Safe & Warm Sue Ryder

Vulnerability and Carbon Monoxide Allowance

September 2024 SGN



Contents

1	Description3
2	Problem statement
3	Scope and objectives4
4	Why the project is being funded through the VCMA5
5	Evidence of stakeholder/customer support5
5.1 5.2 5.3 5.4 5.5	Sue Ryder – because no one should go through death or grief alone5Dr Paul Perkins, Chief Medical Officer6Case Study 1 – Online Bereavement Community user:6Case Study 2 – Grief Kind Space attendee:7SGNs Vulnerability Steering Group7
6	Outcomes, associated actions and success criteria7
6 6.1 6.2	Outcomes, associated actions and success criteria
6.1 6.2	Outcomes
6.1 6.2 7	Outcomes
6.1 6.2 7 8	Outcomes
6.1 6.2 7 8 9	Outcomes 7 Success Criteria 8 Project partners and third parties involved 8 Potential for new learning 9
6.1 6.2 7 8 9 10	Outcomes 7 Success Criteria 8 Project partners and third parties involved 8 Potential for new learning 9 Scale of VCMA Project and SROI Calculations, including NPV 9

1 Description

Project title	Safe & Warm - Sue Ryder
Funding GDN(s)	SGN
New/Updated (indicate as appropriate)	New
Date of PEA submission:	September 2024
Project contact name:	Janet Duggan
Project contact email:	janet.duggan@sgn.co.uk
Total cost (£k)	£409,861
Total VCMA funding required (£k)	£409,861

2 Problem statement

According to the Department for Energy Security and Net Zero (DESNZ), the number of households who are required to spend more than 10 per cent of their income (after housing costs) on domestic energy rose in 2023 to 36.4 per cent of households (8.91 million), up from 27.4 per cent in 2022 (6.66 million). Lower income households are more likely to respond to higher energy prices by cutting energy use below safe levels. Some will find themselves in the situation where energy will become unaffordable, resulting in self-disconnection or unmanageable energy debt.

Typical energy bills under the January to March 2024 price cap were almost 60% higher than in winter 2021/22 and with a further 10% increase from October 1st, 2024, and a forecast increase again for 2025 energy costs remain unaffordable for many. DESNZ have also reported "after considering energy rebates, energy efficiency and household changes the overall required energy costs increased by 27 per cent between 2022 and 2023 in real terms".

Nationally, Citizen's Advice helped over 220,000 people with crisis support in 2023 – their highest figure to date, this trend has continued in 2024. They are reporting a marked increase in people presenting with complex problems, and multiple debts so when someone presents with energy issues, such as affordability, billing, and customer service, they also need support in other areas.

Sue Ryder is a national charity providing end-of-life care and bereavement support around the UK. Being diagnosed with a terminal or life-limiting condition and experiencing a bereavement are some of the most challenging periods that we will face in our lives, including placing a strain on their finances.

According to Marie Curie's 2022 report 'Dying in poverty', more than 90,000 people a year experience poverty during the last year of their lives. Many of those who experience financial hardship do so as a direct result of their illness. People with a life-limiting illness may have to reduce their working hours or stop work altogether, and those close to them may have to do the same to provide care.

As well as reduced household income, many also see an increase in their costs. One significant increase, particularly for people who choose to be cared for at home, is the cost of energy. The 2023 report by Marie Curie, '<u>One charge to many</u>,' shared that a terminally ill person's energy bill can rise by a staggering 75% after their diagnosis. This increase is partly driven by a need to keep the home warmer than usual. The importance of this should not be underestimated, as it can help people with a life-limiting illness to remain as comfortable as possible. The financial strain of heating bills can be further compounded by the cost of running energy-intensive medical equipment. '<u>One charge to many</u>' also found that in England and Wales in 2022, nearly 150,000 people died at home from conditions where common care and treatments include at least one common medical device.

The cost-of-living crisis has exacerbated energy costs for people at the end of life. Sue Ryder polling in 2023 found that over four-fifths (81%) of people receiving palliative and end-of-life care have been unable to run essential medical equipment due to high energy costs. Respondents told Sue Ryder this has led to poor pain

and symptom management, increased visits from healthcare professionals and needing emergency healthcare assistance.

