In Confidence

Draft

Full Project Proposal

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Short-Time Flexible Respite for Family Carers Living with Dementia

Summary: This proposal sets out a 3 to 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.

But, and perhaps even more importantly, we believe that the earlier families are prepared to consider regular professional support of the form we are proposing, the longer they will be able to enjoy living "for the day", to come to terms with what might be their future, to continue to give their care to their loved one, and to make the most of all the support that we/must offer.

And we believe that "Caring for the Carer" cannot be separated from "Caring for the Cared-for". They are totally interdependent and leads to the ethos of "Caring for the Family".

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 the existing flexible respite implemented in Halesworth[1] (appendix 4a) 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 the carer 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 (Final Trial Report). 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

What is "Flexible Carer Respite Support"? 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 cared-for. 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. Yes, it is about companionship and befriending but is also about developing a close and trusted relationship with the family. At the same time, they will be in "in locus parentis" and legally responsible during the time that they are involved so that the family carer can know that their loved one is safe and secure during their "time for themselves". In many respects it is a role like that of a live-in carer. We strongly believe

[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

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 collaborate with 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 to 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 6) 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 Flexible Respite service to all our carers. 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
Families' 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

It is recognised that, for many reasons, there is always resistance for families to seek help and, especially to think of introducing professional care into their home. This implies significant uncertainty in the potential demand and take-up for the service. Therefore, this projection must be considered as an educated estimate and initial target for us to work towards.

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, improving 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 a total of between **£30 and £60 per week.** This seems a very low overall price to pay i.e. a very sensible investment against future expenses. And for the family contributing between £10 and £20 per week, a very affordable "insurance" against future expense.

Earlier planning for home care support: It is believed that the financial arrangement whereby the family carer contributes 1/3[2] 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 by delaying/reducing the costs of domiciliary care, and, perhaps, avoiding the substantial costs involved in long term residential or nursing care.

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).

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. This will form the basis of the routine reporting of KPIs, client feedback, and other data to the funding agencies.

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 Project has a duty of care to all the carers and cared-for whom we will be supporting in the proposed project. All those trustees and volunteers who were directly involved in the Trial and currently in 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 OBE – Trustee and Manager of the Flexible 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 begin by joining our Carers Club & Info Café which is much like an

[2] We believe that this arrangement involving a limited and relatively small payment of £10 to £20 a week from our families will encourage them to "step a toe into the water" regarding seeking professional support. We also appreciate that we know of families in our catchment for whom £1 extra is a significant ask in the family weekly budget. We will make steps to help them.

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 7b) 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 (appendices 7a, 7b, and 7c).

The Flexible Respite Support Trial has been solely and fully funded from our reserves and was extended on that basis for a limited period until an interim and more permanent funding can be secured, and that the Flexible Respite Initiative will be financially managed separately from the core existing charitable activities.

Recently, we have received a grant from Debenham Parish Council of £10,000 which together with £6,000 from our reserves has enabled us to initiate the project. However, our successful application to Suffolk Carers Fund will enable us to successfully not only deliver a truly special example of "Care in, and by, and to, our community" but also to assist in exporting it to the wider Suffolk community.

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 although primarily focusing on the health and well-being of the carer and enabling them to successfully continue to care for their loved ones for longer, also directly supports and stimulates those they care for with friendship and companionship and security. 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.)

Appendix 1: Carer Breakdown

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

Caring for a loved one – husband, wife, partner, parent, friend – who has dementia is always very physically and emotionally tough – stressful, demanding, isolating, worrying, etc. When their loved one's symptoms and behaviour are relatively mild, they may be just frustrating and capable of it being assumed that "He/she is just getting old, forgetful, and a bit grumpy", but it is also the time when those closest, start worrying that there may be a deeper reason (dementia?). However, they very often feel embarrassed (even guilty) to go to their GP and ask for help. We hope that with national and local efforts to increase dementia awareness they will recognise that they need to "grasp the nettle" and seek to "find out". Of course, receiving a positive diagnosis is what they fear most, and being left in a world of uncertainty and worry for how they will cope with caring for their loved one as the illness progresses. However, there is a wealth of support in the Health, Social Care, and Community-based organisations that can help – "We can't take it away, but we can help to make it a lot better". This is what The Debenham Project has been all about for over more than 16 years.

- Symptoms of carer breakdown build gradually as one becomes more involved in managing day to day care. When one is constantly 'firefighting', it leaves little or no time for seeking support or self-care.
- Caring for a loved one 24/7 is exhausting both physically and emotionally and leaves little or no time for even basic self-care.
- Mental and physical wellbeing of the carer is key to preventing carer breakdown and the need for residential care.
- Managing care of a loved one and seeking the right kind of support is stressful. Finding time to speak to different agencies when seeking help is difficult when one is constantly caring.

Ultimately, carer breakdown directly leads to the need for a higher level of support from Social Care.

Nevertheless, the progression of the illness does inevitably reach the point when it becomes almost impossible for a family carer to survive the continual stress of caring for their loved one. However, the desire to love and care for their husband, wife, partner, parent, friend overrides their need to care for themselves and ends in Carer-Breakdown.

This almost always ends in a crisis requiring intervention by DIST, REACT & Social Care, or worse, hospitalisation, or even worse, a tragedy. Hopefully, it results in the introduction of professional assistance in support for the daily physical needs of the cared-for but rarely encompasses their social aspects, or the MH aspects of the carer's needs.

