

Helping people living with dementia stay safe & warm at home

Vulnerability and Carbon Monoxide Allowance

March 2024
SGN



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1 Description

Project title	Helping people living with dementia stay safe & warm at home
Funding GDN(s)	SGN
New/Updated (indicate as appropriate)	New
Date of PEA submission:	February 2024
Project contact name: (SGN)	Janet Duggan
Project contact email: (SGN)	janet.duggan@sgn.co.uk
Total cost (£k)	£93,541.15
Total VCMA funding required (£k)	£93,541.15

2 Problem statement

In 2022, there were an estimated 3.26 million households living in fuel poverty in England, based on the LILEE metric (Department for Energy Security and Net Zero, 2023). This is an increase from 3.1 million in 2021 and doesn't take into consideration the cost-of-living crisis that has hit households throughout the winter of 2022-23 and beyond. National Energy Action's October 2023 figures show 6.5 million UK households are in fuel poverty, based on the definition of low-income households spending more than 10% of their income on their energy bills. Fuel poverty is driven by energy efficiency, energy costs and income. It is recognised that nearly half of low-income households are still living in hard to heat homes, and the rate of improvements was well below what is needed to lift people out of fuel poverty by a target date of 2030.

Dementia is a life limiting terminal condition and has a devastating impact, not only on the person with dementia but on the whole family as they watch their loved one decline and lose their independence. Dementia progressively impairs cognition, speech, mobility, and memory, and in some cases causes incontinence, hallucinations, agitation/aggression, and behaviours that challenge. As dementia progresses, families can become isolated from their community and need to access a wide range of support - emotional, social, practical, and financial - as well as access to care.

According to the Department of Health there are now more than 850,000 people living with dementia in the UK, costing the economy around £26.3bn a year. It is estimated that by 2025, one million people in the UK will have dementia, and this will increase to two million by 2050. 1 in 3 people born this year will develop dementia in their lifetime. Two thirds of the cost of dementia (£17.4b) is paid for by people living with dementia and their families, either in unpaid care (£11.6b) or in paying for private social care (Chief Medical Officer's Annual Report 2023), meaning that they have less available income to pay for their daily living costs.

Across Hampshire and the Isle of Wight there are over 24,000 people living with dementia (Alzheimer's Research UK) 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. In addition, there are many more people living with Mild Cognitive Impairment (MCI), previously called pre-dementia, or people on a waiting list for diagnosis. 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.

Hampshire is one of the top five UK areas with the highest incidence of dementia (Alzheimer's Research UK). It has been forecasted in the [Hampshire & Isle of Wight Joint Strategic Needs Assessment](#) that the need for dementia care and support in Hampshire and the Isle of Wight is only going to increase. Access will be key as many people living with dementia live in our rural communities with poor transport links.

The high prevalence of dementia in Hampshire and the Isle of Wight is not surprising given we have an older age profile than most areas in England with 21% of the population currently 65 years old and over (432,185) 'vs' 18.4% in England. With Hampshire being 22.6% and the IOW being 28.2%. Unsurprisingly, the cities of

Portsmouth and Southampton have a lower elderly population. 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.

Dementia Support Hampshire & IOW's community services provide personal support to people living with dementia and their family carers. Due to the increased cost of living and the rise in energy costs, they have seen more of the people they are supporting are having to make choices between heating their home and buying food.

Not only has the service seen referrals more than double year-on-year (from 275 to 553 new beneficiaries in 2023/24), and the number of individual interactions increase by 346% (from 977 to 4356 in 2023/24), the teams are seeing that support needs are becoming more complex as family carers are struggling to cope with the additional pressures placed upon them, resulting in increased anxiety, leading to a decline in wellbeing.

Given this huge increase in need, and the complexity of support needed, Dementia Support Hampshire & IOW are launching ten new peer support groups across the county this year, to ensure people receive the vital support that they need.

Dementia Support Hampshire & IOW support many people who are living on their own, potentially with a single pension as the only source of income. With any disposable income being spent on respite care and other costs associated with their dementia, home repairs and boiler maintenance can be costly or not prioritised.

