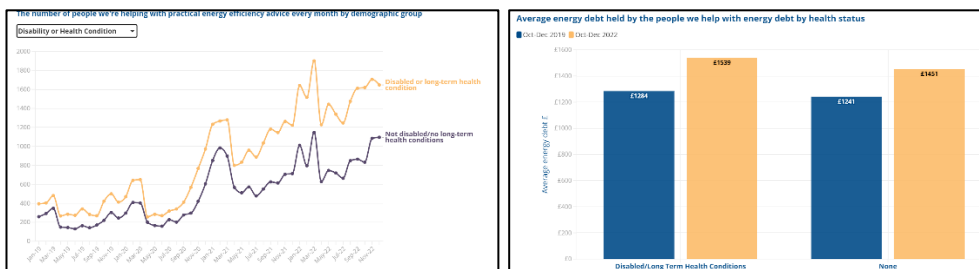
Project title	Supporting Families Together in partnership with CHAS and BGET
Funding GDN(s)	SGN
New/Updated (indicate as appropriate)	New
Date of PEA submission:	April 2024
Project contact name:	Margaret Hamilton
Project contact number/email:	Margaret.hamilton@sgn.co.uk
Total cost (£k)	£274,312
Total VCMA funding required (£k)	£97,103

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:



During this time, Children's Hospices Across Scotland (CHAS) have been very aware of the impact the cost-of-living crisis is having for many families with children and young people who have life-threatening and life-shortening conditions. They are experiencing greater levels of stress as increased energy costs impact on household income. The community nursing team and social work teams are experiencing an increase in support services required from families especially those 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 some families, equipment such as ventilators are used to sustain life. Essential equipment like ventilators, food pumps, syringe drivers, hoists, warming blankets and so on add up to larger bills which are now unaffordable. These additional energy costs cannot be avoided, families have no choice whether to use them less or switch them off as they are essential, they are left with spiralling costs that they simply must meet.

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 and young people 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

paramount. 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.

These families, as well as facing the heart-breaking reality that their child will die young, also have to cope with the stresses of caring 24/7, as well as the financial pressures of increased energy usage to keep their homes warm at all times. For most families they are faced with energy debts, and as they find ways to try and reduce their household outgoings, additional expenditure such as appliance servicing and replacement of older appliances can put them at risk of the dangers associated with carbon monoxide or rationing their energy supply to keep up with the rising energy costs.

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

Most families in this situation are also 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.

There are currently 16,700 children with short-life expectancies across Scotland and last year CHAS supported 477 of the most complex and severe cases. Over half of the families referred to CHAS come from areas of multiple deprivation and required specialised care packages based on each family's individual needs. Most are having to make impossible decisions about protecting the health of their child versus protecting financial security. Simply in order to keep equipment running, families are making choices between heating their home and putting food on the table.

During Winter 2023 CHAS have seen an increase in families who have found energy bills unaffordable and are facing unbearable decisions around the care for their children.

Partnering with SGN and British Gas Energy Trust will help us provide the necessary support for families across Scotland to help them use their energy safely, efficiently, and affordably.

3 Scope and objectives

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

SGN, CHAS and British Gas Energy Trust are delivering a partnership running from May 2024 to March 2026. This initiative will support families CHAS is working with across Scotland, in their two hospices (Rachel & Robin House), in hospital and at home. The CHAS Financial Wellbeing and Energy Advice Team will provide one to one support to families who are referred through the community nursing and social work teams as identified as needing further support to maintain a safe and warm home.