Carer Breakdown is the primary trigger for, following a crisis, an extended hospitalisation ultimately leading to permanent residential or nursing care for their loved one. The costs to the State and the family are huge.

The road to prevention of carer breakdown, or at least delaying the need for critical intervention, lies in interactively supporting the carer to be able to continue in their primary role of caring for their loved one and handling all (24/7/52) that it involves. It means recognising that dementia is an illness of two patients, one with complex clinical neuro-MH-physical symptoms of a progressive illness, the other with complex clinical socio-MH-physical symptoms of a progressive caring induced mental illness. Meeting the needs of the cared-for must not dominate the needs of the carer.

"The carer can't care if the carer isn't cared for"

Appendix 2: The Debenham Project

The Project was initiated on April 23rd, 2009, at a meeting to discuss the impact of dementia on the Debenham and its surrounding villages, and particularly on how we could support our families, neighbours and local residents struggling to cope with the impact of the illness(s) on their lives. It was publicly launched at the beginning of the following October to an audience of over 150 local residents, carers, care professionals, county, district and parish council representatives, charities, etc. The presentations captured the essence of the Project as:

Focusing on supporting local Family Carers in their role of caring for their loved one.

Providing activities, services, information, and advice.

Coming alongside our friends and neighbours

An ambition to make a positive difference to the quality of life for those who are living with dementia, not only locally, but also across the Suffolk

Getting on and doing something

Evolving from the bottom up as needs and ideas present opportunities.

And characterised by:

"Caring in the Community", "Caring for the Community", and "Caring by the Community"

We started with a Helpline, a Lunch Club, Leaflets and our Website offering straightforward information based upon lived experience. The Project rapidly expanded and evolved its support activities, and services. Today, the breadth of support we offer (Poster Panel), as a community-based charity, and is taken up (appendix 3), is certainly comparable with any throughout the County and nationally.

Currently the activities, groups and services we provide are: Carers Club and Info Café, Fit Club, Songs for Sharing, TLC (Talking, Listening, and Caring), Forms and Paperwork, Pre and Post Diagnosis Support, Care to Dance, Signposting, and Annual Project Social Events.

For the future we hope to soon have: a Care Allotment and a Short-time Respite Support Service.

Currently the Debenham Project has a team of 62 regular volunteers and at least a further 13 who help on an occasionally or one-off basis and delivering over 100 hours per week of unpaid care (appendix 3).

The Debenham Project continues to evolve its already wide range of support for families living with dementia. From the very beginning we recognised that we must focus our efforts in a limited area surrounding Debenham – broadly this encompasses a population of between roughly 7,500 and 8,500 with an estimated 70 to 100 people (appendix 5) with significant symptoms of the illness(s). The catchment area stretches from Mendlesham to the North, to Worlingworth to the east, to Grundisburgh to the South, and to Stonham Aspal to the West (roughly IP6 9, IP13 6, IP13 7, IP14 5, IP14 6, IP23 7). This primarily covers the area served by The Debenham GP practice, but also parts of the Mendlesham and Framlingham practices.

Currently, surely, we work with smaller numbers than some other much larger charities – but that is the nature of a true community-based charity – personal and intimate and unconditional in our caring – And it succeeds!

The families we support develop strong and mutually supporting friendships and trust in each other and in all our volunteers – a" Social Structure" which we think of as "The Debenham Project Family". When a cared-for eventually dies we continue to support the carer, and over the years, many have become regular volunteers with the Project, helping and passing on their experience.

Whilst the project will always be focused on supporting the family carer of someone with dementia it also seeks to be inclusive for all elderly members of the community who may benefit from the activities and services it offers e.g. Seated exercise, transport, and music.

Appendix 3: Community Involvement

Statistica data (as at 24/06/26) on the involvement of local carers and cared for, volunteers, professional supporters and other participants in the individual activities, groups and services

	Volunteers (Main)	Volunteers: Occasional)	Carers	Cared-For	Past Carers	Passenger journeys	Other Participants	Professional
Carers	5	4	12	12	4		4	
Fit Club	2		5	4	1		8	2
Songs for Sharing	5	2	7	7			7	
TLC	5	1	7	4			2	
Care to Dance	5	2	6	6	1			2
Transport	21	2				74	24	
Coopersfield Lunch Club	5	1	8	11	1			
Hut	1	16	7	8	4		4	
Forms	2		4					
Pre/Post Diagnosis	2		7	7				
Carer Liaison	2							
Project Management	2							
Promotion	2							
Finance	1	2						
Admin	2							
Respite initiative		2	4	4				4

N.B. These numbers do not directly equate to the total numbers of volunteers, carers, cared-for, etc. as many help/participate in several activities/groups.

Statistical data on average weekly/monthly time given by volunteersvolunteers.

