In Confidence

Revised Full Project Proposal

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Short-Time Flexible Respite for Family Carers Living with Dementia

Summary: This proposal sets out a 3–5 year Debenham Project initiative to provide short-time, flexible respite for family carers supporting people living with dementia in Debenham and surrounding villages. Its core benefit lies in the significantly improved well-being of both the family carer and the loved one they care for. Building on a successful small-scale trial, the service would offer typically 4–8 hours per month of specialist professional dementia care, giving carers safe time to rest, recover, and manage essential tasks while helping to reduce stress, delay carer breakdown, encourage earlier engagement with support services, and avoid more costly crisis interventions.

At an estimated project cost of £42,966 over three years or £85,318 over five years, with families contributing one-third of care costs and The Debenham Project covering two-thirds, the initiative presents a low-cost, shared-cost, preventative model. Its estimated respite cost of around £20–£40 per week compares strongly with dementia-specialist home care at £420–£840 per week, live-in care at £1,400–£2,000 per week, residential dementia care at £1,449 per week, nursing dementia care in the East of England at £1,577 per week, and emergency hospital admission for over-65s at £6,300–£7,000 per week. The cost case is therefore that modest early respite investment may help carers sustain home-based care for longer, reduce avoidable crisis responses, delay escalation into higher-cost statutory care, and provide evidence for wider commissioning of a community-based dementia support model.

1. Introduction

Who Cares for the Carers?

Over the past 16 years of supporting families who are living with dementia in and around Debenham, by far the most common concern expressed by family carers is that they need some time for themselves – just time for themselves when they can relax and recuperate without the constant stress, exhaustion, and mind-numbing constant 24/7 need to be alert to the needs of their loved one – and to protect their relationship despite all the frustrations and difficulties the illness presents. Without regular opportunities for respite, family carers (and those they care for) struggle against a bleak future until, eventually, and often triggered by a crisis, they can “care no more”. This is “Carer Breakdown” (appendix1) with all its potential implications in:

Emergency intervention by General Practice (GP), Dementia Intensive Service (DIST), Reactive Emergency Assessment Community Team (REACT), and Social Services

Acute and Extended hospital admissions

Transfer of the cared-for from the family home into nursing or residential care

These represent major concerns not only, in terms of public expenditure, but also for the family relationships which underpin unpaid care, and the mental health and well-being of both carer and cared-for. Although there is no easy or cheap solution to these concerns, from ours and other community-based dementia support projects' experience and understanding, we believe that offering even just a few hours per month of respite to carers when they can safely and securely leave their loved one in the hands of a specially trained professional carer, can make the difference between "I can't cope anymore" and "I can (and want to) cope for a while longer".

Again and again, when a family carer is "on the precipice", it is the smallest hand that can lead them "back from the edge". And perhaps it can play a part in "never reaching that edge". This is the premiss of our proposal.

2. Background

From the inception of the Debenham Project (appendix 2) we have been aware that unpaid (family) carers cannot and should not try to care for a loved one without the prospect of regular respite from the constant 24/7 demands of their role (appendix 1). In the early days the provision of this "care for the carer" was funded from the Social Services budget and managed and provided by Suffolk Family Carers. Since then, however, there have been many adjustments to priorities and we believe that preventative support focusing on the health and well-being of carers, has been neglected, especially in terms of their respite and mental health.

As a direct result of extensive conversations with current and past family carers, combined with our own experience and close relationships with our families in the activities and groups that we run (appendix 3). the decision was taken to explore offering some form of flexible limited respite using professional agency staff.

Building on the model of existing flexible respite implemented in Halesworth[1], beginning in September 2025, we initiated a 6-month trial (appendices 4a. 4b, 4c) offering a few hours per month of professional specialist dementia care to enable er to have "a bit of time for themselves" in the knowledge that their loved one was secure and in safe hands. This trial offered support to 4 families for 4 hours per month. The benefits (and costs) were closely monitored. It has enabled us, in collaboration with the care provider agency, to establish a sound foundation for the proposed project.

