

Alzheimer's Dementia Support Services - Kent

Vulnerability and Carbon Monoxide Allowance

August 2024

SGN



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1 Description

Project title	Alzheimer's Dementia Support Services - Kent
Funding GDN(s)	SGN
New/Updated (indicate as appropriate)	New
Date of PEA submission:	August 2024
Project contact name:	Janet Duggan
Project contact email:	janet.duggan@sgn.co.uk
Total cost (£k)	£210,862
Total VCMA funding required (£k)	£210,862

2 Problem statement

According to the Department for Energy Security and Net Zero, 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. Although the price cap is lowering again from April this year, with no further cost of living payments scheduled, we can say with some certainty that the effects of the cost-of-living crisis will continue to be felt by our residents. DESNZ have also reported that rising housing costs have brought an estimated 51,000 households into fuel poverty this year and "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. The change in energy prices after government support is estimated to have increased fuel poverty by around 238,000 households over this period."

Nationally, Citizen's Advice helped over 220,000 people with crisis support in 2023 – their highest figure to date. They are also seeing 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.

Dementia is a life-limiting terminal condition and can have a devastating impact on those receiving the diagnosis and on their families. Most people associate dementia with older people, but there are over 40,000 in the UK under 65 years affected by this condition. Those living with young-onset dementia require specific age-appropriate support. There are over 200 subtypes of dementia, and each type stops a person's brain cells from working properly in specific areas affecting their ability to remember, think, and speak. Each dementia can affect a person's mobility, speech, memory, and cognition. Dementia can also contribute to incontinence, hallucinations, and behaviours that challenge. Alzheimer's & Dementia Support Services (ADSS) often see carer breakdown as the condition progresses. This breakdown sometimes results in isolation, withdrawal from community engagement, and a decline in carers' wellbeing making them less resilient in their caring role.

The government guidance document All Our Health states that Dementia costs UK society £34.7bn per year, which is due to rise as the population ages. 850,000 people are living with dementia in the UK and by 2025 over 1m people could have dementia in the UK and in 2040 this number will exceed 1.6m.

([Dementia: Applying All Our Health](#))

ADSS is the leading specialist dementia service in Kent with a local reputation for providing excellence in dementia care and support. ADSS' services are in North and West Kent and in the unitary authority of Medway.

Kent and Medway have a diverse population with pockets of deprivation across the county. Affluent areas across West Kent are densely populated coastal towns with high levels of deprivation and an aging population. Just over a fifth of Kent's population is aged 65 and over (20.5%) compared to a national average of 18.4%.

The largest number of people from black Asian and minority ethnic (BAME) populations live in Medway, Dartford Gravesham & Swanley (ADSS area of operation). [Dementia UK](#) has reported the prevalence rates for young onset dementia is higher in BAME populations.

Across Kent and Medway there are currently an estimated 27,000 people living with dementia, it is recognised approximately 15,000 have mild dementia, 8,750 have moderate dementia and 3,500 have severe dementia. In 2021 it was highlighted by [NHS Kent & Medway CCG Engagement team](#) that two-thirds of people with dementia live in their own homes and one-third live in care homes. The number of people living with dementia in Kent and Medway is expected to rise to over 38,000 by 2030.

ADSS is an integral part of the Kent and Medway Integrated Care System Dementia Pathway and has over 32 Dementia coordinators linked to Primary Care Networks (26 PCNs working through 121 GP surgeries) throughout its area of operation. In addition, ADSS works collaboratively with Memory Assessment Services, local authorities, Age UK and various voluntary bodies across Kent. Dementia coordinators are a pivotal part of ensuring individuals living with dementia are identified and holistically assessed and are responsible for producing person-centred support plans. Their support is provided before, during, and post-diagnosis to both the person living with dementia and as importantly their carers. In 2023 the Dementia coordinators received 4048 new referrals an increase of 214% on the previous year making an average of 1405 people supported each month.

