Appendix 4c: Trial Final Report, Carer Feedback, and Assessment

THE DEBENHAM PROJECT
Dementia - Caring for the Carers
A Dementia Friendly Community

Respite Scheme End of Trial Report

March 2026

Author: Carol Garrett (Trustee), with support and input from Caroline Manning (joint manager of the respite support scheme) and Roger Cockerton (Trustee and Treasurer).

Context and Identified Need

The inception of the respite support scheme originated from feedback provided by both current and former carers regarding what they deemed most valuable in their roles supporting loved ones. The overwhelming consensus among carers was that the provision of respite support would have a profoundly positive impact on their mental, emotional, and physical wellbeing. The support offered by the Debenham Project directly aligns with the Charity's objectives:

"To relieve the needs, and to promote and protect the good health of persons suffering from dementia, as well as their carers and family, in particular but not exclusively, by assisting in the provision of support, services, respite and guidance to the carers and family of such people. It is recognised that this object may be furthered by either giving support or services directly to the carers, or those with dementia, or jointly."

Baseline Data

1. 86% of those consulted expressed that they would appreciate respite support.
2. Barriers to accessing respite support were also identified, though these are not detailed in this section.

Additional Comments Establishing the Need

1. Carers expressed the desire for a half-day break to engage in activities such as walking or visiting the gym, with a particular emphasis on regaining fitness.
2. Requests were made for time alone to shop, complete housework, or simply enjoy personal time.

3. One carer highlighted the benefit of attending a free fitness class, noting that having care provided for their partner allowed for genuine relaxation. There was also mention of the need for support to cover appointments or to enable occasional walks or swims.
4. Respite care was described as much appreciated, with carers expressing hope for its availability.
5. There was a wish for half-day care to pursue hobbies, indicating the restorative impact of such breaks.
6. Some carers indicated that just three hours a week would be invaluable, enabling participation in art groups or social outings, which are currently not possible without their partner present.

Selecting the Care Provider

1. Eight care providers were approached to support the trial. Only one demonstrated the necessary flexibility for both the trial period and longer-term requirements.
2. This provider specialises in support within rural Suffolk and possesses a proven track record with similar projects.
3. The care company agreed to offer services to the project at a discounted rate compared to their standard fees.

Deliverables

1. Trustees approved a six-month trial, structured with a three-month interim review, involving four carers initially, with the possibility of including three additional carers at a later stage.
2. Four families were each offered up to four hours of respite support per month.
3. The allocated budget for the trial was £2,976, with participating families contributing £10 per hour towards care costs.

Evaluation Processes, Methods and Outcomes

1. Interim evaluation of the scheme with participating families was conducted informally through conversations at monthly TLC meetings and email consultations.
2. Ongoing feedback was gathered from the care provider through regular, informal face-to-face meetings.
3. An official end-of-trial meeting was held with the care provider to review outcomes.
4. End of trial feedback from the participating families is overwhelmingly positive and is detailed in Appendix A.

Obstacles and Issues

1. Queries arose regarding invoicing when families cancelled support visits at short notice. An updated process was agreed with the care provider, ensuring families acknowledge responsibility for last-minute cancellations.
2. This revised responsibility has been incorporated into the support agreement between the Charity and the participating families.

Outcomes and Deliverables

1. A total of 76 hours of support was delivered to four families during the trial period.
2. All four families reported that the support provided was of significant importance to them. Further feedback can be found in Appendix A.

Costings

1. The total budget for the six-month period was £2,976.
2. Actual expenditure amounted to 47% of the budget, as families contributed 32% of costs and one family ceased to use the service in December when their loved one was admitted to hospital.

Respite trial care costs			
	Cost of care	**Family contribution**	**DP contribution**
Family 1	615.35	223.95	391.4
Family 2	620.97	210	410.97
Family 3	384.41	130	254.41
Family 4	532.26	180	352.26
Totals	2152.99	743.95	1409.04

Key Insights for Future Delivery

1. Improvement in the quality of baseline data concerning carer needs is essential.
2. Clear criteria for determining which families are offered respite support needs to be established. The plan is to combine elements from the original questionnaire with the "Carer Well-being and Support (CWS) questionnaire for carers of people with a mental health problem or dementia" developed by the Royal College of Psychiatrists. This tool will facilitate assessment and monitoring of need through a RAG (Red, Amber, Green) rating system.
3. Utilising this assessment tool will help mitigate risks related to challenges over family selection for support.
4. Copies of our original questionnaire and the CWS questionnaire are attached to this report.

An Overview of Major Challenges Encountered and Risk

1. No major challenges have arisen during the trial. The care provider has been consistently collaborative and flexible in its approach and service delivery.
2. There is no significant financial risk to the Debenham Project Charity, as the respite support scheme does not constitute a commitment to families and is adjusted according to available resources.

Recommendations and Next Steps

1. Expand the respite support service in accordance with additional available funding. This may involve including more families and increasing hours for existing families to address immediate needs or pressure points.
2. Continue to uphold the current aims of the respite support:
    - Provide carers with opportunities for personal time to rejuvenate and prevent carer crisis.
    - Support carers and families in recognising the preventative benefits of early support and assist them in transitioning to accepting care.
3. Utilise the RAG rating system to manage the growth and expansion of support within the limits of available resources.
4. Maintain an informal record of decisions regarding support allocation to manage potential risks related to selection challenges.

Appendix A

Feedback from Respite Users

Family 1

My husband now requires constant support to remain safe, leaving me with no time for myself. He enjoys gardening and likes to feel useful but cannot distinguish between weeds and flowers, leading to challenges in managing the garden. As a result, I find it increasingly difficult to maintain my own wellbeing, as I no longer have time to pursue my hobbies.
Receiving respite has enabled me to return to my art class. My husband enjoys outings with his carer, who has become a friend to him. The care provided has been tailored to his interests, including visits to gardens and coffee outings. Having a male carer, who presents as a friend rather than solely as a carer, has been particularly beneficial.
I can relax, knowing that he is safe.

Family 2

With my husband's mobility issues, I am unable to have time to myself and we struggle to go out together. The support has been invaluable, allowing me to attend a Pilates class. While Pilates may not appeal to everyone, for me it offers an hour of respite,

enabling complete relaxation and leaving me feeling mentally and physically refreshed. This, in turn, helps me to face the rest of the day more positively. I also feel physically stronger, which I hope will allow me to continue caring for my husband at home for longer.

Family 3

My wife is very afraid of being alone and relies heavily on my presence. She is generally content with people and environments she can identify with. I use my four hours of support as two separate two-hour blocks: one for her to attend a keep fit session at Dove Cottage with her carer, and the other for the carer to stay with her at home while I run errands. She has also begun attending a day care centre twice a month and is gradually accepting time away from me.

Currently, I spend my free time on routine tasks such as shopping, haircuts, emails, and car maintenance, but I hope to play croquet as the weather improves. I am very grateful to the Debenham Project for offering this respite support, which has helped me recognise the need for it and the benefits it brings.

Since experiencing the benefits of having time for myself and observing my wife's acceptance, I have arranged for her to attend a day club once a week.

Family 4

Initially, I was hesitant to participate in the respite care programme, but after much gentle encouragement, I agreed to take part. Since my husband met his current carer Chris, who is similar in age and personality, we have both greatly benefited from the service. Chris enables my husband to enjoy walking and exercise, which I could not provide due to my own mobility issues. I also benefit from having quality time to spend with my friend.

Otherwise, my husband and I are together constantly. Having a few hours each month to enjoy different activities is very precious, and I do not regret for a moment being persuaded to participate.