3. Flexible Carer Respite Support

[1] Recently received the award of Highly Recommended at the "UK Dementia Awards 2026" in the Respite Care and Carer Support category, a national award that recognises the very best in dementia care across the United Kingdom – see Latest News

What is a “Flexible Carer Respite Support” carer? Let’s start with what it is not. It is not a friend or neighbour “baby sitting”, neither is it a volunteer befriender chatting and reminiscing of times gone by, nor a professional delivering routine personal care to the care-for on a daily basis. What it is, is a special role in which, for an hour or two each week a specially trained professional carer takes on all the responsibilities of the family carer. Basically, they become integrated with the family and look after the cared-for, in any and every way necessary, as if they were a part of the family. At the same time, they will be in “in locus parentis” and legally responsible during the time that they are involved. In many respects it is a role similar to that of a live-in carer. We strongly believe that this is not a role suitable for a volunteer befriender, especially in the case of caring for someone with dementia.

4. Project Proposal

The Debenham Project is planning to set up, organise, and manage a 3 to 5-year project, following on from its small-scale trial (appendix 4a). The proposal is to offer funding for short-time flexible respite to primary family carers resident in Debenham and all its surrounding villages (population: circa 9.500) caring for someone with dementia. This will be, typically, 4 to 8 hours per month. It will enable carers to employ a specialist professional dementia care worker to join in with the caring role and enable the family carer to have “some time for themselves”, or to do those things that they find difficult without the constant “interruption or overhearing” from their loved one.

It will be in collaboration with a (possibly more than 1) professional care agency who can offer the kind of carer-focused support that the Debenham Project is recognised for – an unconditional holistic approach.

The partner agency(s) will offer a generous discount on their standard fees, and The Debenham Project will cover 2/3 of the costs. The Debenham Project will monitor the beneficial results in:

Improvement in carer well-being, and reduction in stress and other MH symptoms,

Integration of the professional carer into the family support environment, and

Earlier engagement with health, social care, and voluntary support services.

It will also seek to establish the costs in terms of:

The expenditure on professional carer support

The involvement in voluntary project management and carer support

Costs relating to statutory regulation and governance.

Involvement in crisis intervention

The Debenham Project will report on:

The initiation, early progress, and continuing achievements at 6 monthly intervals following project initiation.

Additionally, we will:

Seek to involve The University of Suffolk in a joint research project to independently assess the short - and longer-term - impact of the project, and the benefits of flexible short-time respite in dementia care.

5. Aims and Objectives

Whilst the practical reality of the proposed project is to:

1. Offer the opportunity for carers to have some time for themselves to "refresh" / "escape", even if only for a short time, through the provision of a personal professional respite carer who understands and will support both carer and cared-for as a "friend of the family".

We hope that it will also be a catalyst for families to recognise the preventative value of seeking support early – the "I wish I had ....." syndrome -by:

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.

And helping carers to avoid a crisis/breakdown happening, or at least, significantly delaying the time when professional care and intervention become a necessity to support and safeguard the family (carer and cared-for) by:

3. Seeking to engage earlier with the range of support offered by The Debenham Project and other agencies

And further, to demonstrate the value of a community-based charity working with a professional agency to deliver a significant improvement to the well-being of those living with dementia by:

4. Developing a truly holistic style of professional care which comes alongside the family, understands all that caring for someone entails, and shares the load – not task-based but carer & cared for centred.

And to also answer the question "Is it value for money" by:

5. Developing a solid body of evidence of the health and wellbeing benefits and cost-effectiveness of regular short-time respite to justify further investment in a continuing programme of provision for the longer term.

6. Providing the statistical and anecdotal evidence for the Health and Social Care agencies to consider and fund Short-Time Flexible Respite Care as an integral part of all dementia support care packages.

6. Projected Care Provision and Cost

Since its inception the number of family carers actively supported by the Debenham Project (appendix 5) increased over the early years to a rough average of somewhere between 25 and 35. Together with those others, to whom we have provided information and advice and/or referred to other agencies, this suggests that we had managed to "reach" perhaps even as many as 60% of the "knowable" number of families living with dementia in our area. However, following COVID, we have still not fully recovered to that level of penetration. There is no doubt that the prevalence of dementia has not changed, but somehow, or some why, the pandemic has caused a hiccup in the referrals to community-based dementia support organisations. The Debenham Project is already addressing this as a priority by working with the Memory Assessment Unit, Shaftesbury Suffolk Dementia Support, Suffolk Family Carers, and the local GP practice and expects referrals to significantly increase towards pre-Covid levels.

The following projection is based on steadily increasing the overall number of supported families and opening the service to all our carers following the trial. In line with current Government predictions an inflation rate of 2.5% per annum has been assumed.