Almost all (98%) of respondents reported that rising costs have also impacted where they would like to receive end-of-life care. Everyone should have the right to receive end-of-life care in their preferred location and it is incredibly concerning that financial pressures have affected people's decision making. A Censuswide survey on palliative care commissioned by Sue Ryder in March 2022 found that 74% of people say they would choose to die at home and evidence suggests that this is a reality for many. According to the <u>Nuffield Trust</u>, the proportion of deaths in the usual place of residence has increased over time, from 35% in 2004 to 50% in 2022. Rising costs mean there is a very real risk that people will not be able to die at home.

Bereavement can also have significant financial implications, both short and long term. In response to Sue Ryder polling, over a third (34%) of people reported that their financial situation had worsened because of their bereavement. This rose to 47% for those aged 18-24 and to 79% for those whose spouse/partner had died. Respondents told Sue Ryder that financial pressures following their bereavement had a negative impact on their emotional wellbeing (44%) and resulted in them having to borrow money to cover the cost of essentials (43%). The polling also revealed that the cost-of-living crisis has put further financial strain on many – over a third (35%) said the impact of the bereavement they have faced in the last two years has made it harder to cope financially with the cost of living.

Financial pressures can be severely compounded by a lack of adequate support, which is all too often a reality. Sue Ryder's research, '<u>A better route through grief</u>' revealed high levels of unmet need for people who have experienced a close bereavement, with 70% of respondents reporting that they could not access the bereavement support they would have liked.

The research revealed the most common types of bereavement support that people wanted but did not receive were counselling (28%) and financial support (28%). Broader research suggests that mental health conditions left untreated can lead to worsening mental health problems, unemployment, and poor quality of life, all of which could impact a person's ability to keep safe and warm in their home from loss of earnings or impaired decision making. Although mental health issues and grief differ, they can be experienced in similar ways and therefore point to an urgency of addressing the unmet need to prevent people becoming financially vulnerable as a result of terminal illness or grief.

'<u>A better route through grief</u>' also showed that people in SGN regions are some of the least likely to access formal bereavement support, with lowest access recorded in the South West of England (31%), Scotland (29%) and South East England (25%). While the South West and South East of England have some of the highest numbers in terms of the number of services available for formal support, they were in the bottom groups for services accessed, suggesting either a low awareness of the services, or high barriers to access.

3 Scope and objectives

By working in partnership with Sue Ryder, the objective of the partnership is to support people facing life limiting conditions and bereavement with access to help that alleviates fuel poverty and energy safeguarding services. Together we aim to raise awareness of key energy safeguarding services including the Priority Services Register, CO safety and the support available to people living in fuel poverty amongst Sue Ryder service users, staff, volunteers, and customers.

The scope of the partnership Safe and Warm with Sue Ryder will include:

1) **Training Sue Ryder employees and volunteers:** Sue Ryder Practice Educators and Wellbeing team members will be trained in Fuel Debt Advice in the Community (C&G Level 2 Award) by National Energy Action, who will then train additional Sue Ryder staff and volunteers to help them identify patients and families in fuel crisis, the symptoms of fuel poverty, and where to signpost to for onward support

2) **Marketing and awareness campaigns:** Multi-channel resources will be developed to promote the Priority Services Register and energy safeguarding services (including a comprehensive guide to fuel poverty, support

available and signposting information), targeting Sue Ryder service users, shop customers, staff, and volunteers

3) **Providing energy safeguarding information and advice:** via Sue Ryder Hospices, Community Nursing Teams, Grief Kind Spaces, Sue Ryder Online Bereavement Services and Sue Ryder Retail

4) **Onward referrals:** Clients will be referred to SGN's partnership network for additional support, including home energy assessments and debt assistance

4 Why the project is being funded through the VCMA

This project meets the Vulnerability and Carbon Monoxide Allowance (VCMA) eligibility criteria as it provides direct support to vulnerable households who would benefit from dedicated energy safeguarding support and or who are struggling to maintain a safe and warm home.

The project delivers against SGNs Vulnerability Strategy, by providing targeted support to households living with critical ill health, and most at risk of living in fuel poverty based upon their personal circumstances.

This partnership service goes above and beyond our core responsibilities as a Gas Distribution Network and is eligible under the VCMA funding criteria as it will provide support to those people in some of the priority groups and in the regional communities most at risk, providing information on using 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 number two with outcomes connected to three and four.

