

Helping people living with dementia stay safe and warm

Vulnerability and Carbon Monoxide Allowance

February 24

SGN



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1 Description

Project title	Helping people living with dementia stay safe and warm
Funding GDN(s)	SGN
New/Updated (indicate as appropriate)	New
Date of PEA submission:	January 2024
Project contact name:	Janet Duggan
Project contact number/email:	Janet.Duggan@sgn.co.uk
Total cost (£k)	£164,053
Total VCMA funding required (£k)	£164,053

2 Problem statement

Dementia is a terminal condition and has a devastating impact. The whole family is affected as they watch their loved one decline and lose their independence. Dementia progressively impairs cognition, speech, mobility and memory. As dementia progresses, families need to access a wide range of support - emotional, social and financial - as well as access to care.

Overwhelming prevalent in older people, with 90% of our beneficiaries aged 70+ years. Across West Sussex there are over 17,000 people living with dementia (West Sussex Joint Dementia Strategy, 2020-23) and this is expected to increase by 16% by 2025, and 36% by 2030, as the population ages – age is the greatest risk factor in developing dementia. Due to their age, and dementia, many of those we support are digitally excluded. Therefore, they are less able to access help, support, and advice online. This leaves them in need of accessible advice services, available on the phone or face to face.

The constituencies of Chichester, Bognor Regis and Littlehampton are in the top 2.5% in the UK for dementia prevalence. It has been forecasted in the [West Sussex Joint Dementia Strategy \(2020-2023\)](#) that the need for dementia care and support in West Sussex is only going to increase. Access will be key as many people living with dementia live in our rural communities with poor transport links or the coastal communities with high levels of poverty.

The high prevalence of dementia is not surprising given we already have an older age profile than most with 25% of the population currently 65 years old and over. An online survey conducted by Opinium in 2022, on behalf of Age UK, found three-quarters of older people in the UK are worried about the rising cost of living, according to research for Age UK. Over half (54%) of those surveyed said they'll have to heat their home less, and a quarter (24%) said they'll have to choose between heating their home and the food they buy. In total, two-fifths (43%) said they would have to cut back, go into debt or simply will not be able to afford to pay their bill.

Due to the nature of dementia; as their disease progresses; people spend increasing amounts of time at home. [The Cost of Cold Age UK](#) Campaign research shows that older people's mental health is affected by living in a cold home. It can also reduce dexterity; often already compromised due to age or existing conditions such as rheumatoid arthritis; leading to frustration and despair. With reduced muscle mass and poorer circulation their bodies are not able to physiologically keep them warm during the cold periods. This is also evidenced in Science Direct through their cold homes and mental health harm evidence from the UK Household Longitudinal Study.

Sage House's Wayfinders services provide personal support to people living with dementia and their carers. Since Covid-19 they have seen that more of the people they are supporting were making choices between heating their home and buying food, this was especially evident over winter 2022/23 as we experienced the increased cost of living and energy costs in particular.

Due to the rising prevalence of dementia, as well as the dual impact of Covid-19 and the cost-of-living crisis, Sage House have seen the need for their Wayfinding service rise rapidly. Not only has the service seen an increase of referrals of 262% since 2020 (from 321 to 843 new beneficiaries in 2022/23) the teams are seeing that the support needs are becoming more complex.

Sage House currently support over 2,500 people from over 1,000 households. Given this huge increase in need, and the complexity of support needed, they have recently increased the Wayfinding team to ensure people are helped. However, with over 50 new people reaching out for support each month, the service is still oversubscribed and in need of further support.

Sage House and the Wayfinders service support many people who are living on their own, potentially with a single pension as the only source of income. This means that home repairs and boiler maintenance can be costly or not prioritised. The Wayfinders teams visit people in their homes, and often see people who are living within the most deprived decile of the UK are spread widely through West Sussex. They include areas of Bognor Regis and Littlehampton. However, the team also visit people in areas not considered “deprived” but having lived for many years on pension income, do not have much income for essentials including energy.

It is through working with people living with dementia that Sage House and the Wayfinders service team see safety risks in the home, for example, cold and damp homes, not having a carbon monoxide alarm, and even including leaving gas cookers on. In some cases, people with dementia have been known to place plastic kettles on gas hobs as they have forgotten how to use the newer technology.