	Project				
	Year 1	Year 2	Year 3	Year 4	Year 5
Supported families	6	8	10	10	10
Av. hrs/mth per family	4	6	8	8	8
Total Cost	£8,352	£17,122	£29,232	£29,928	£30,624
Family contribution	£2,880	£5,760	£9,600	£9,600	£9,600
Cost to DP	£5,472	£11,362	£19,632	£20,328	£21,024
Univ of Suffolk	£3,000	£1,000	£1,000		
Contingency	£500	£500	£500	£500	£500
Total	£8,972	£12,862	£21,132	£20,828	£21,524

Overall Project Cost	3 year total	5 year total
	£42,966	£85,318

7. Benefit and Value

Carer Health and Well-Being: All our experience suggests that regular respite leads to improved well-being and ability to cope with the caring role and thereby improve the quality of life for both carer and cared-for. It also seems logical that it will also extend the period during which independent caring of a loved one at home remains practicable.

Prevention: Improved health and well-being of the family carer reduces the likelihood and number of crises that may require intensive support from the health and social care agencies (appendix 8) and (appendix 9) The costs of such interventions are very high for both the family and the authorities:

- Dementia-specialist home care: **£420–£840 per week**
- Specialist dementia live-in care: **£1,400–£2,000 per week**
- **residential dementia care cost (UK): £1,449 per week**
- **Nursing Dementia (**East of England) **: £1,577 per week**
- Over - 65 emergency hospital admission: **£6,300–£7,000 per week** (average stay 12 days)
- Average bed cost: **£345 per day** (UK - no treatment)
- Delayed Discharge (Ipswich Hospital): **£211 per day** (no treatment)
- 10-day delay = **£2,114;** 30-day delay = **£6,343;** 60-day delay = **£12,687**

These figures do not include the initial costs of crisis interventions by DIST, REACT, Emergency services, and other responding agencies.

By way of comparison, the Flexible Short-Time Respite Care proposed amounts to between **£20 and £40 per week.** This seems a very low price to pay.

Earlier planning for home care support: It is believed that the financial arrangement whereby the family carer contributes 1/3 of the care costs whilst The Debenham Project covers 2/3 of the total, will encourage carers to consider investing in a more regular and appropriate care package earlier (appendix 9). This, in turn, will make life significantly easier later on as the illness progresses.

Social Value: The Short-Time Respite Care Initiative will be a further key element of our overall community - based services and activities. The Debenham Project has become a highly valued element of our commitment to "Caring for the Community, Caring in the Community, and Caring by the Community, and enjoys a very high level of active involvement by local residents in terms of volunteering and participation (appendix 3).

Assessment:

Integration: The development of the Trial and this proposal has resulted from close collaboration with the professional care provider which will continue. It is believed that the initiative will firmly reinforce the value of voluntary, professional, and other health and care agencies working together in the community.

Evolution: This model of care support can be readily transferred to other communities, e.g. Stowmarket, Eye, Hadleigh, Ipswich, Bury, Woodbridge etc. where there is active voluntary

dementia support. It offers a potential for significant change in the current approach by Social Care towards carer-centred support – An important addition to the toolkit for professional and voluntary agencies to help families living with dementia cope with the impact of the illness on the lives and reduce the overall cost of having to react when "the .... hits the fan".

8. Management and Governance

Management: Following on from the trial, the Respite Initiative Project will be managed and administered by a trustee and the task leader of our TLC peer group.

Advisory: To ensure close involvement with the families we are supporting, the management team will facilitate a "Project Advisory Group" comprising the management team, members representing the carers, and the local dementia advisor of Shaftesbury Suffolk Dementia Support.

Governance: The management team will prepare and publish a 6-monthly report for the trustees (copied the funding agency) detailing progress, carer feedback, formal assessment, and recognised benefits to date.

Safeguarding: The primary responsibility for the safety of the families being supported by the proposed project rests with the care provider. However, we fully recognise that The Debenham Projects has a duty of care to all the carers and cared-for whom we will be supporting in the proposed project. All trustees and volunteers currently directly involved in the Trial and the subsequent Flexible Respite Initiative Project have received safeguarding training and, as appropriate, DBS checks.