5 Evidence of stakeholder/customer support

5.1 Sue Ryder – because no one should go through death or grief alone

For more than 70 years, Sue Ryder has been a source of strength and support for anyone living with a lifelimiting illness or grief. Through hospices and palliative care hubs, three of which provide support to SGN customers in Bedfordshire, Berkshire and South Oxfordshire, Sue Ryder provides end-of-life and palliative care to people faced with life-limiting conditions. In 2023-24, the charity supported over 8,700 people through their hospice teams at home or in one of their centres and campaigned for better support for those facing terminal illness or experiencing bereavement.

Alongside their expert end-of-life care, Sue Ryder has been investing in and growing a range of Online Bereavement Support which includes:

- Online Bereavement Counselling delivering 4,700 hours of free counselling in 2023/24
- Online Bereavement Community used by 220,000 people last year
- Online Information and Resources expert information and articles, with 30,000 visitors to Sue Ryder's financial information pages in the last 12 months alone
- Grief Coach personalised support delivered straight to a user's mobile phone for 12 months
- Grief Guide a self-help platform with over 80,000 users.

The charity has also launched a new community-based service called Grief Kind Spaces. These are safe, supportive places for people to come together and share their experiences of grief, helping attendees to feel heard and less alone. Five Grief Kind Spaces currently operate in the SGN southern region.

Sue Ryder understands being safe and warm should be one less thing to worry about when dealing with death and grief, and in partnership, SGN and Sue Ryder will ensure there is support for these vulnerable groups during the most difficult time in their lives.

5.2 Dr Paul Perkins, Chief Medical Officer

"We have found ourselves living in a society in which dying well, and grieving are things people can't afford.

Sue Ryder's expert medical teams provide specialist pain and symptom management to people living with lifethreatening illnesses, and holistic grief support to people experiencing bereavement and loss. When someone is living with a terminal illness, their household income is reduced because they become too unwell to work whilst their family may have to cut down on work or leave work entirely to provide care and spend valuable time with them.

Making difficult choices about whether to keep warm, turn an oxygen machine on, whether they can afford to go to the doctor or if they can afford their medication, is heart breaking. Even those things constituting quality of life often must be compromised on such as having a relaxing bath which can help with pain, having the light on to not feel alone in the dark, having the family around for a meal or watching their favourite TV show, all comes at a cost.

This collaborative partnership can change this. By making more people aware of the symptoms and effects of fuel poverty, and the support and services Sue Ryder can offer to them at home and in the community, we can lessen the burden on these households. Working together will mean that fewer people are forced to go without medical equipment they rely on, which in turn could help decrease the need for emergency hospital admissions, relieving the ever-growing pressure on the NHS over the winter months and fewer people will struggle to stay safe and warm whilst coping with grief."

5.3 Case Study 1 – Online Bereavement Community user:

Sue Ryder asked members of their Online Bereavement Community to share their experiences of financial struggle and fuel poverty. A service user based in Oxfordshire, said:

"I found it very challenging to cope when my husband died in November 2022. He was in hospital for five weeks. He had several heart attacks and his foot amputated – it was touch and go. We got a huge £3,000 gas bill which I thought could not possibly be right. He thought he would be coming home, and told me not to worry about it, that he would sort it out. Then he fell out of bed and died very suddenly.

He was an accountant and very good with finances. I never had to deal with money and was hopeless. So, I was stuck when I had to sort everything out. It was a nightmare. The gas company were awful. I had to say the same thing over again, and would just receive higher bills, threatening the worst, even though I had told them he died. His money was stopped, and I had to immediately refund the overpayment. The joint account was only receiving a small amount. There was the funeral to be paid for, and I'm a carer to our autistic son, so I had all that increased worry.

It took so much energy out of me that I had to go to A&E. I had chest pains. I couldn't sleep. I felt like I was going mad. I was scared to put the heating on, and was freezing cold, huddled with a hot water bottle. It was horrendous. I couldn't believe how bad I was being treated.