With 40 areas in Hampshire ranked in the 10% most deprived areas in the UK (The Indices of Deprivation), many people living with dementia, with only their pension as income, do not have money for essentials including energy. This can be supported by [SGN's Vulnerability Index data](#) which highlights Portsmouth, Havant and Southampton in the top 10 communities in greatest need most likely to need the support of their utility companies to use energy safely, efficiently and affordably.

3 Scope and objectives

Working in partnership with Dementia Support Hampshire & IOW this initiative will target vulnerable households who may be experiencing barriers to accessing services, to help alleviate fuel poverty and increase energy safety awareness.

Through the partnership we 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
- Providing support to help keep people affordably warm:
 - Providing crisis fuel vouchers for households in energy crisis

- Support access to hardship funds

By working together our objective is to increase the support services for families living with dementia in Hampshire and the Isle of Wight by;

- Providing one-to-one personalised advice and support in the home (Safe & Warm Dementia Support Workers)
- Upskilling staff and volunteers across the charity to identify households in need to provide basic advice and safety checks
- Providing one-to-one personalised advice and support at our existing support groups in the community increasing home visit referrals
- Sharing information and advice at community events to increase home visit referrals

4 Why the project is being funded through the VCMA

This project is proposed for funding through the Vulnerability and Carbon Monoxide Allowance (VCMA) which aims to work with households experiencing fuel poverty. This project does this by providing direct support to households who are affected by people living with dementia who are struggling to maintain a safe and warm home.

The project delivers against SGNs Vulnerability Strategy, by providing targeted support to households with someone living with dementia(s) a customer group who is more vulnerable 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 pillars 2 (3 & 4)

5 Evidence of stakeholder/customer support

5.1 Dementia Support Hampshire & IOW

Dementia Support Hampshire & IOW was founded in 2022 by people who have experienced dementia in their own families and struggled to find the support they needed. All the trustees and senior management have lived experience of dementia through caring for a loved one with the disease, and 80% of their volunteers have lived experience, or have cared for people with dementia in a professional capacity, in health and social care roles.

They provide purposeful, emotional, physical, social, and practical support and activities to improve and enrich the lives of people living with dementia, offering support from the first signs of memory loss to end of life, for anyone and everyone impacted by dementia, be it the person with dementia, their family, friends, or caregivers.

The services are delivered face-to-face at support groups and information days located in the heart of the community, over the phone - via a helpline that is available 8am-6pm Monday-Friday, on-line via an informational website providing local information and pathways, on social media, and in their monthly e-newsletter.

Prior to setting up Dementia Support Hampshire & IOW they consulted widely with community health and social care professionals and people living with dementia, including family carers. This included focus groups, individual interviews, information days in the community, visits to local libraries, and a survey.

The study revealed that people found navigating the complex dementia journey extremely difficult, and that this impacted negatively on their health and wellbeing. 100% said they experience worry, fear, or anxiety, 97% said they were feeling anger or frustration, 87% were experiencing exhaustion or fatigue, and 82% felt isolated and lonely.

People said that they found access to services poor or very poor; 66% found it difficult to access information and advice, 84% found a lack of emotional support, 73% could not get practical help with things like claiming benefits or filling in forms, 70% struggled to find peer support, 79% found it difficult to find bereavement support. The top three services that people said would make a positive difference to their daily life was information, signposting, and emotional support/someone to talk to.

People also 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 and the desire for a “one stop shop” co-ordinated approach.

Through the partnership the ambition is a future where everyone affected by dementia - the individual, their family, and their caregivers - has access to person-centred care and support that maximises their quality of life and enables them to live as independently as possible in their own homes staying connected to their families, friends, and local community for as long as possible.

People living with dementia have always been, and will always be, at the heart of everything they do.

5.2 Impact and Case Studies

Dementia Support Hampshire & IOW provide the opportunity for people to engage with others living with dementia in the local community, and participate in arts & crafts, cognitive stimulation activities, reminiscence, music, movement, and conversation. All of which help to reduce isolation and loneliness and improve wellbeing, leading to happier, healthier individuals, better equipped to deal with the day-to-day challenges that a dementia diagnosis brings.

They also offer one-to-one sessions for clients to talk about their worries, or to ask for help and support to apply for benefits, power of attorney, home help, respite, residential care, or other support available to them. By providing accurate and accessible information, they help people with dementia and their families to have a greater say in their lives and health, leading to a reduction in avoidable inequalities.