Selection for inclusion: The trustees and the management team recognise the difficulty in choosing which families we will be able to include in the initiative (appendices 5a, 5b) and will delegate authority to decide to:

- Dr. Paddy Fielder – Chair of Trustees and task leader of the Pre and Post Diagnosis Support Service supported by:
- Carol Garrett – Trustee and Manager of the Respite Initiative
- Caroline Manning – Task Leader of the TLC Peer Group

A key feature of The Debenham Project "Support" and "Pathway" lies in the way we welcome, get to know, understand, and encourage families as they struggle to cope with the impact of dementia on their lives. Usually, carers and those they care for join our Carers Club & Info Café which is much like an afternoon tea party. It is in this setting that we start to develop our relationships with them. We can begin to feel how they are managing and, as time goes by, as we sense when they need more support, we encourage them to come to our TLC (Talking, Listening, and Caring) peer group. This is led by past carers, and brings together current carers to share their problems and be mutually supportive. It is during these conversations that they open-up, share their worries, frustrations, exhaustions, and stress. It is by us all "listening" that we can help Carol, Caroline, and Paddy to decide.

9. Financial aspects

Since its inception The Debenham Project has successfully maintained a sound financial position and healthy reserves (appendix 8b) with an overall balance between expenditure and income since 2000 of (-£1506) on payments of £78,071, and current reserves of £19,622. However, it is recognised that in the current economic environment the Project will need to increase its fund-raising to cover increases in running costs over the coming years.

The current and forecast financial positions are provided in the Debenham Project Accounts and Projection (appendix 7).

The Trial was solely and fully funded from our reserves and was extended on that basis for a limited period until interim and more permanent funding can be secured, the Short Time Respite Initiative will be financially managed separately from the existing charitable activities of The Debenham Project.

To ensure the long-term viability and provision of service, we will be seeking to be commissioned by Health and Social Care as a demonstrator pilot for a wider adoption in other communities.

10. Conclusion

We believe that this is a particularly exciting venture for The Debenham Project by offering families living with dementia a truly flexible and holistic care regime which totally focusses on the health and well-being of the carers and enables those carers to care for their loved ones for longer. It is particularly special in that is creating a collaboration at the community level between the voluntary and professional care sectors.

We also believe that it will demonstrate a model of dementia support that can be disseminated widely with substantial direct benefits not only for the families but also for the delivery and cost to Suffolk's Health and Social Care agencies.

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Appendices

(Click on (open) to view/download)

1. **Carer Breakdown** (Open)
   When a family carer can no longer continue to care 24/7 and 52 weeks of the year (no holidays!) for the person they love.

2. **The Debenham Project** (Open)
   A brief history and description of the Debenham Project – its ethos, its evolution, its support activities, groups and services, and achievements.

3. **Community Involvement** (Open)
   Statistica data on the involvement and contribution of local carers and cared for, volunteers, professional supporters and other participants.

4. **Trial Implemention**

4a. Description (Open)

A description of the 6 month trial to establish the practicality of delivering the service and exploring its potential to benefit Carers.

4b. Questionnaire (Open)

The questionnaire designed as the basis for the evaluation of the trial.

4c. Trial Final Report, Carer Feedback, and Assessment (Open)

A review of the trial, its achievements, and lessons for the future.

5. Selection Procedure for Carer Respite Support

5a. Assessment for Inclusion in Ongoing Initiative. (Open)

The approach to selection of candidate families prioritised for support within the Initiative

5b. Questionnaire (Open)

A questionnaire for carers of people with dementia

6. Local Dementia Prevalence (Open)Local dementia related statistics and their relationship to the actual and potential percentage of local families who are living with dementia who are/could be benefiting from engaging with The Debenham Project

7. Debenham Project Accounts and Projections

7a. Debenham Project 2025-26 Accounts (Open)

THE DEBENHAM PROJECT (CARING FOR CARERS) Financial statement for the period ended 31 March 2026 and forecast FOR 2026/7

7b. Debenham Project Cash Flow and Reserves (Open)

Historic cash flow and reserves since 2020

7c. 3 Year Forward Projection (Open)

Estimated income and expenditure with and without the Respite initiative

8. Hospital Admissions and Discharges Data (Open)

Average lengths of stay, costs, and lengths of waiting for supported discharge.

9. Home and Residential Care Cost Data (Open)

Average Cost of a Social Care Package for a Family Living with Dementia (UK.)