Volunteer hours				
Activity	**No of volunteers needed to run this activity**	**Hours per session**	**Hours per month of activity**	**Average per week**
Info café	6	2	24	6
Info café prep and clear down and cake purchase	2	10	20	10
TLC	4	3	12	3
Songs for sharing	5	2	10	5
Lunch club	5	2.5	12.5	4
Fit club	3	3	36	9

Care to Dance	4	3	24	6
Transport admin	2	16	32	8
Transport delivery	20	4	80	20
Website	2	1	4	2
Publicity	2	8	16	4
Face to face	2	3	12	3
General admin	1	2	8	2
Allotment	2	1	4	1
Hut	10	5	50	2
Hut admin	1	20	20	1
Garden party	3			20
Total			**364.5**	**106**

Statistics in relation to numbers supported by the Debenham Project, in and the surrounding area.

	Debenham	surrounding villages
Carers	9	14
Cared-for	12	11
Past Carers	12	14
Transport Passengers	62	10
Other Participants	14	0
Total	109	49

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.

Appendix 4b: Questionnaire

The aim of the questionnaire was to create a simple way to collect data in order to measure the impact of the six-month pilot and can be included in our grant applications. The same questions will be used each time.

The questionnaire was offered to our four families at the beginning of the six months, then half way through and at the end.

Aims and objectives for offering respite to our families supported by the Debenham Project.

- To support the carer and their loved one in accepting care and support
- To enable the carer to have some time away from their loved one
- For the cared for to accept support from a carer other than a family member
- Facilitating and subsidising the opportunity for carers to have some time for themselves to "refresh"
- 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.
- Helping carers and their families understand and recognise the time when professional care may be needed to support and safeguard the family.
- Providing practical support in order to avoid a carer crisis/breakdown or, at least, helping to delay when this might happen.

Questionnaire

Question 1 - How would you scale your emotional wellbeing at the moment

1	2	3	4	5
Poor	Slightly poor	OK	Fairly good	Good

Further comments

Question 2 - How easy is it to leave your loved one?

1	2	3	4	5
Very difficult	Fairly difficult	Unsure	Fairly easy	Easy

Further comments

Question 3 - How well does your loved one accept care from others, other than a family member?

1	2. Tried but was difficult	3	4	5
Never tried		Problematic	Fairly easy	No Problem

Further comments

Question 4 - How well do you accept help from others?

1	2	3	4	5
Never tried	Tried but was difficult	Unsure	Fairly easy	No Problem

Further comments

Question 5 - Do you get opportunities to support your own wellbeing?

1	2	3	4	5
Never	Rarely	Sometimes	If I have time	Easily

Further comments

Gathering data and measuring impact.

The data will illustrate the impact of the first six months of Respite Pilot for families

Desired Outcomes

- Carers have improved wellbeing
- Carers have additional time to relax and pursue hobbies
- Increased confidence for both Carers and loved ones to spend time apart from each other.
- Families accept care and support from professional carers for the first or increased time
- Families develop a trusting relationship with professional carers.

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.

Appendix 5a: Assessment for Inclusion in the Ongoing Initiative

It's quite difficult to define criteria for determining which families should be offered the opportunity to be provided with some respite support. Maybe our ultimate aim is to support any family within the project who seeks this type of support supplemented by our knowledge of the family? We would not wish to refuse anyone. We are all about inclusion.

1. Through observation and conversations with our families, we gained understanding of their needs and who were open to additional support.
2. The initial questionnaire informed us of the type of respite that would be beneficial and how it would impact.
3. Our aim is to offer respite to families before we observe carer breakdown in order to avoid or delay the need for crisis intervention, possibly leading to residential or nursing care.

Monitoring of carer experiences and improvement of well-being – key progress indicators. Carer feedback

We encourage our carers to give us feedback on the care they are receiving and how it can be improves. We are in close contact with the care company as they build positive relationships with the families.

Feedback from carers:

1. I can now attend a Pilates class which is supporting my physical and emotional wellbeing.
2. The carer gauges my husband's mood and is able to encourage him to go for a coffee.
3. This time gives me time to do a food shop in peace.

Co-production – asking, listening to and including carers.

Before and during the trail, past and current carer views were sought in both a verbal and written form. The feedback and comments are helping to refine and shape the ongoing delivery and future beyond the trial.

Carer breakdown, causes and implications

Causes

- Care breakdown builds gradually as one becomes more involved in managing day to day care. When one is constantly 'firefighting', it leaves little or no time for seeking support or self-care.
- Caring for a loved one 24/7 is exhausting both physically and emotionally and leaves little or no time for even basic self-care.
- Mental and physical wellbeing of the carer is key to preventing carer breakdown and the need for residential care.
- Managing care of a loved one and seeking the right kind of support is stressful. Finding time to speak to different agencies when seeking help is difficult when one is constantly caring.

Carer breakdown potentially leads to the need for a higher level of support from Social Care,

Appendix 5b: Questionnaire

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

Carer Well-Being & Support

A questionnaire for carers of people with dementia

Before we start filling in this questionnaire with you, there are a few things you should know.

- This questionnaire is for you as a carer to talk about your own circumstances and needs, and not those of the person you care for. We recognise that carer' needs are closely linked with the needs of the person they care for, but this questionnaire has been designed to find out about YOUR circumstances and YOUR needs.

- It can be filled in by anyone who has a role in caring for someone with dementia. You don't have to be a person's main carer or live at the same address as them.

- There are no wrong or right answers. Just provide whatever information you can to help us help you.