3 Scope and objectives

Working in partnership with Sage House the objective of this initiative is to minimise the health and wellbeing impacts on families who are navigating the dementia journey ensuring they have the required energy safeguards in place.

The scope of the partnership will identify and support people living with dementia with energy safeguarding support in 3 key areas:

- Gas safety in the home:
 - Carbon monoxide alarm distribution
 - Locking Cooker Valve installation
 - Support to access the Priority Services Register
- Increasing energy efficiency:
 - Support to access energy efficiency advice and access to energy efficiency schemes, facilitated through the National Energy Foundation
 - Dementia accessible workshops and training on how to use less energy safely
- Providing support to help keep people affordably warm:
 - Providing crisis fuel vouchers for households in energy crisis
 - Support access to hardship funds and access to take home warm packs

By working together our objective is to increase the support services for families living with dementia in West Sussex by;

- Increasing capacity for Wayfinding advice and support providing one to one personalised guidance
- Creating an in-house lead and expert on energy safety and fuel poverty
- Holding workshops and support groups for people affected by fuel poverty
- Upskilling staff across the charity to identify households in need to provide basic advice and safety checks
- Creating a working set up of safety devices to be featured in our “Smart Zone” tech showcase (including Locking Cooker Valves and carbon monoxide alarms)

- Extending reach of advice through Community Outreach sessions

The introduction of a Wayfinding bus to provide advice services to rural and isolated communities, as well as enabling pop up sessions in the most deprived communities (especially Bognor Regis and Littlehampton). The bus would also provide further support to communities who are unable to come into Sage House and offer local access to;

- Carbon monoxide alarms and Locking Cooker Valves
- Support to sign up to the Priority Services Register
- Community Warm Space and subsidised meals in Sage House café, as well as access to a small foodbank and emergency fuel vouchers
- Grab bags of warm items - hats, gloves, slippers, weighted and heated blankets

4 Why the project is being funded through the VCMA

The project aligns to the strategic goals through enabling extremely vulnerable customer groups (those living with dementia, unpaid carers of those with dementia, and older people) to access key services, live in safe and warm homes. This will be achieved through advice and guidance, as well as practical support such as carbon monoxide alarms, power cut packs, priority service registrations, locking cooker valves.

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 energy crisis support, access to energy efficiency and CO 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 (outcomes in pillar 3 and 4).

5 Evidence of stakeholder/customer support

5.1 Sage House

People living with dementia have always been central to Dementia Support and deciding which services and projects it runs. It was founded in 2014 by a group of people who had experienced dementia in their own families and trying to find the support they needed. 81% of our trustees and senior management have personal experience of supporting people with dementia. We have established a service user consultation and feedback group who meet regularly to provide feedback on our services. We conduct a 6-monthly survey with carers using our services to ensure services are meeting our beneficiaries' needs and we collect informal user feedback on an ongoing basis. Our Wayfinders capture data about the people they support and the issues they are facing. We have used all of these channels to discuss the winter cost-of-living project and to get feedback about last year's initiative. This has ensured we take account of the sensitivities around using free food services and winter packs so that everyone who needs to will feel comfortable doing so.

Prior to setting up Sage House Dementia Support consulted widely with dementia delivery and commissioning agencies and consulted people living with dementia through our partners in the West Sussex Dementia Network. This included focus groups and personal journeys facilitated by five voluntary organisations, individual interviews, visits to local libraries, staff focus groups and stakeholder events. We also piloted some

activity sessions for people with dementia which acted as focus groups and carried out a door drop survey among residents which generated 53 online responses and 476 written responses.

The study revealed that people living with dementia, their carers and families felt that navigating the complex journey created by the early stages of dementia care was extremely difficult. People highlighted the need for a collaborative service and a clear desire among those affected to keep active and remain at home, close to their families, for as long as possible. It was clear people were having difficulty in finding information and knowing what you need to know at the right time; there was a desire for a personal one to one service with the potential for a “buddy” system and time to talk; and the desire for a “one stop shop” co-ordinated approach.