3 Scope and objectives

By working in partnership with Alzheimer's and Dementia Support Services (ADSS), the objective of the partnership is to work with people with dementia in Kent; to enable them to target vulnerable households who may be experiencing barriers to accessing services, to help alleviate fuel poverty and increase energy safety awareness.

Through the partnership the newly appointed and dedicated project coordinator will work with ADSS' existing dementia coordinators to identify and support people affected by dementia in North Kent, Medway and West Kent 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 efficiency advice and access to energy efficiency schemes, facilitated through the National Energy Foundation

Providing support to help keep people affordably warm:

- Supporting access to hardship funds
- Supported access to benefits entitlements checks

The partnership will provide support and education to sustain or improve household energy and safety signposting to Fuel Debt advice for households in need. The Project coordinator will undertake Level 2 Fuel Debt advice in the

Community Training with National Energy Action. Through developing a new dedicated area on ADSS' website and enhancing the CRM system Salesforce, ADSS will be able to track, monitor and report household engagement.

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 people who are 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 who is living with dementia 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 pillars 2 with outcomes in 3 and 4.

5 Evidence of stakeholder/customer support

5.1 Alzheimer's Dementia Support Services (ADSS)

ADSS has been supporting people affected by dementia for over 33 years and is best placed to have informative conversations and support those living in their own homes, so they remain safe and warm throughout their dementia experience. ADSS' Vision is that everyone in Kent and Medway gets the support they need to live the life they want. ADSS' Values are very important to the everyday running of the charity where they believe in being person-centred and inclusive, promoting everyone's rights and dignity by working together to deliver excellence in information and support in a caring and compassionate environment, whilst acting with integrity and honesty. ADSS will uphold these values in its partnership with SGN.

In April 2022 ADSS expanded their services beyond Dartford Gravesham and Swanley which they had served since their inception in 1991. Thanks to securing new contracts with Kent County Council and Kent and Medway NHS they are now providing additional services in West Kent Swale and Medway.

As part of the new contract, ADSS employed 32 Dementia coordinators across all areas as well as commencing partnership working with AGE UK Faversham and Sittingbourne in delivering well-being groups.

ADSS provides a range of services including information and guidance, community support and activity groups, one-to-one support in people's own homes and day support. ADSS' community reach and delivery will support the mobilisation requirements of SGN partnership outcomes and objectives.

ADSS facilitates an [annual evaluation](#) of its services and in 2023 the charity delivered over 765 group sessions, (2,314.5 hours of support) with over 9,000 attendees. The report also highlighted that 100% of those supported felt that staff were caring and compassionate and 98% felt listened to - this evidence shows ADSS staff's ability to

develop and maintain a positive rapport with those they supported. The Evaluation also identified that 74.5% of people who took part felt that ADSS' services helped them to live safely and independently in their own homes. ADSS expects that the SGN partnership will help increase these statistics in the forthcoming year.

ADSS passionately believes in the power of specialist support for people with dementia. The condition brings with it many challenges and stigma with a real and urgent need for understanding. This is proven by a ground-breaking piece of research called [IDEAL study](#) (Improving the Experience of Dementia and Enhancing Active Life) conducted by the University of Exeter which has proven that people affected by dementia have much better outcomes if they have access to:

- Staying safe and well
- Staying connected
- Keeping a sense of purpose
- Staying active
- Staying positive

The SGN/ADSS Partnership meets the 'Staying Safe and Well' outcome and can only promote better outcomes for those living with dementia in Kent and Medway.

5.2 Impact and Case Study

ADSS meets the Key Performance Indicators set by Kent County Council. Most people accessing its services feel less lonely, live safely and independently, and feel part of a community. ADSS has provided specialist information and advice and those we support have been able to make their own choices. ADSS is achieving its mission to give people the support and care they need to take control of their lives and manage their symptoms. It is working towards increasing the number of its post-diagnostic wellbeing and activity sessions in Kent and Medway to accommodate everyone who needs their support. These sessions reduce isolation and loneliness, and improve well-being, leading to happier healthier lives for people affected by dementia, making them better equipped to deal with the challenges of their dementia diagnosis.