- The first section of the questionnaire asks about how you have been over the past 4 weeks. We recognise that this may have been an unusual time for you. However, we would like you to respond about your well-being in the last 4 weeks specifically. If you would like to tell us why this has been an unusual time, there is space to do so in the section about your needs, on page

A. Well-Being

The questions in Part A are about aspects of **your general well-being**. All of the questions are about how you have been over the past four weeks.

For each question, **tick one box on each line** that best reflects your caring responsibilities as a whole.

Please write today's date: _____

Your role as a carer

The first set of questions asks about your **role as a carer**. (Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	A little	Not at all
1. not having enough time to yourself?	☐	☐	☐	☐
2. having to put the needs of the person you care for ahead of your own needs?	☐	☐	☐	☐
3. not being able to take a break from caring?	☐	☐	☐	☐
4. not being able to plan for the future?	☐	☐	☐	☐
5. not being able to continue caring due to reasons beyond your control (e.g. becoming ill yourself, looking after very young children)?	☐	☐	☐	☐

Your relationship with the person you care for

The next questions are about your **relationship with the person you care for**. (Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	A little	Not at all
6. strains in your relationship with the person you care for?	☐	☐	☐	☐
7. the person you care for being too dependent on you at the moment?	☐	☐	☐	☐
8. the person you care for becoming too dependent on you in the future?	☐	☐	☐	☐
9. the person you care for saying things that upset you?	☐	☐	☐	☐
10. feeling irritable with the person you care for?	☐	☐	☐	☐

11. reaching "breaking point", where you feel you can't carry on with things as they are?	☐	☐	☐	☐

Your relationships with family and friends (Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	A little	Not at all
12. strains in your relationships with family and friends, because of your caring responsibilities?	☐	☐	☐	☐
13. "drifting apart" from family and friends, because your caring responsibilities limit the time available to keep in contact with them?	☐	☐	☐	☐
14. feeling isolated and lonely because of the situation you are in?	☐	☐	☐	☐
15. not getting the support you need from family and friends?	☐	☐	☐	☐

Your financial situation (Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	A little	Not at all
16. your own financial situation?	☐	☐	☐	☐
17. the financial situation of the person you care for?	☐	☐	☐	☐
18. having to cover extra costs of caring (e.g. extra help in the home, trips to hospital)?	☐	☐	☐	☐

Your physical health (Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	A little	Not at all
19. your own physical health?	☐	☐	☐	☐
20. your caring role making your physical health worse?	☐	☐	☐	☐

Your emotional well-being (Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	A little	Not at all
21. being unable to cope with the "constant anxiety" of caring?	☐	☐	☐	☐
22. feeling depressed?	☐	☐	☐	☐
23. being unable to see anything positive in your life?	☐	☐	☐	☐
24. lack of sleep brought about through worry or stress?	☐	☐	☐	☐
25. lack of sleep caused by the person you care for keeping you awake at night?	☐	☐	☐	☐

26. feeling so exhausted that you can't function properly?	☐	☐	☐	☐

Stigma and discrimination

(Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	A little	Not at all
27. people treating you differently because of the illness/condition of the person you care for?	☐	☐	☐	☐

Your own safety

(Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about the person you care for…	A lot	Quite a bit	A little	Not at all
28. accidentally doing something that puts you at risk (e.g. leaving the gas on)?	☐	☐	☐	☐
29. being aggressive or threatening towards you (e.g. verbal threats, sexual aggression, physical intimidation)?	☐	☐	☐	☐

The safety of the person you care for

(Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about the person you care for…	A lot	Quite a bit	A little	Not at all
30. harming themselves?	☐	☐	☐	☐
31. getting themselves into dangerous situations?	☐	☐	☐	☐
32. relapsing or deteriorating, such that it puts their safety at risk?	☐	☐	☐	☐

B. Support

The questions in Part B ask **how satisfied** you are, in general, with the **support you may receive** to help you in your role as a carer. Support may be provided by people working in the voluntary, private or statutory sectors, such as GPs, social workers, housing support workers, community psychiatric nurses, care workers, psychologists, psychiatrists, and carer support services or groups run by the voluntary sector.

Please tick the box on each line that best reflects your level of satisfaction with **the support you receive as a whole**.

Information and advice for carers

The next questions ask about how satisfied you are with **information and advice** for carers. (Please tick one box on each line.)

In general, **how satisfied** are you…	Very dissatisfied	Somewhat dissatisfied	Somewhat satisfied	Very satisfied
1. that you have enough information about the condition/illness of the person you care for to enable you to feel confident in caring for them?	☐	☐	☐	☐
2. that you have enough information about how their condition/illness is likely to develop in the longer-term?	☐	☐	☐	☐
3. that you can get whatever information you need when you need it (e.g. through your doctor or on your own)	☐	☐	☐	☐
4. with how easy it is to understand the information you have?	☐	☐	☐	☐
5. with the amount of advice available to you (e.g. from healthcare workers or other carers)?	☐	☐	☐	☐
6. that you are clear about who to go to for the information and advice you need?	☐	☐	☐	☐
7. that you are clear about who to contact if there is an emergency and you need help right away?	☐	☐	☐	☐
8. that you are clear about who to call if you have a routine inquiry?	☐	☐	☐	☐

Your involvement in treatment and care planning

(Please tick one box on each line.)

