Draft Project Proposal

Short-Time Respite for Family Carers Living with Dementia

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" (appendix 1) 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 (appendix 4), beginning in September 2025, we initiated a 6-month trial (appendix 4) offering a few hours per month of professional specialist dementia care to enable carers to have “a bit of time for themselves” in the knowledge that their loved one was secure and in safe hands. This trial is initially supporting 4 families for 4 hours per month but this number is likely to increase to 6. The benefits (and costs) are being closely monitored. It has enabled us, in collaboration with the care provider agency, to establish a sound foundation for the proposed project.

3. 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. The proposal is to offer funding for short-time respite to primary family carers resident in Debenham and 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, reduction in stress, and other MH symptoms,

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

Engagement with health, social care, and voluntary support services.

It will also 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 short-time respite in dementia care.

4. 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 - a personal professional respite carer who understands and will support both carer and cared-for as a “friend of the family”.

We believe that it will also be a catalyst for families to recognise the preventative value of seeking support early – the “I wish I had …….” syndrome.

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.

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

3. Seeking to avoid a carer 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).

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.

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.

To answer the question “Is it value for money”?

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

5. 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 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 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 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.

Projected Provision and cost

	Trial	
	Sep 25 - Jan 26	Feb 26 - May 26
Supported families	4	6
Av. hrs/mth per family	4	4
Total Cost	£1,392	£2,088
Family contribution	£480	£720
Cost to DP	£912	£1,368
Univ of Suffolk Independent Assessment		£500
Contingency		£500

Total	£912	£2,368

	Project				
	Year 1	Year 2	Year 3	Year 4	Year 5
Supported families	8	8	8	10	10
Av. hrs/mth per family	6	6	8	8	8
Total Cost	£16,704	£17,122	£23,386	£29,928	£30,624
Family contribution	£5,760	£5,760	£7,680	£9,600	£9,600
Cost to DP	£10,944	£11,362	£15,706	£20,328	£21,024
Univ of Suffolk	£3,000	£1,000	£1,000	£1,000	£1,000
Contingency	£500	£500	£500	£500	£500
Total	£14,444	£12,862	£17,206	£21,828	£22,524

6. 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 9) and (appendix 10). 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 day** (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 the crisis interventions by DIST, REACT, Emergency services, and other responding agencies.

By way of comparison, the regular 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 10). 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.

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 and Eye, both with active voluntary dementia support. It offers a potential for significant change in the current approach to carer-centred social care – 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”.

7. 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 the 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 for consideration by the trustees of The Debenham Project.

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 we will be supporting in the trial in the Initiative. All trustees and volunteers currently directly involved in the Trial and the subsequent Respite Initiative 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 (appendix 6) and will delegate authority to decide to:

- Carol Garrett – Trustee and Manager of the Respite Initiative
- Caroline Manning – Task Leader of the TLC Peer Group
- Dr. Paddy Fielder – Task Leader of the Pre and Post Diagnosis Support Service

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 that they need more support, we encourage them to come to our TLC (Talking, Listening, and Caring) peer group, led by past carers, which 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.

8. 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.

Whilst the Trial is being solely and fully funded from our reserves and will be extended for a limited period or until 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.

In order 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.

9. 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 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

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 15 years.

Nevertheless, the progression of the illness inevitably reaches 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 inevitably ends in a crisis requiring intervention by DIST and 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”

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, as a community-based charity, we offer, and is taken up, 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, 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 55 regular volunteers and at least a further 13 who help on an occasionally or one-off basis.

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.

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 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.

3. Community Involvement

Numbers involved in activities, groups and services

	Volunteers (Main)	Volunteers (Occ.)	Carers	Cared-For	Past Carers	Passengers	Other Participants	Professional
Carers	5	4	14	15	8			
Fit Club	2	2	5	4	1		8	2
Songs for Sharing	5	2	8	10	1		4	
TLC	5	1	7	4			2	
Care to Dance	4		4	4				2
Transport	23	2				74		
Coopersfield LC	5	1	7	8	1			
Hut	1	16	7	8	4		4	
Forms	2		4					
Pre/Post Diagnosis	2							
Carer Liaison	2							
Project Management	2							
Promotion	2							
Finance	1	2						
Admin	2							
Other		7						

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.

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
Publicitiy	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**

4. 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 enjoy "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.

5. 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

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Debenham GP catchment area Estimated prevalence (30 - 35% undiagnosed)

2014: 70 – 100 2025: 90 - 120

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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.

6. Selection for Inclusion

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 wouldn't 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 delay the need for residential 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.

7. Questionnaire

The aim of the questionnaire is 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 will be 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 Poor	2 Slightly poor	3 OK	4 Fairly good	5 Good

Further comments

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

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

Further comments

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

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

Further comments

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

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

Further comments

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

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

8. Debenham Project Accounts and Projection

Debenham Project Current Financial Position and Projections

- Current year’s statement (appendix 8a)
- Cash Flow and Reserves (appendix 8b)
- 3 year Forward Projections (appendix 8c)

8a. Debenham Project 2025-26 Forecast

THE DEBENHAM PROJECT (CARING FOR CARERS)
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		

8b. Debenham Project Cash Flow and Reserves

Year	19/20	20/21	21/22	22/23	23/24	24/25	25/26	2019 - 2026
Receipts	£9,384	£14,224	£8,839	£14,487	£8,450	£12,518	£8,663	£76,565
								£0
Payments	£9,943	£8,938	£14,304	£14,464	£11,443	£10,812	£8,167	£78,071
								£0
Net Receipts / (Payments)	-£559	£5,286	-£5,465	£23	-£2,993	£1,706	£496	-£1,506
Reserves	£22,469	£27,755	£22,290	£22,313	£19,320	£20,830	£19,622	

8c. 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)	(260)	(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)

Cashfow 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 activty inflows		3,645	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 actvities		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	8,358	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	28/29
4	78	81	83	87	3,899	4,007	4,170
6	117	122	125	130	5,849	6,011	6,255
8	157	162	167	174	7,799	8,014	8,340
10	196	203	209	217	9,748	10,018	10,425
12	235	244	250	261	11,698	12,021	12,510
14	274	284	292	304	13,648	14,025	14,595
16	313	325	334	347	15,598	16,028	16,679
18	352	366	376	391	17,547	18,032	18,764
20	391	406	417	434	19,497	20,035	20,849

9. 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**.

10. 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:

5. UK average: **£1,597 per week**
6. 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.