The scope of the initiative provided by CHAS and the specialist team 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 through the Financial Wellbeing & Energy Advice team who are providing one to one holistic in-home support, whilst promoting wider the benefits through the community nursing, social work teams, hospices, and multi-channel platforms.
- Providing energy safeguarding support to all families to help them become more resilient in situations where they lose energy or water supply at property.
- Providing direct and practical energy advice service to help families facing financial pressures around energy costs. Helping them understand their energy usage, budget their household costs, support with energy debts, access to emergency crisis funding via fuel vouchers and onward support to help them improve the warmth in their home through funded local or government schemes.
- Providing access to income maximisation help increase money in families' pockets, supporting them access benefits and other support services specifically for the vulnerable circumstance of the family.
- For those families who are connected to mains gas supply or use coal or oil provide access to and advice regarding safe usage of these fuels, have access to and help with both safe installation and regular maintenance of such systems & appliances as well as the use and installation of Carbon Monoxide monitoring devices. This is addressing a clear risk. In times of particular financial stress there is likelihood that spend and outgoings which can be deferred, will be deferred.
- For those families unable to afford to service their gas appliances, access to SGN's Care and Repair Scheme to provide free gas appliance servicing, reducing risk of unsafe appliances and CO within the home.
- Providing energy crisis funding throughout the winter to families struggling to maintain a safe and warm home, critical for the wellbeing and health of family members.
- Providing respite and activities work through to end-of-life care and post bereavement counselling, which includes whole family practical, psycho- social and medical support.
- Providing 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, React, and Kayleigh's Wee Stars

This initiative will be supported by a coordinator who will provide quarterly insight and case studies on the impact this collaborative initiative is providing for CHAS families supported.

4 Why the project is being funded through the VCMA

The project delivers against SGN's Vulnerability Strategy, by providing targeted 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.

The partnership service aligns to our strategic ambition to support customers in energy crisis, helping those in fuel poverty to access financial crisis support, and other services including the Priority Services Register, awareness of the dangers of Carbon Monoxide and energy efficiency advice, empowering vulnerable households to use energy safely, efficiently, and affordably.

This partnership aligns to the SGN commitment to deliver support services customers aligned to our four strategic pillars:

1. Services Beyond the Meter
2. **Supporting Priority Customer Groups**
3. Fuel Poverty & Energy Affordability
4. Carbon Monoxide Awareness

This project aligns to strategic pillar 2 (with outcomes in pillars 3 and 4).

5 Evidence of stakeholder/customer 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.

5.2 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.

5.3 CHAS

As the Scottish charity for children's palliative care, Children's Hospices Across Scotland (CHAS) supports families who have a child with a life-limiting condition. Their expertise in this very specific area of care means they have both the networks and brand relevance to deliver this project to families in Scotland. Families can access this service feeling reassured that they are being supported by a charity that truly understands the sensitive issues that affect them and will provide practical support, care, and advice.

CHAS has a large network of professional relationships, with over 350 staff and 400 volunteers, and thousands of expert relationships in NHS Scotland, local authorities and third sector organisations. This will provide a means to reach families who need the support. In addition, their reach via social media channels on Twitter, Facebook, Instagram, and LinkedIn will provide another direct route to share advice and to promote the Priority Service Register directly with families and the other professionals who support them. Through the financial wellbeing and energy advice team, they are able to direct families and professionals caring for them to a wealth of resources, relevant information, and support.

CHAS recognises the clear benefits of working with young people and their families to co-design and inform their work. They have both current and bereaved parent volunteers as experts supporting the development of their strategic plan, as Trustees, as research participants, for media purposes and as fundraisers. Young people and their siblings are consulted on changes to their services and are helping with changes to one of their Hospices. It can 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 are currently reviewing how best to facilitate families coming together in addition to the informal, in person meetings had in the Hospices. This

provides reassurance to other families that they are not alone on their journeys and enable them to collectively reflect and evaluate.

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

5.4 Case Study 1

An energy efficiency survey was taken at V's home in Edinburgh August 2023.

V resides at the family home with her husband J and their three children, one is registered with CHAS as having a life shortening illness and requires continual care 24/7. Essential clinical equipment is required for their son, which adds to the family's electricity consumption.

During the survey, it was noted that the property was insulated to current standards, although there were two areas, which could be improved upon at a DIY level.

General energy advice was given to both V and J, who were already quite conscious of their energy consumption, and they also demonstrated a high level of energy efficiency awareness.

They informed us that having just moved into the council owned property; they were tied into the existing energy supply for the duration of a 'transitional' period. I suggested to them that they might want to consider alternative energy suppliers when they were able to. I also informed them as to what they should consider before switching supplier, such as fixed / variable tariffs and any early 'exit' fees they might incur. They welcomed the suggestion that regular meter readings were recorded during this period.