Below are a few anonymous quotes from clients:

“The group is our lifeline at a very scary time. Talking to others in the same situation and getting advice from the lovely ladies who run the group has made all the difference to both of us.”

“Probably one of the best phone calls I made. Great group of people warm, supportive, and caring. Staff and the volunteers very helpful and knowledgeable.”

“Companionship, friendship, and assistance with form filling. I could not have coped without their help.”

“It has been a lifeline, the first support we’d received several years after diagnosis. A friendly, accepting group, professional in every way. A new family and set of friends offering advice and support to us both.”

“This group provides the opportunity to meet sympathetic friends, not just to socialise, but also to help you find all that you need to exist in this increasingly complicated world. Without this sort of support life can be so isolating.”

To ensure that the support is accessible to all, services are free of charge, funded by the generosity of private and corporate trusts and foundations, corporate partnerships, local business', individuals in the community and through fundraising efforts and events.

Dementia Support Hampshire & IOW monitor outputs, outcomes, and impacts, by keeping daily logs about who has used their services. Looking at how often they attend, which services they engage with, and ask them for feedback about how it makes them feel. Using the Warwickshire Wellbeing Scale to measure wellbeing at the start of their journey and again after ten interactions. They periodically ask clients to complete a questionnaire to tell them how they are doing, so they can measure the impact the services are having. Feedback about the quality and type of services offered is requested to ensure the service is meeting people's needs.

5.3 Case Study

Caroline is 74 years old and was living alone in a privately rented flat and spent her days wandering around the local shopping centre. She was referred to Dementia Support Hampshire & IOW by One Community, as a member of staff had identified that Caroline was confused. Our first meeting with Caroline lasted about 3 hours, listening to Caroline's worries and concerns, her fears about the future. It was clear that she had some cognitive impairment, confusion, and some other signs of dementia. It was also clear that she was very lonely. We invited Caroline to join our weekly support and social group, where we told her she would be accepted for who she is. Caroline began to attend the weekly group, and gradually started to make some friends, as time went on, we became concerned about her living arrangements as Caroline told us her house was cold and that she didn't have any hot water, that she boiled a kettle to wash herself and her clothes. We suggested that she should have a care assessment with social services, and whilst Caroline was incredibly nervous about this, she agreed to proceed if we were involved. We contacted the adult services duty team, and they were already aware of Caroline but had not managed to help her previously as she would not engage with them. She was allocated a case worker who liaised with us, and together we supported Caroline through the process. Caroline was awarded extra care housing, in a safe and warm environment, with help to manage her personal care and daily living. Caroline still attends our support and social group every week and has made lots of friends who accept her as she is – she even meets up with them outside of the group. She is healthier, happier, and less fearful of what the future holds. She has a support network and feels safer and less lonely.

“Over a period of weeks, and months I saw Caroline grow in confidence, laugh, talk with her friends at the group, and remember activities that they have done. Dementia Support Hampshire & IOW supported Caroline to find a new housing solution and she really has come into her own. I am so glad that I introduced Caroline to Dementia Support Hampshire & IOW because the work they are doing has made such a difference to not only Caroline's life but to the others who go along to the group.”

Andrea Fudge, Volunteer & Community Development Co-ordinator, One Community

“Thank you so much for all the help you have given Caroline she wouldn't be moving today if you hadn't been there with all your wonderful support.”

Amanda Cloke, Case Worker, Adults Health and Care, Older Adults Eastleigh Community Team

5.4 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 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 two-year partnership will enable SGN and Dementia Support Hampshire & IOW to:

- Introduce a team of two part-time Safe & Warm Dementia Support Workers to visit people in their own home to improve energy efficiency and safety
- Increase the knowledge of all Dementia Support Hampshire & IOW staff and volunteers to include energy safeguarding
- Increase numbers of people living with dementia on the Priority Service Register
- Raise awareness on CO safety and access to free CO alarms
- Provide information and access to Locking Cooker Valves for those living with dementia(s) or other cognitive impairment(s)
- Create a referral pathway between SGN and Dementia Support Hampshire and IOW