Our services are designed to enable people to remain independent at home and reduce or delay the need for long term residential care. Wayfinding support helps people to access support for care costs and helps people to navigate the complex health and social care systems.

Wayfinding - ongoing support to navigate the dementia journey

Our free of charge Wayfinding service provides both practical advice and emotional support to make sense of the journey ahead. Appointments are offered in-person, or over the phone. A meeting with a Wayfinder is often the very first point of contact with Sage House, the beginning of an enduring relationship, speaking with the same member of the team each time, developing close bonds and a full understanding of everyone’s unique circumstances. The advice is practical, and support is often emotional and spans a broad spectrum of challenges associated with dementia and caring for a loved one.

“Support has been second to none. My Wayfinder was there through some very difficult times.” - Carer who has been supported by Wayfinders at Sage House

Wayfinders help to reduce anxiety and the risk of carer burnout by helping people to navigate the dementia journey. By providing accurate and accessible information, they help people with dementia and their families to make informed decisions from coping with a diagnosis, accessing further care, through to end of life.

5.2 Case Studies (Sage House – Andrew and Derek)

How Sage House has supported/is there for both Andrew and his dad, Derek, through the most challenging times for their family.

In December (2021), Derek, age 73, had been in hospital over Christmas where he managed to get out at midnight and was walking around Chichester in his pyjamas, fortunately someone found him and called the police. This was an extremely distressing time for his wife Sandra and family. Andrew says, “I’ve never seen my mum like that on that evening. It’s just like her heart was in her mouth. It completely changed her, and the same with me.” Following his eventual discharge Derek and his wife Sandra came to Sage House for Derek’s NHS dementia assessment and was connected into our Wayfinding assistance in January (2022).

Derek was diagnosed with Alzheimer’s and Sandra’s mental health took a turn for the worse, triggered by the severe worry over Derek and her younger days of depression. Her health deteriorated and tragically Sandra passed away in February (2022).

Andrew, who is in his 30’s, had not long returned to live at home battling with his own personal poor mental health and wellbeing, spending more time in his bedroom, watching TV, not going out, depressed, isolated, and becoming agoraphobic/ feeling trapped and helpless. Further from his mind was as a young person he would have to care for his father, following the death of his mother. Andrew and his brother and sister wanted Derek to stay at home, and not go to a care home. His dementia meant that he wasn’t aware of the passing of his wife and the family felt leaving home would be too much change for Derek.

With no other option, and concern over his dad’s future and the memories of his mum. Andrew, whilst coping with the grief of losing his mum, agreed to take care of his dad, and both could stay at home.

In March (2022) Andrew reached out to Sage House for help and guidance for their combined personal situations. Andrew and Derek were linked to one of our Wayfinders who has supported Andrew 1:1 on a continuous basis since this first meeting. Support has included putting in place lasting powers of attorney, referrals to social services for intensive support, equipment services for GPS tracker, and community Occupational Therapists for house improvements, such as handrails. His Wayfinder has supported him in

making grants for energy support, as well as a grant for a new heating system and boiler at their home as it is currently heated by storage heaters.

But also importantly combined with dementia knowledge (such as, routines, meal planning, creating signs for rooms), understanding the ongoing changes with his dad's moods, and for Andrew's own mental health support, additional referrals to Carers Support, MIND and Pathfinders. A key step was to arrange some respite time for Andrew, and company and support for Derek in our Day Breaks at Sage House, where Derek now comes 2 days per week.

In Andrew's words:

"With Sage House's help, I have carers come to our home for dad's personal care. I can't do that. Otherwise, I look after him with everything else, I make lunches when we're at home, evening dinners, clean and make his bed, and drive him to and collect him from Sage House and other places he goes. Sage House helped with organizing a wellbeing grant for me with the local gym. I wanted to meet more people. It's been so difficult to meet people with my poor mental health and looking after dad.

Natasha, our Wayfinder, she's been an incredible help, it's like, without her help I wouldn't have known where to start, or I may never have got this far, to be honest. Without Sage House there'd be a lot of people that would be very, very stuck. There are no real obvious pathways of help. You have to know these things to find them, otherwise you have to dig, dig, dig, and dig to get the help. Sage House has helped me tremendously, and I am in a much better place mentally now than I was 1 year ago, while knowing that we are receiving the very best support."