In general, **how satisfied** are you with…	Very dissatisfied	Somewhat dissatisfied	Somewhat satisfied	Very satisfied
9. your involvement in important decisions (e.g. medication, hospitalisation)?	☐	☐	☐	☐

10. your ability to influence important decisions?	☐	☐	☐	☐

Support from medical and/or care staff

The following questions ask about **the support you may receive from medical and/or care staff** - that is, the people providing treatment and care for the person you care for (e.g. GPs, social workers, housing support workers, community psychiatric nurses, workers from the voluntary sector, psychologists and psychiatrists). (Please tick one box on each line.)

In general, **how satisfied** are you with…	Very dissatisfied	Somewhat dissatisfied	Somewhat satisfied	Very satisfied
11. how easy it is to get help and support from staff for the *person you care for* (e.g. to prevent relapse)?	☐	☐	☐	☐
12. how easy it is to get help and support from staff for *yourself* (e.g. advice on how to deal with certain behaviours)	☐	☐	☐	☐
13. the quality of help and support from staff for the *person you care for*?	☐	☐	☐	☐
14. your relationships with key staff who support the *person you care for?*	☐	☐	☐	☐
15. how well the staff you have contact with are communicating with each other (i.e. that they share important information)	☐	☐	☐	☐
16. how seriously staff take what you say to them?	☐	☐	☐	☐
17. the level of understanding staff have of what it must be like to be in your situation?	☐	☐	☐	☐

C. Your Needs

The questions in Part C are about **your needs for support** to help you in your role as a carer

1. Which of the following types of support, if any, do you use to allow you to take a break from caring?

	Not at all	Occasionally	In emergencies or I need a break	Regularly
Friends/family providing care				
Paid carers coming into the home				
Paid carers providing care away from the home (e.g. care home)				
Supported activities out of the home, for the person you care for				
Supported breaks for you and the person you care for, away from the home				

Other respite care				

2. If you do not have any types of support, why might this be the case?

	I need help but I don't know where or how to get it	I would like some help on an ad hoc basis but don't know how to arrange this	I can manage at the moment	I don't need help at this stage

3. Would you like more support to help you in your role as a carer?

No, not at all ☐

Yes, a little ☐

Yes, a lot ☐

4. What types of additional support would you most like to receive?

5. Is there anything else that's important to your well-being that you'd like help with or would like to change?

D. The needs of the cared for person

About the Person or Persons You Care For

This next section asks about the person you care for with dementia. There is space at the end of the questionnaire if you would like to tell us about any further caring responsibilities you may have.

1. Who do you care for?

a) My **son/daughter**

b) My **partner/spouse**

c) My **brother/sister**

d) My **parent**

e) My **friend**

2. Which of the following statements best describes your role as a carer at the moment?

a) I am the **only** care giver

b) I **share** caring responsibilities with others, but I am the **main** caregiver

c) I **share** caring responsibility with others

d) I share caring responsibilities but **someone else is the main** caregiver

e) Other (please explain)

Appendix 6: Local Dementia Prevalence

Debenham GP Practice	Registered Patients with dementia	
2014: 70	2017: 63	2020: 70
In 2020 this represented 3.2% of over 65s		
27 unpaid family care	16 social care @ home	17 residential care

.....

Debenham GP catchment area	Estimated prevalence (30 - 35% undiagnosed)	
2014: 70 – 100	2025: 90 - 120	

.....

Shaftsbury Suffolk Dementia Support			Current clients registered with :		
Debenham GP	41	Mendlesham GP	39	Framlingham	30

.....

Debenham Project	Current carers	Past Carers	Participants	Transport
2017:	34	36		
2020:	41	39		
2025:	21	23	17	42

.....

UK Estimates	Mild	Moderate	Severe
2025: 982K Total	50%	37%	13%

What might these numbers mean?

Of the total estimated number of individuals with dementia, 25 – 30% will always be unknowable because their symptoms have not developed to the extent that they seriously impact on their, and their families, quality of life such that they may seek information and advice from health care, social care, or other support services. It may also be compounded by denial by the individual, or by the concern of their wife, husband, partner, family as betraying their loved one to an extended debilitating illness.

Almost all of those with severe symptoms, and a proportion of those with moderate symptoms, will be professionally cared for in a residential or nursing setting. Ultimately, in the dementia journey, a point is reached when it is no longer possible for the family carer to cope safely in their caring role (both for the person they are caring for and also for themselves).

The number of family carers actively supported by the Project increased over the early years to a rough average somewhere between 30 and 40. 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 as much as 60% of the “knowable” number of families living with dementia in our area. However, following COVID, we have significantly not recovered to that level of penetration. There is no doubt that the prevalence of dementia has not changed.

Respite Support Proposal: The following projection is based on achieving an increased number of supported families and opening up the service to all our carers following the trial. It is just intended to give a feel for the potential need for ongoing funding.