Case study:

Jane is a lady with a diagnosis of Mixed Dementia and was referred to ADSS by her GP. Jane was finding it hard to sleep and was often awake in then night where she presented with agitation, which subsequently started to effect Clive, Jane's husband.

When the holistic assessment took place, the dementia coordinator was able to listen to Jane who clearly enjoyed talking about her life and the experiences she had had, she told the coordinator about her and Clive getting married in 1970 and that they have one son. She also said that she often goes out in the car for a drive with Clive and she enjoyed this.

Clive explained to the dementia coordinator that he finds it difficult to get some respite, he recognises that he is Jane's sole carer and that he does need some down time. He openly asked the dementia coordinator if there were any local social activities that Jane could attend and enjoy, to allow him to have some time to himself on a regular basis.

The dementia coordinator discussed the social and wellbeing groups held by ADSS and other organisations in the local area. There were some activities that appealed more to Jane and Clive then others and the dementia coordinator explained that it is their choice, but we would be able to help make the referrals to get the wheels in motion. These agreed outcomes were added to Janes person centred support plan, so she and Clive could revisit this when they needed to, to remind themselves what the coordinator agreed to help them with.

During the visit Clive also explained that Jane now had a named social worker, the dementia coordinator took the details in case there was any additional information or support Jane and Clive needed at a later stage.

The dementia coordinator also identified during the home visit that Jane smoked, this prompted her to check if there were smoke alarms in the house and identified that there wasn't. This led to an open conversation around safety in the home, the dementia coordinator explained to Jane and Clive that she could make a referral to Kent Fire and Rescue for a home safety check where they would be able to install smoke alarms for free and any other equipment they may need such as fire blankets. Clive was very happy for this to be carried out.

Three days after visiting Clive and Jane the dementia coordinator received a call from Clive, followed by an email showing pictures of a fire that had happened the night before in their kitchen. Jane had placed the electric kettle on top of the gas cooker, and it had caught alight. On this occasion Jane had woken Clive and he was able to put the fire out safely. However, this ordeal had caused great distress to Clive, and he was expressing that he was no longer able to cope.

The dementia coordinator offered reassurance to Clive and explained that she was going to contact Kent Fire and Rescue and update them on the situation. After speaking to Kent Fire and Rescue they agreed to visit the same day to install smoke detectors and in addition gave him advice relating to switching the gas off overnight and installing a Locking Cooker Valve.

The impact of the dementia coordinator being able to support Clive in such difficult times was evidently invaluable, acting as an advocate and support network to him when he needed it the most. Reducing the risk in the home by contacting Kent Fire and Rescue after their near miss of a really serious fire and allowing Clive to recognise that he was finding things extremely difficult and that it was okay to admit this.

Jane received urgent respite care and Clive was able to take some time out and stay with family, the dementia coordinator remains in contact with Clive who has explained that Jane remains in respite and that they are now looking for permanent care.

Quotations from those living with dementia and their carers accessing ADSS services and support:

"Pam was able to give me advice about how to apply for financial help and has explained about other services that maybe useful to us in the future."

"ADSS do such an important job in the community, we wished we had found it sooner in her diagnosis. As we were educated by your staff, ADSS is very clear in what they do."

"Absolutely ADSS look at the grey areas, match the person to the service, not just push things on them."

"It's great to have information and support, from a more practical route rather than medical."