It was noted that the family were using their conventional electric oven on a frequent basis, so suggested that a new combi-oven would be more useful from an energy perspective and also more convenient as they require the preparation of different meals during the day. A selection of combi – ovens were made available to them through the BGET extra practical measures fund. Their chosen type has since been delivered at no charge and V tells us that it sees frequent use.

In addition, we applied for a Home Heating Advice Scotland grant which they were subsequently awarded. This award totalled £1,000 toward their energy account. They were very grateful for this, as both had incurred substantial financial costs in the process of moving house.

Prior to the energy advice referral, they had been referred for income maximisation and a benefits check. It was identified that a sibling suffers from ADHD and requires a lot of support and input. A claim was made for Child Disability Payment, and this was awarded at Middle rate care and Low-rate mobility. This then meant that their Universal Credit could increase with a disabled child amount and a carer's amount. The total financial gains for the year through these benefits and backdates is £11,472.40.

5.5 Case Study 2

C resides in the family home in Fraserburgh, which he shares with his mother, his brother, and his niece, who is registered with CHAS as child suffering a terminal illness. C's brother also lives with an ongoing medical condition. The child is oxygen dependent and requires 24/7 cares and attendance.

A referral was made to our energy advice team via CHAS admin to visit the family home to undertake a home energy visit, which was conducted in August 2023. The property is an owner-occupied bungalow. Areas assessed were its construction, glazing, doors, heating system, roof, and floor type. All aspects of the property met expected modern standard with full insulation levels to walls and roof. Glazing and doors were to a better than average standard. Heating system was efficient, modern and in good working condition.

During the visit, we gave general energy efficiency advice to the family, although they quickly demonstrated that they had good existing knowledge of the same.

Given their location, we suggested to C that their property was ideally suited to the installation of a solar photovoltaic system, along with battery storage. With his agreement, I then raised a referral to Home Energy Scotland, who have since been in touch with C, to assist with the funding options available. This remains ongoing.

On my return from the visit, we applied for a Home Heating Advice grant for C's family. They were later awarded a total of £1,350 which was credited directly into their energy supplier account.

A referral was also made for income support with the family wellbeing team at CHAS. C has recently become kinship carer to his niece and sought advice about benefit entitlements and discounts. As the child is a 'Looked After Child,' C is limited to which benefits he can claim. Assistance was given to claim Child Disability Payment for his niece under special rules for people who are terminally ill. This was awarded at High Care and backdated to birth. Assistance was also given to claim Child Benefit and Scottish Child Payment for his niece. The financial gains for these benefits and backdate total £9874 for the year.

A benefits check was also offered to his elderly mother, and she was found to be in receipt of all of her entitlements.

6 Outcomes, associated actions, and success criteria

6.1 Outcomes

Working together, the two-year partnership will enable CHAS, BGET and SGN to reach around 1000 families providing direct one to one support for 400 families (1100 beneficiaries) and providing a further 600 families through CHAS community volunteers over the duration of the project through awareness raising of fuel poverty, energy safeguarding, PSR /CO awareness.

The partnership will support 400 families providing in home or direct support by providing

- in-depth fuel poverty support to families who are living with a child who has a life shortening condition who are at risk of self-disconnection, rationing their energy supply, issues with fuel billing or energy debt
- advice and promotion of energy efficient behaviours including heating system advice, energy efficient measures, helping people to understand energy bills and meters, accessing discounts (e.g. WHD), accessing energy vouchers and tariff/supplier switching
- fuel and other debt advocacy, including wider debt and benefits advice and referral if necessary to families reducing financial stress and worry and improving health and wellbeing (average value)
- support families to access hardship funds or vouchers in house from CHAS and externally from other charitable funds
- raise awareness of the Priority Service Register amongst vulnerable families and increase registrations amongst CHAS supported families – around 60% will join PSR
- awareness of CO dangers, preventions, and mitigations and how to be safe with the families
- provide families with free CO alarms
- referrals for families to grants and schemes for energy saving measures (e.g. through Warmer Homes Scotland)
- provide free essential servicing for families who are at risk of inefficient/unsafe appliances within the home

6.2 Associated Actions

Also as part of this partnership, as well as supporting the 400 families, we aim to reach at least 300 people per annum in the wider CHAS community, staff and volunteers providing information on energy saving advice and

dangers of CO information via various activities e.g. delivering briefings to front-line staff, attending relevant forums and networks to distribute information, articles through all relevant media channels.