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Appendix 7a: Accounts THE DEBENHAM PROJECT
FINANCIAL STATEMENT FOR THE PERIOD ENDED 31 March 2026 and Forecast FOR 2025/26

The Debenham Project Current Accounts and Projected Outturn

INCOME AND EXPENDITURE ACCOUNT		**ACTUAL 31 March 2025/26**		**ForecastAnnual 2025/26**
INCOME		£		£
Donations with gift aid		879		2,000
Other Donations		3,087		4,200
Gift aid recoverable from hmrc		220		500
Fit Club Contributions		590		1,000
Donations made in Memoriam (ex with gift aid)		1,920		2,100
Travel Reimbursements		1,008		1,600
Fundraising		150		150
Respite Programme		280		1,000
East of England COOP				100
Interest		109		180
Other income		420		420
Gift Aid Recovery from prior years				
Total income		8,663		13,250
EXPENDITURE	£		£	
Printing and Stationery	286		600	
Postage	7		150	
Project Management	767		1,400	
Info Cafe Carers Club	1,335		1,800	
Fit Club	901		1,200	
Food and Friends	855		1,200	
Insurances	142		400	
Other	65		150	
Telephone and Internet	262		750	
Volunteer Travel Costs	1,519		2,000	
Songs for Sharing	46		500	
Rent Dove Cottage	800		1,600	
Care to Dance	353		400	
Respite support costs	828		2,610	
Total expenditure		8,167		14,760
Excess of Income over expenditure		496		-1,510

BALANCE SHEET

NON CURRENT ASSETS		-		-
CURRENT ASSETS				
CASH AT BANK (CURRENT ACCOUNT)		2,218		
BANK DEPOSIT ACCOUNT		16,172		
EAST OF ENGLAND COOP		3		
DEBTORS		1,205		
PREPAYMENTS		-		
ACCRUED INCOME				
TOTAL CURRENT ASSETS		19,598		
CURRENT LIABILITIES				
CREDITORS FALLING DUE WITHIN ONE YEAR	-			
OTHER CREDITORS				
ACCRUALS		-		
NET CURRENT ASSETS		19,598		
TOTAL ASSETS LESS TOTAL LIABILITIES		19,598		

REPRESENTED BY

GENERAL RESERVES BF	19,126
RESTRICTED RESERVE	-
TRANSFER FROM INCOME & EXPENDITURE ACCOUNT	496
RESERVES CFD	19,622

Appendix 7b: Debenham Project Cash Flow and Reserves

Year	19/20	20/21	21/22	22/23	23/24	24/25	25/26
Receipts	£9,384	£14,224	£8,839	£14,487	£8,450	£12,518	£8,663
Payments	£9,943	£8,938	£14,304	£14,464	£11,443	£10,812	£8,167
Net Receipts / (Payments)	-£559	£5,286	-£5,465	£23	-£2,993	£1,706	£496
Reserves	£22,469	£27,755	£22,290	£22,313	£19,320	£20,830	£19,622

Appendix 7c: 3 Year Forward Projection

Income and expenditure forecast

	Forecast Outturn 25/26	Quarter 1 26/27	Quarter 2 26/27	Quarter 3 26/27	Quarter 4 26/27	Total 26/27	Quarter 1 27/28	Quarter 2 27/28	Quarter 3 27/28	Quarter 4 27/28	Total 27/28	Quarter 1 28/29	Quarter 2 28/29	Quarter 3 28/29	Quarter 4 28/29	Total 28/29
Donations	7,100	1,800	1,800	1,800	1,800	7,200	1,800	1,800	1,800	1,800	7,200	1,850	1,850	1,850	1,850	7,400
Legacy/in memeoriam gifts	2,100	400	400	400	400	1,600	400	400	400	400	1,600	400	400	400	400	1,600
Travel scheme	1,600	400	400	500	500	1,800	550	550	550	550	2,200	575	575	575	575	2,300
Fundraising	879			800		800			800		800			800		800
Interest	180	45	45	40	40	170	40	40	35	35	150	30	30	25	25	110
Carer respite contributions	1,320	720	960	960	960	3,600	1,260	1,260	1,260	1,260	5,040	1,290	1,290	1,290	1,290	5,160
Other	420		420			420		480			480		500			500
	13,599	3,365	4,025	4,500	3,700	15,590	4,050	4,530	4,845	4,045	17,470	4,145	4,645	4,940	4,140	17,870
Charitable activities	5,100	1,350	1,350	1,350	1,350	5,400	1,400	1,400	1,400	1,400	5,600	1,450	1,450	1,450	1,450	5,800
Volunteer drivers costs	2,000	550	550	550	550	2,200	600	600	600	600	2,400	650	650	650	650	2,600
Insurances	400	100	100	100	100	400	100	100	100	100	400	110	110	110	110	440
Fundraising				200		200			200		200			200		200
Rent	1,600	400	400	400	400	1,600	425	425	425	425	1,700	425	425	425	425	1,700
Admin expenses	3,300	900	900	900	900	3,600	950	950	950	950	3,800	1,000	1,000	1,000	1,000	4,000
Other	150		150			150			150		150			150		150
Christie respite scheme	3,903	2,182	2,910	2,910	2,910	10,912	3,764	3,764	3,764	3,764	15,056	3,896	3,896	3,896	3,896	15,584
	16,453	5,482	6,360	6,410	6,210	24,462	7,239	7,239	7,589	7,239	29,306	7,531	7,531	7,881	7,531	30,474
Deficit	(2,854)	(2,117)	(2,335)	(1,910)	(2,510)	(8,872)	(3,189)	(2,709)	(2,744)	(3,194)	(11,836)	(3,386)	(2,886)	(2,941)	(3,391)	(12,604)
Deficit without respite	(271)	(655)	(385)	40	(560)	(1,560)	(685)	(205)	(240)	(690)	(1,820)	(780)	(280)	(335)	(785)	(2,180)
Net cost of respite	2,583	1,462	1,950	1,950	1,950	7,312	2,504	2,504	2,504	2,504	10,016	2,606	2,606	2,606	2,606	10,424
No respite in subsequent periods																
Opening reserve position	16,272	16,272	15,617	15,232	15,272	16,272	14,712	14,027	13,822	13,582	14,712	12,892	12,112	11,832	11,497	11,892
Closing reserve position		15,617	15,232	15,272	14,712	14,712	14,027	13,822	13,582	12,892	12,892	12,112	11,832	11,497	10,712	9,712
With respite																
Opening reserve position	16,272	16,272	14,155	11,820	9,910	16,272	7,400	4,211	1,502	(1,242)	7,400	(4,436)	(7,822)	(10,708)	(13,649)	(4,436)
Closing reserve position		14,155	11,820	9,910	7,400	7,400	4,211	1,502	(1,242)	(4,436)	(4,436)	(7,822)	(10,708)	(13,649)	(17,040)	(17,040)

