

Appendix 4a: Trial

On the basis of close relationships between families and volunteers (many of whom have not only lived but also professional experience of dementia caring) and the families we support, at the beginning of 2025 the charity's trustees decided to explore the possibility of funding family carers for short-time respite (often described as "replacement care") in which specialist professional carers can link with families so that the family carer enjoys "some time off". The aim being to help them cope with the continual stress involved in the role as an unpaid carer. The result, as described by the following notes, was a 6-month trial to develop and test how we could achieve this.

1. The trial grew out of comments and feedback from existing and past carers as to what they would most value in terms of caring for their loved ones.
2. These carers said that some form of respite support would make a huge and positive difference to their mental, emotional and physical wellbeing.
3. This support by the DP, would align completely with the Charity's objects, namely:

"by assisting in the provision of support, services, respite and guidance to the carers and family of such people".

Long term vision/aims and objectives.

1. Facilitating and subsidising the opportunity for carers to have some time for themselves to "refresh"
2. Encouraging carers (and their families) to invest in appropriate professional care to relieve the pressure "not just for a day" but as an ongoing package.
3. Helping carers and their families understand and recognise the time when professional care may be needed to support and safeguard the family.
4. Expanding this support to all our families according to identified need.

Methodology

1. Current and past carers' views were sought via a questionnaire (appendix 7).
2. 86% of those surveyed said they would appreciate some respite support.
3. Barriers for carers seeking support included:
 - a. It's a minefield and I got pushed from pillar to post
 - b. I don't have the time/energy
 - c. I don't know who to contact
 - d. I don't need it as I'm coping
 - e. I am not confident it would work for me and my loved one
4. Some comments from those surveyed:
 - a. It would be great to have a half day where I could go for a walk or go to the gym. I'm not as fit as I used to be and would like to get fitter again.
 - b. I would like time to myself, time to go shopping, even for just an hour. Time to do housework.
 - c. It would be wonderful to have someone to call on to cover for appointments- dentist, doctor etc. and also maybe to have chance to get a walk or swim in occasionally!
 - d. I think this respite care would be much appreciated if you can arrange it. At the moment my partner would not cooperate, saying he didn't need a

babysitter. But sometime in the future I sure things will change and I would be really grateful to have some time out.

- e. Would really like availability of half a day care to go and pursue my hobby
 - f. I would be happy with three hours a week so I could go to my art group or coffee with friends. I don't have a break at the moment.
5. Held several meetings with Halesworth Dementia Carers Fund to learn from their experiences and consider best practice.
 6. Met with several local Care Companies and a self-employed carer to discuss operational and practical options.
 7. Continued conversations with all carers within the project as to their needs, requirements and aspirations.

Financial and contractual monitoring.

1. The Respite trial is managed and overseen by one Project Trustee and one volunteer.
2. Reports on the trial are provided to the full Trustee Board for each Board meeting.
3. Contractual monitoring is in its early stages and is managed through face to face meetings, phone calls and emails between the provider and the Trustee/volunteer as required. These have been frequent, informal and very successful to date. Moving forwards, this monitoring will be more formalised through quarterly meetings with the Care Provider.
4. At the end of each month:
 - a. Each family identifies the number of hours respite support received.
 - b. The provider sends the Trustee an invoice for each family within five days of the end of a calendar month.
 - c. The Trustee cross -references and reconciles any discrepancies.
 - d. Each family is invoiced for their contribution to the cost.
 - e. The Trustee send s the project treasurer sufficient details to enable him to pay the provider.
 - f. All invoices and documentation are saved on the project icloud space to address resilience and continuity.

In relation to contributions from carers:

- It was suggested by a Trustee at a Board meeting that we should explore with our participating families whether, and to what extent, they might contribute to the cost of the respite support.
- This discussion took place in a sensitive way during a TLC meeting.
- All families agreed that they felt it appropriate and feasible to make a contribution. One family suggested 50% of the per hour cost but the general consensus was that 33% would be acceptable.
- This was subsequently agreed by the Trustees for the trial.

In relation to the Halesworth scheme (this is the most up to date info)

- Between May 2023 and April 2024, the fund looked after 34 clients with respite of 2 – 4 hours a week.
- The total number of hours of care provided that year was 2,214 hours at a cost of £48,684.74.
- Since the charity was formed and the respite service started in 2014, the fund has provided 23,584 hours of care at a cost of £416,027 to 163 people with dementia and their families.