6.3 Success Criteria

Our aim is for all families supported by home visits for energy advice to be better able to manage their energy safely, efficiently, and affordably reducing the risk of further fuel debt:

- 400 families supported health and wellbeing –safeguarding families
- 400 supported with in depth fuel poverty advice and debt advocacy
- 400 supported with income max and debt advice
- 400 supported with energy advice and promotion of energy efficient behaviours
- 400 will receive CO awareness conversations
- 100 will receive a CO alarm
- 300 will access hardship funding for household essentials (value £120 on average CHAS funding 36k over 2 years)
- 150 will receive winter crisis funding (energy vouchers £50 per family) SGN £8200
- 400 with receive PSR awareness advice
- 240 energy PSR sign ups
- 400 water PSR sign ups
- 400 Warm Home Discount conversations
- 100 Warm Home Discount referrals
- 50 families will receive free gas appliance servicing through SGN’s Care and Repair scheme
- 300 referrals to grants and schemes for energy saving measures (e.g. through Warmer Homes Scotland)

Additional Outcomes -

- 600 families have access to energy saving advice, PSR and CO awareness to wider CHAS community

7 Project partners and third parties involved

CHAS has many existing partnerships within the statutory and voluntary sector, including NHS Scotland and local authorities.

The formal partners in this project will be Children’s Hospices Across Scotland (CHAS), British Gas Energy Trust (BGET) and SGN (Scotland).

8 Potential for new learning

Monitoring and evaluation

Qualitative and quantitative reporting will be provided by CHAS through this partnership on the outcomes agreed.

These will include measures such as:

Quantitative

- Number of specific activities carried out
- Number of direct interventions with fuel suppliers
- Number of EFV issued
- Number of other fuel funding sources approached for family support
- Number of CO awareness sessions carried out

- Number of referrals to PSR
- Number of wider, general debt cases
- Number of other financial support mechanisms accessed on behalf of families

Qualitative

- Feedback, indicators, outputs, and outcomes reported on quarterly
- Service user before-and-after-support surveys and follow-up calls
- Case studies
- Family reports and quotes

Learning

It is hoped that the main learning outcomes would be as follows

- A greater awareness of the unique needs of families living with a child who will die young
- An insight into the pressures upon family budgets of the increased fuel needs of these families
- An understanding of the cumulative effects upon mental health of these children and families
- Information to inform a different approach to how fuel debt is managed by these families
- An understanding of how a diagnosis of a life shortening condition affects the whole family

CHAS will commit to sharing all learning and experience as widely as possible via their own work as well as by attendance at such conferences, symposiums and other events as agreed.

9 Scale of VCMA Project and SROI Calculations, including NPV

Social Value Measurement

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 using the DNO methodology/rulebook with additional proxies developed for GDN activity. Carrying out an in-depth assessment of the predicted outcomes we forecast a positive net social return in investment (SROI) of £0.89.

Total cost	£269,674.02
Total gross present value	£510,658.04
NPV	£240,984.02
SROI	£0.89

10 VCMA Project start and end date

The project will run from 1 May 2024 to March 31, 2026

11 Geographic area

Scotland wide

12 Internal governance and project management evidence

SGN has worked alongside CHAS to co-design this partnership and ensure that its ambition contributes to the delivery of our Vulnerability Strategy, the guidance from our Vulnerable Customer Steering Group and adheres

to the updated VCMA governance criteria. The SROI has been externally assessed by SIA Partners using the DNO / GDN common rulebook.

To support the partnership to deliver the success criteria outcomes as detailed, the partners will review progress monthly and quarterly to learn, share best practices and address any delivery issues.

The PEA has been reviewed and approved by the business lead Linda Spence and the Director of Customer Services Maureen McIntosh.