Cashflow Forecast

	Forecast Outturn 25/26	Quarter 1 26/27	Quarter 2 26/27	Quarter 3 26/27	Quarter 4 26/27	Total 26/27	Quarter 1 27/28	Quarter 2 27/28	Quarter 3 27/28	Quarter 4 27/28	Total 27/28	Quarter 1 28/29	Quarter 2 28/29	Quarter 3 28/29	Quarter 4 28/29	Total 28/29
Existing charitable activities inflows																
Donations		3,000	1,800	1,800	1,300	7,900	1,800	1,800	1,800	1,300	6,700	1,850	1,850	1,350	1,850	6,900
Legacy/in memeoriam gifts		400	400	400	400	1,600	400	400	400	400	1,600	400	400	400	400	1,600
Travel scheme		400	400	500	500	1,800	550	550	550	550	2,200	575	575	575	575	2,300
Fundraising				800		800			800		800			800		800
Interest		45	45	40	40	170	40	40	35	35	150	30	30	25	25	110
Other			150			150			150		150			150		150
Charitable activity inflows		3,845	2,795	3,540	2,240	12,420	2,790	2,790	3,735	2,285	11,600	2,855	2,855	3,300	2,850	11,860
Existing charitable activities																
Charitable activities		1,350	1,350	1,350	1,350	5,400	1,400	1,400	1,400	1,400	5,600	1,450	1,450	1,450	1,450	5,800
Volunteer drivers costs		550	550	550	550	2,200	600	600	600	600	2,400	650	650	650	650	2,600
Insurances		100	100	100	100	400	100	100	100	100	400	110	110	110	110	440
Fundraising				200		200			200		200			200		200
Rent		400	400	400	400	1,600	425	425	425	425	1,700	425	425	425	425	1,700
Admin expenses		-	1,800	-	-	1,800	1,800	-	-	1,900	3,700	1,900	-	-	2,000	3,900
Other			150			150			150		150			150		150
Charitable activity outflows		2,400	4,350	2,600	2,400	11,750	4,325	2,525	2,875	4,425	14,150	4,535	2,635	2,985	4,635	14,790
Net chartiable activity cashflows		1,445	(1,555)	940	(160)	670	(1,535)	265	860	(2,140)	(2,550)	(1,680)	220	315	(1,785)	(2,930)
Cash balance bfd		15,000	16,445	14,890	15,830	15,000	15,670	14,135	14,400	15,260	15,670	13,120	11,440	11,660	11,975	13,120
Cash balance cfd		16,445	14,890	15,830	15,670	15,670	14,135	14,400	15,260	13,120	13,120	11,440	11,660	11,975	10,190	10,190
Carer respite contributions inflow		720	960	960	960	3,600	1,260	1,260	1,260	1,260	5,040	1,290	1,290	1,290	1,290	5,160
Christie respite scheme outflow		(2,182)	(2,910)	(2,910)	(2,910)	(10,912)	(3,764)	(3,764)	(3,764)	(3,764)	(15,056)	(3,896)	(3,896)	(3,896)	(3,896)	(15,584)
Net outflow		(1,462)	(1,950)	(1,950)	(1,950)	(7,312)	(2,504)	(2,504)	(2,504)	(2,504)	(10,016)	(2,606)	(2,606)	(2,606)	(2,606)	(10,424)
Combined net cash position		14,983	12,940	13,880	13,720	5,358	11,631	11,896	12,756	10,616	3,104	8,834	9,054	9,369	7,584	(234)

Respite workings

	25/26	26/27	27/28	28/29
inflation factor	1	1.025	1.035	1.035
	Per hr	Per hr	Per hr	Per hr
Project contribution	29.57	30.31	31.37	32.47
User contribution	10	10	10.5	10.75

Project contribution

nos per week	cost per week			
4	118	121	125	130
6	177	182	188	195
8	237	242	251	260
10	296	303	314	325
12	355	364	376	390
14	414	424	439	455
16	473	485	502	519
18	532	546	565	584
20	591	606	627	649

User contribution

nos per week				
4	40	40	42	43
6	60	60	63	65
8	80	80	84	86
10	100	100	105	108
12	120	120	126	129
14	140	140	147	151
16	160	160	168	172
18	180	180	189	194
20	200	200	210	215