6.2 Success Criteria

Through our partnership, we will be able to effectively support 1,028 households living with dementia, their families, and carers in Hampshire and the Isle of Wight to be safe and warm at home. We will be able to deliver the following outcomes:

- Provide Fuel Debt Advice in the Community 6281-16 (NEA C&G Level 2 Award) energy training to 2 Dementia Support Hampshire & IOW staff, to identify customers in fuel poverty and how to access support via the Priority Services Register and other energy safeguarding support schemes
- Provide 1,028 vulnerable households energy efficiency common measures and behavioural advice
- Support up to 100 vulnerable households with referrals for more in-depth energy advice where need identified
- Provide up to 1,028 vulnerable households where applicable with; utility tariff advice, meter reading/billing support, and advice on trust and hardship funds such as Warm Home Discount
- Support 1,028 vulnerable households by providing information on carbon monoxide awareness, Locking Cooker Valve, and supported access to the Priority Services Register – with the expectation at least 25% are signed up to the PSR
- Complete a minimum of 800 home safety visits to identify ways to help keep people living with dementia safe and warm in their homes, by;
 - Identifying 60 households that would benefit from an LCV and onward referral to SGN
 - Distributing 100 carbon monoxide alarms to households where required
 - Providing 100 fuel vouchers at a value of £49 per voucher for households found to be in fuel crisis through Charis Grants
 - Providing 50 heated throws (with automatic shut off that prevents over-heating)
- Reach a minimum of 10,000 people via a winter readiness safe and warm multi-channel campaign providing information on the Priority Services Register and tips on energy safeguarding measures

7 Project partners and third parties involved

Dementia Support Hampshire & IOW – delivery of services in the community and via home visits

SGN – regional gas network providing programme funding and support to the delivery team, including training on energy schemes including Priority Services Register and carbon monoxide (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 work closely with other SGN partnerships in Hampshire, including; The Princes Royal Trust for Carers in Hampshire, Home and Well, Action Hampshire and the Home and Well Good Neighbours Network ensuring cross referral pathways and avoiding duplication.

In addition, the partnership will work with a network of local partners to identify eligible people living with dementia across Hampshire and the Isle of Wight; Hampshire County Council, Southampton City Council, Portsmouth City Council, IOW Council, Hampshire & IOW ICB, Southern Health NHS Foundation Trust, Solent NHS Trust, Hampshire Hospitals NHS Trust, University Southampton Hospital Trust, Portsmouth Hospitals University NHS Trust, IOW NHS Trust, Alzheimer's Society, Age Concern Hampshire, Borough Councils, Parish Councils, Primary Care Networks, and other organisations and voluntary groups supporting people living with memory loss or dementia.

8 Potential for new learning

Monitoring and evaluation

This partnership has been co-designed by Dementia Support Hampshire & IOW and SGN, building capacity by providing access to key services including the Priority Services Register, 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 clients to write more in-depth personalised reviews as 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 to share ideas and challenges through 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 households affected by people living with dementia. Through working across Hampshire and the Isle of Wight, we 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.

Dementia Support Hampshire & IOW will share best practice and learnings from Sage House, a dementia charity in West Sussex which has recently embarked in a partnership with SGN.

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.

This project has the potential to be upscaled as a model, working with other GDN's, enabling more people to be supported.

9 Scale of VCMA Project and SROI Calculations, including NPV

We worked with leading social impact research consultancy Sirio Strategies 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 £5.63.

Social Value Measurement

Total cost*	£91,418.53
Total gross present value	£606,021.57
Net Present Value (NPV)	£514,603.04
SROI	£5.63

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

10 VCMA Project start and end date

The project will run from April 2024 – March 2026 (2 years)

11 Geographic area

Hampshire and the Isle of Wight

12 Internal governance and project management evidence

Description of GDN(s) review of proposal and project sign off, with details on how the project will be managed

SGN has worked alongside Dementia Support Hampshire & IOW 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 Sirio Strategies using the industry standard framework supported by the GDN rulebook. As detailed above Sirio Strategies have reviewed the current partnership scope which has been forecast at adding an additional £5.63 for each £1 invested, this will be monitored closely to ensure we adhere to the VCMA governance criteria.

SGN and Dementia Support Hampshire and IOW 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.