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 people who are navigating their journey with dementia.

In 2023 our strategic steering group re-iterated 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

Working together the two-year partnership will enable SGN and Sage House to:

- Introduce a Wayfinder bus service to take support into new communities
- Increase capacity within the Wayfinding team
- Create an in-house expert on energy efficiency and safety
- Increase the knowledge of all Dementia Support Wayfinders to include energy safeguarding
- Deliver workshops on energy safety and efficiency
- Increase numbers of Dementia Support customers on priority service network
- Distribute carbon monoxide alarms
- Increase numbers of locking cooker valve installations
- Develop an e-learning session for SGN staff on supporting people with dementia

6.2 Success Criteria

Through our partnership, we will be able to effectively support people living with dementia, their families and carers in the West Sussex area to be safe and warm at home. We will be able to deliver the following outcomes:

- Additional 500 people living with dementia supported by the Wayfinding service
- Reach 1,500 vulnerable households with information on carbon monoxide awareness, Locking Cooker Valve, and supported access to the Priority Services Register.
- Distribute 150 carbon monoxide alarms, based on 10% of people reached taking up the offer
- Provide training to the Sage House and Wayfinders teams in energy safeguarding, enabling advice to be cascaded to all enquiries
- Deliver 125 community pop ups each offering 1:1 appointments for approximately 10 people in harder to reach communities
- Deliver a winter warmth social media campaign prior to winter 2024, targeting over 20,000 people aged over 65 living within catchment, providing information and guidance about energy safeguarding
- Provide 100 fuel vouchers at a value of £49 per voucher for households found to be in fuel crisis

7 Project partners and third parties involved

Sage House – delivery of services at Sage House via the Wayfinders services

SGN – regional gas network providing programme funding and support to the delivery team, including training on energy schemes including PSR and CO safety, access to a broader referral partner network, and direct services for customers including but not limited to dedicated energy advice services, fuel vouchers, Locking Cooker Valves and CO alarms.

National Energy Action – providing energy advisory training where required for energy support officers.

Gas Safe Charity Think CO programme – providing training specifically for carbon monoxide awareness.

The partners will continue to closely work with a network of local partners to identify eligible people living with dementia across West Sussex; West Sussex County Council, West Sussex NHS Partnership, Alzheimer's Society, Citizens Advice – West Sussex, Age UK West Sussex

8 Potential for new learning

Monitoring and evaluation

- The partners will work closely to ensure that we're monitoring outcomes against the success criteria by delivering monthly reporting against KPIs, including identification of good practice and case studies
- Measuring our impact through regular service feedback questionnaires. We will use a tailored five-point evaluation questionnaire to monitor the specific components that we want to improve for beneficiaries.
- Feedback from questionnaires enable us to measure how well we are helping by providing practical advice, are attendees reporting better access to information and support. We are also looking at aspects of general health and well-being such as feeling more connected to others and less anxious.
- 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.

Learning

This project has the potential to be upscaled as a model enabling more people living with dementia to receive support. We are supporting people in a new and innovative way that not been done before. We have a national ambitions program that is seeking to replicate the Sage House model in other communities.

An end of year evaluation of end of year performance will identify key achievements, strengths and weaknesses and insights will be shared in the VCMA Annual Report and via the VCMA Annual Showcase.

9 Scale of VCMA Project and SROI Calculations, including NPV

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 on investment (SROI) of £1.80.

Social Value Measurement

Total cost*	£161,279.16
Total gross present value	£450,846.47
Net Present Value (NPV)	£289,567.31
SROI	£1.80

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

10 VCMA Project start and end date

The project will run from March 2024 to end of March 2026 – 2 years.

11 Geographic area

West Sussex

12 Internal governance and project management evidence

SGN has worked alongside Sage House 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 rulebook/methodology with GDN specific proxies incorporated. As detailed above SIA partners have reviewed the current partnership scope which has been forecast at adding an additional £1.80 for each £1 invested, this will be monitored closely to ensure we adhere to the VCMA governance criteria.

SGN and Sage House 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.