Net cost to Debenham Project

					annual	
nos per week					26/27	27/28
4	78	81	83	87	3,899	4,007
6	117	122	125	130	5,849	6,011
8	157	162	167	174	7,799	8,014
10	196	203	209	217	9,748	10,018
12	235	244	250	261	11,698	12,021
14	274	284	292	304	13,648	14,025
16	313	325	334	347	15,598	16,028
18	352	366	376	391	17,547	18,032
20	391	406	417	434	19,497	20,035

Appendix 8: Hospital Admissions and Discharges Data

🏥 Average Length of Stay (LOS) for Under-65s in England

The national data doesn't publish LOS specifically for "under-65s" as a single group, but we *can* infer it reliably from the age-stratified patterns in the Health Foundation's analysis of hospital stays.

From the national figures:

- Overall average LOS in 2022: **8.3 days**
- LOS for older adults (85+): **12.5 days**
- LOS for emergency admissions overall: **9.1 days**

Because LOS rises sharply with age — and the 85+ group pulls the average *up* — the LOS for under-65s is **significantly lower** than the national average.

✅ Best evidence-based estimate: 4–6 days

This aligns with:

- Lower frailty burden
- Fewer multi-morbidities
- Higher proportion of short-stay emergency admissions.
- Lower rates of delayed discharge

This 4–6 day range is widely used in service-planning models when age-specific LOS is not published.

Average Length of Stay (LOS) for Dementia-Related Hospital Admissions (England & Wales)

The most authoritative figure comes from the **National Audit of Dementia**, analysed in a large retrospective cohort study of **10,106 dementia inpatients** across **200 hospitals**.

Median LOS for dementia-related admissions: 12 days

(IQR 6–23 days)

This is the best national benchmark available and is widely used in service-planning, frailty modelling, and dementia-care improvement work.

Daily cost of a hospital admission for someone aged 65+

The NHS does **not** publish costs specifically by age group.
However, the **cost per day depends on the type of admission**, and older adults are overwhelmingly admitted as **non-elective (emergency)** cases.

The most reliable figures come from a **UK Parliamentary Written Answer (2023)**, which provides the official NHS cost-per-day for different types of beds:

£900–£1,000 per day for a typical over-65 emergency admission.

If the patient requires:

- **frailty care**,
- **complex discharge planning**,
- **rehab**, or
- **dementia-related support**,

...the cost can be **significantly higher**, especially if critical care is involved.

37% of all delays were due to waiting for social care services in late 2022.

- Social-care-related delays were rising before the pandemic and accounted for **40% of delays** in early 2020.

For patients who *are* delayed due to social care in Suffolk, local system leaders typically report:

Delays of 3–14 days are common.

Delays of 2–6 weeks occur for complex dementia or care-home placements.

Typical social-care-related delays are several days to multiple weeks.

This is supported by:

- High numbers of patients waiting for home-care packages.
- Shortage of care-home beds
- Workforce shortages in domiciliary care
- Complex discharge planning for frail and dementia patients

The Health Foundation explicitly notes that the **1.3-day average masks much longer waits for those actually delayed**.

Appendix 9: Home and Residential Care Cost Data

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

There is no single "standard" dementia care package, because costs depend on whether the support is:

- **Home care (hourly)**
- **Live-in care**
- **Residential dementia care**
- **Nursing dementia care**

But we *can* give accurate national averages from the sources returned in search.

1. Home Care (Hourly Support at Home)

Dementia care is typically **15% more expensive** than standard home care because of the specialist skills required.

Typical UK hourly home-care rates (2025):

- Standard home care: £25–£35 per hour
- Dementia-specialist home care: **£30–£40 per hour** (after the 15% uplift)

A typical package for a family supporting someone with moderate dementia is:

- **2–3 visits per day (1–2 hours each)**
- Weekly cost: **£420–£840**
- Annual cost: **£22,000–£44,000**

2. Live-In Dementia Care (24-hour support at home)

Live-in care is increasingly common for families wanting to avoid residential care.

2025 national averages:

- Standard live-in care: **£1,100–£1,800 per week**
- Specialist dementia live-in care: **£1,400–£2,000 per week**

Annual cost:

- **£73,000–£104,000**

3. Residential Dementia Care Homes

The most robust national dataset (Lottie, 2025) shows:

Average weekly residential dementia care cost (UK): £1,449

Regional examples:

- East of England (your region): **£1,442 per week** for residential dementia care

Annual cost:

- **£75,000+**

4. Nursing Dementia Care Homes

For people with dementia plus complex medical needs:

4. UK average: **£1,597 per week**
5. East of England: **£1,577 per week**

Annual cost:

- **£82,000+**

5. Lifetime Cost of Dementia Care

The Alzheimer's Society estimates:

- **Average lifetime cost of dementia care: ~£100,000**
- **63% of this cost is paid by families themselves.**

This is because dementia is *not* considered a health condition eligible for NHS-funded care unless needs are severe enough for Continuing Healthcare.

The "average" package for a family

Most families supporting someone with dementia at home use a **mixed package**:

- 1–3 hours of home care per day
- Occasional respite
- Carer support
- Day services (where available)

This typically costs:

£400–£900 per week

£20,000–£45,000 per year

Families needing live-in care or residential care face much higher costs.