This year I feel worn out. Especially now I've learned that the winter fuel payment is being cut. I think 'bang goes any holidays'. It's so unfair. My feet are killing me in the cold as I have problems with peripheral neuropathy. I sit inside with outdoor clothes on, and when my boiler broke, I had to pay over £4,000. I was freezing while it was being done. I just had to stay in one little room with the expensive fan heater on. I was given a heated blanket by a neighbour, but the kitchen was still cold. I found a warm bank to go to, but I was scared of catching COVID as I'm over eighty years old so very vulnerable. I did catch it in the end, but luckily, I recovered.

I've finally sorted a direct debit to pay off the utility bill. It's more than I can afford, but I don't understand what else I can do. I don't qualify for benefits. When you are grieving, there's this bereavement fog which makes it hard to sort out complicated stuff. I can't figure out how to get the best deals. At my age, with arthritic fingers, it's hard to do things on the computer. And waiting on the end of the telephones is difficult too, and there's no paper trail either. That's the trouble."

5.4 Case Study 2 – Grief Kind Space attendee:

My father died unexpectedly, and I found the amount of paperwork overwhelming. I had to deal with all the paperwork and bills as there was no one else to manage them. It was exhausting and every time I rang a supplier there was no compassion, it was as if they were stuck on a script and couldn't even say I'm sorry for your loss. I tried to change the energy bills into my name as we wanted to work on dads flat before selling it, but they wouldn't allow it. Instead, I had to keep paying the bills that came in my dad's name, and I found that traumatic. I was paying my own bills, and my dad's bills and all the time I was waiting for access to his bank account so that I would have some money. The amount of electricity we used was tiny, just lighting really, but it felt like a lot of phone calls and trauma for such a small thing that should have been easy. I felt that I owed it to my dad to pay all his bills, as well as the cost of his funeral.

5.5 SGNs Vulnerability Steering Group

Our Vulnerability 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 people living with critical illness and those most likely to suffer detriment by living in a cold and unhealthy home.

In 2024 our strategic steering group reiterated the vital impact we could have by coordinating 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

In partnership with Sue Ryder, we will keep customers Safe and Warm, whether they are facing a life-limiting condition or experiencing bereavement. Over the duration of the partnership, we aim to deliver the following outcomes:

- Through training and information, increase the knowledge of Sue Ryder staff and volunteers around fuel poverty, energy safeguarding and increased energy efficiency, driven by a dedicated Project Lead and Energy Support Officer
- Increased awareness on the extent of fuel poverty within households facing terminal illness or coping with bereavement, the serious impact of a cold home on people who are in serious ill-health or grieving, and easy access to practical information to mitigate its negative impact
- Deliver information and support to households facing terminal illness or coping with bereavement, in a holistic way, including providing in-person support through Sue Ryder Hospices, Community Nursing Teams, Grief Kind Spaces, Sue Ryder Retail and online through a range of bereavement services
- Provide information on the benefits of the Priority Services Register to people living with a terminal illness and bereaved people and support to access as required
- Provide safety awareness of the dangers of carbon monoxide in the home and how to mitigate this including providing CO alarms, when required

• Increased confidence from the bereaved community in what to do if struggling with fuel debt and onward referrals for crisis support where needed

6.2 Success Criteria

To support 5,139 people impacted by bereavement and terminal illness with information and services that will help them to maintain a safe and warm home.

We aim to achieve this by:

- Training Sue Ryders community on energy safeguarding and triage;
 - Providing training to 200 Sue Ryder staff and volunteers on how to identify fuel poverty and provide energy safeguarding support and onward referral where required for case worker support
 - Training 6 Sue Ryder staff members in Fuel Debt Advice in the Community 6281-16 (C&G Level 2 Award) via National Energy Action
- Community marketing targeted energy safeguarding messaging to people at end of life or recently bereaved on the help available;
 - Energy safeguarding information with 160k+ social media followers, 65,000 supporters, 3,000 staff and 8,000 volunteers
 - Creating a comprehensive Safe and Warm Guide to be distributed to patients, service users and via 109 shops with at least 4,000 customers engaging with the resources provided - each guide will include a link to the Safe and Warm online hub driving traffic to this central digital resource
 - Delivering a Winter Campaign via 109 Sue Ryder shop windows in January 2025 and 2026.
- Dedicated energy advice to support Sue Ryder team to help deliver energy safeguarding services;
 - Providing 5,139 people with a terminal illness or experiencing bereavement with personalised energy information through the Sue Ryder network of staff and volunteers across Sue Ryder Hospices, Community Nursing Teams, Grief Kind Spaces, Sue Ryder Retail and Online Bereavement Support
 - Developing a Safe and Warm online hub (sueryder.org/safeandwarm) with helpful information about the links between serious ill-health, grief, and fuel poverty, where to get a CO alarm (online or from a Sue Ryder shop/Grief Kind Space), and information about the Priority Services Register, referral partners and support available, with an estimated reach of 10,000
 - Delivering in person energy safeguarding information on the PSR, CO Awareness and other energy safeguarding services via the Sue Ryder Grief Kind Spaces attended by around 500 beneficiaries and over 90 volunteers and extending the Grief Kind Space service to reach a further 75 beneficiaries and 30 volunteers
 - Across the partnership forecast 5,139 conversations about the Priority Services Register and support 1,500 vulnerable customers sign up with the Priority Services Register
 - Identify and refer 1,500 households for additional help through SGN's Safe and Warm partnership network for relevant services and StepChange for debt support
 - Provide 5,139 vulnerable households with CO safety conversations with an estimated 360 CO alarms distributed.

7 Project partners and third parties involved

- SGN for funding, expert energy information and content
- Sue Ryder for the delivery of the core scope and success criteria
- National Energy Action training partner for Sue Ryder Project Lead and Project Champions
- Citizens Advice and National Energy Foundation for case worker support and assessment for energy
 efficiency measures such as fuel vouchers and support on energy matters including energy efficiency
 advice
- StepChange for referrals through Sue Ryder, where customers need debt and money advice

8 Potential for new learning

Monitoring and evaluation

This partnership has been co-designed by Sue Ryder and SGN, building capacity by providing access to key services including the PSR, interventions that address fuel poverty and broader safeguarding and wellbeing services to those in need. As we continue to evolve the partnership and progress with the delivery, the following activities will be in place to monitor and evaluate project progress and impacts:

- Quantitative and qualitative customer outcomes
- Feedback questionnaires to ensure that the services are valued by those who use it
- The questionnaires have additional space for attendees to write more in-depth personalised reviews and this qualitative data is invaluable to us in helping assess and shape our services
- Ongoing referrals from/to partners to ensure that we're delivering outcomes that address both crisis and long-term fuel poverty / health outcomes
- Each month we will review the progress of the support service against the detailed success criteria in section 6.2 and work through challenges and opportunities where required, including the review of individual and organisational partnership case studies.

Learning

We are keen to learn from this project and for successes to be incorporated into ongoing projects that engage with people facing a terminal diagnosis/life-limiting condition or experiencing a bereavement. Through working across SGN's southern and Scottish footprint the group will review the success of training, workshops, and case studies to identify and share best practice. In addition to networking, the project offers learning opportunities across stakeholder organisations which result in an improved understanding of clients' needs.

SGN will share the outcomes via stakeholder mechanisms including the SGN Safe and Warm partnership network the GDN Vulnerability Working Group as well as via the VCMA Annual Showcase and VCMA Annual Report.

9 Scale of VCMA Project and SROI Calculations, including NPV

We and the other Gas Distribution Networks worked with leading social impact research consultancy SIRIO Strategies on the development of the Industry Standard Social Value Framework and supporting GDN Rulebook. We have used that GDN Rulebook 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 assessment of the predicted outcomes we forecast a positive net Social Return on Investment of £4.24 for the partnership.

Social Value Measurement

Total cost*	£400,011
Total gross present value	£2,094,093.86
Net Present Value (NPV)	£1,694,082.86
SROI	£4.24

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

10 VCMA Project start and end date

The project will run from October 2024 to March 2026

11 Geographic area

The project will take place across the SGN Southern Network

12 Internal governance and project management evidence

SGN has worked alongside Sue Ryder 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 assessed internally using the GDN Rulebook developed by SIRIO Strategies as part of the Industry Standard Social Value Framework. As detailed above we have reviewed the current partnership scope which has been forecast at adding an additional £4.24 for each £1 invested, this will be monitored closely to ensure we adhere to the VCMA governance criteria.

SGN and Sue Ryder will meet monthly and quarterly to review outcomes, learn, share best practices, and address any delivery issues.

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