"They have never not been able to answer my questions"

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 the dementia journey. 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 18-month partnership will enable SGN and ADSS to employ a full-time Energy Project Coordinator to oversee the success of this project in;

- Improving skills to identify and support eligible households into energy schemes including the PSR, energy efficiency advice, energy crisis support and carbon monoxide awareness and distribution and the Locking Cooker Valve
- Supporting households with energy safeguarding services and feeling more confident to maintain a safe and warm homeSupport and attend home visits with Dementia Coordinators where appropriate
- 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)
- Dedicated energy advice area on ADSS' website and targeted social media to proactively engage with people who are living with dementia in North Kent, Medway and West Kent
- Enhance the CRM to proactively track, monitor and report household engagement, improve efficiency of existing processes enabling ADSS's to reach and support more people
- Support for group sessions either ADSS or other external providers that enables more people living with dementia to access safe and warm spaces and the support they can provide

6.2 Success Criteria

Through our partnership, we will be able to effectively support 2,600 households affected by dementia, including their families and carers across Kent and Medway, ensuring that they are aware and supported to be safe and warm in their homes. We will be able to deliver the following outcomes:

- Deliver a winter warmth social media campaign prior to winter 2024, targeting over 15,000 people affected by dementia living within North Kent, Medway and West Kent, providing information and guidance about energy safeguarding
- Train a project coordinator from ADSS in Fuel Debt Advice in the Community 6281-16 (NEW C&G Level 2) via National Energy Action
- Deliver in person Training to 50 frontline workers/volunteers in energy safeguarding enabling triage and basic advice
- Provide advice and guidance to 2,600 households with common energy and safety measures through home visits and information on carbon monoxide awareness, Locking Cooker Valves, and supported access to the Priority Services Register
- Provide 1,300 vulnerable households to sign up to the Priority Services Register
- Approximately 800 CO alarms distributed following CO awareness discussions
- Identify 900 households that will benefit from more in-depth energy advice and guidance – particularly those living in the more deprived areas of Kent and Medway with an onward referral to Yes Energy Solutions. Support will include income maximisation, behavioural energy advice, advice on and support to access energy efficiency measures and access to hardship funding
- Deliver 50 energy advice sessions at dementia wellbeing groups providing safeguarding information reaching 600 vulnerable households
- Identify 100 households that would benefit from an LCV and onward referral to SGN

7 Project partners and third parties involved

- 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
- Partner – Alzheimer's & Dementia Support Services (ADSS) – delivery and coordination of the service
- Partner - Gas Safe Charity Think CO programme – providing training specifically for carbon monoxide awareness to staff and volunteers
- Kent Local Authorities (including Kent County Council, Gravesham Borough Council, Dartford Borough Council, Medway Council, Swale Council, Swanley District Council, Sevenoaks Town Council, Sevenoaks District Council, Maidstone Council, Various Parish councils - providing referrals and initial support for residents
- Memory Clinics – providing referrals and diagnostic support
- Post Diagnostic support groups – providing social inclusion, peer support and education platforms
- Age UK Sittingbourne & Faversham (KCC contract partner) – providing social inclusion, peer support and education platforms

In addition, the following third-party organisations; KCC Community Wardens, Admiral Nurses, Dementia Friend Communities, AGE UK, Primary Care Networks, Integrated Care Board, Imago, Involve, Carer First, Medway Community Health, Darent Valley Hospital, Medway Hospital, Maidstone Hospital, Sevenoaks Cottage Hospital, Medway Safeguarding Team, Medway Social Services, Kent County Council Social Services and Voluntary Organisations.

8 Potential for new learning

Monitoring and evaluation

This partnership has been co-designed by ADSS 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 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 people living with dementia. Through working across Kent, 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.

This project has the potential to be upscaled as a model, working with other GDN's, enabling more people living with dementia 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 £1.70.

Social Value Measurement

Total cost*	£206,077.21
Total gross present value	£556,798.20
Net Present Value (NPV)	£350,720.99
SROI	£1.70

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

10 VCMA Project start and end date

The project will run from 1st September 2024 to 31st March 2026

11 Geographic area

North Kent, Medway and West Kent

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 Alzheimer's and Dementia Support Services 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 Social Value framework and GDN rulebook. As detailed above SIRIO Strategies have reviewed the current partnership scope which has been forecast at adding an additional £1.70 for each £1 invested, this will be monitored closely to ensure we adhere to the VCMA governance criteria.

SGN and ADSS 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.