

# In Confidence

Full Project Proposal

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## Short-Time Flexible Respite for Family Carers Living with Dementia

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

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

### 1. Introduction

#### Who Cares for the Carers?

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

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

Acute and Extended hospital admissions

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

These represent major concerns not only, in terms of public expenditure, but also for the family relationships which underpin unpaid care, and the mental health and well-being of both carer and cared-for. Although there is no easy or cheap solution to these concerns, from ours and other community-based dementia support

projects' experience and understanding, we believe that offering even just a few hours per month of respite to carers when they can safely and securely leave their loved one in the hands of a specially trained professional carer, can make the difference between "I can't cope anymore" and "I can (and want to) cope for a while longer".

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

## **2. Background**

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

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

Building on the model of existing flexible respite implemented in Halesworth<sup>1</sup>, 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 carers to have "a bit of time for themselves" in the knowledge that their loved one was secure and in safe hands. This trial offered support to 4 families for 4 hours per month. The benefits (and costs) were closely monitored. It has enabled us, in collaboration with the care provider agency, to establish a sound foundation for the proposed project.

## **3. Flexible Carer Respite Support**

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

## **4. Project Proposal**

The Debenham Project is planning to set up, organise, and manage a 3 to 5-year project, following on from its small-scale trial (appendix 4a). The proposal is to offer funding for short-time flexible respite to primary family carers resident in Debenham and all its surrounding villages (population: circa 9,500) caring for someone with dementia. This will be, typically, 4 to 8 hours per month. It will enable carers to employ a specialist professional dementia care worker to join in with the caring role and enable the family carer to have "some time for

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<sup>1</sup> 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](#)

themselves”, or to do those things that they find difficult without the constant “interruption or overhearing” from their loved one.

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

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

- Improvement in carer well-being, and reduction in stress and other MH symptoms,
- Integration of the professional carer into the family support environment, and
- Earlier engagement with health, social care, and voluntary support services.

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

- The expenditure on professional carer support
- The involvement in voluntary project management and carer support
- Costs relating to statutory regulation and governance.
- Involvement in crisis intervention

The Debenham Project will report on:

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

Additionally, we will:

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

## **5. Aims and Objectives**

Whilst the practical reality of the proposed project is to:

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

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

2. Encouraging carers (and their families) to invest in appropriate professional care to relieve the pressure “not just for a day” but as an ongoing package.

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

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

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

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

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

5. Developing a solid body of evidence of the health and wellbeing benefits and cost-effectiveness of regular short-time respite to justify further investment in a continuing programme of provision for the longer term.
6. Providing the statistical and anecdotal evidence for the Health and Social Care agencies to consider and fund Short-Time Flexible Respite Care as an integral part of all dementia support care packages.

## 6. Projected Care Provision and Cost

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

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

|                        | Project                 |                         |         |         |         |
|------------------------|-------------------------|-------------------------|---------|---------|---------|
|                        | Year 1                  | Year 2                  | Year 3  | Year 4  | Year 5  |
| Supported families     | 6                       | 8                       | 10      | 10      | 10      |
| Av. hrs/mth per family | 4                       | 6                       | 8       | 8       | 8       |
| Total Cost             | £8,352                  | £17,122                 | £29,232 | £29,928 | £30,624 |
| Family contribution    | £2,880                  | £5,760                  | £9,600  | £9,600  | £9,600  |
| Cost to DP             | £5,472                  | £11,362                 | £19,632 | £20,328 | £21,024 |
| Univ of Suffolk        | £3,000                  | £1,000                  | £1,000  |         |         |
| Contingency            | £500                    | £500                    | £500    | £500    | £500    |
| Total                  | £8,972                  | £12,862                 | £21,132 | £20,828 | £21,524 |
| Overall Project Cost   | 3 year total<br>£42,966 | 5 year total<br>£85,318 |         |         |         |

## 7. Benefit and Value

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

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

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

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

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

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

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

### **Assessment:**

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

**Evolution:** This model of care support can be readily transferred to other communities, e.g. Stowmarket, Eye, Hadleigh, Ipswich, Bury, Woodbridge etc. where there is active voluntary dementia support. It offers a potential for significant change in the current approach by Social Care towards carer-centred support – An important

addition to the toolkit for professional and voluntary agencies to help families living with dementia cope with the impact of the illness on the lives and reduce the overall cost of having to react when “the .... hits the fan”.

## 8. Management and Governance

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

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

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

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

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

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

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

## 9. Financial aspects

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

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

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

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

## **10. Conclusion**

We believe that this is a particularly exciting venture for The Debenham Project by offering families living with dementia a truly flexible and holistic care regime which totally focusses on the health and well-being of the carers and enables those carers to care for their loved ones for longer. It is particularly special in that it 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 Implementation**

#### **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 on the involvement of local carers and cared for, volunteers, professional supporters and other participants in the individual activities, groups and services

|                                        | Volunteers<br>(Main) | Volunteers<br>(Occ.) | Carers | Cared-<br>For | Past<br>Carers | Passengers | Other<br>Participants | Professional |
|----------------------------------------|----------------------|----------------------|--------|---------------|----------------|------------|-----------------------|--------------|
| Carers                                 | 5                    | 4                    | 14     | 15            | 8              |            |                       |              |
| Fit Club                               | 2                    | 2                    | 5      | 4             | 1              |            | 8                     | 2            |
| Songs for<br>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<br>Hut                 | 5<br>1               | 1<br>16              | 7<br>7 | 8<br>8        | 1<br>4         |            | 4                     |              |
| Forms                                  | 2                    |                      | 4      |               |                |            |                       |              |
| Pre/Post<br>Diagnosis                  | 2                    |                      |        |               |                |            |                       |              |
| Carer Liaison<br>Project<br>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.

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

| <b>Volunteer hours</b>                                |                                                             |                              |                                            |                             |
|-------------------------------------------------------|-------------------------------------------------------------|------------------------------|--------------------------------------------|-----------------------------|
| <b>Activity</b>                                       | <b>No of volunteers<br/>needed to run<br/>this activity</b> | <b>Hours per<br/>session</b> | <b>Hours per<br/>month of<br/>activity</b> | <b>Average per<br/>week</b> |
| Info café                                             | 6                                                           | 2                            | 24                                         | 6                           |
| Info café prep and<br>clear down and<br>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         |
| <b>Total</b>       |    |    | <b>364.5</b> | <b>106</b> |
|                    |    |    |              |            |

## 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

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<br>Never<br>tried | 2. Tried<br>but was<br>difficult | 3<br>Problematic | 4<br>Fairly<br>easy | 5<br>No<br>Problem |
| Further comments    |                                  |                  |                     |                    |

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

|                  |                                    |             |                  |                    |
|------------------|------------------------------------|-------------|------------------|--------------------|
| 1<br>Never tried | 2<br>Tried but<br>was<br>difficult | 3<br>Unsure | 4<br>Fairly easy | 5<br>No<br>Problem |
| Further comments |                                    |             |                  |                    |

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

|                  |             |                |                        |             |
|------------------|-------------|----------------|------------------------|-------------|
| 1<br>Never       | 2<br>Rarely | 3<br>Sometimes | 4<br>If I have<br>time | 5<br>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



# 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 improved. 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 trial, 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



### 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's 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 <u>past 4 weeks</u> , <b>how concerned</b> were you about...                                                                  | A lot                    | Quite a bit              | A little                 | Not at all               |
|------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. not having enough time to yourself?                                                                                                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. having to put the needs of the person you care for ahead of your own needs?                                                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. not being able to take a break from caring?                                                                                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. not being able to plan for the future?                                                                                                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. not being able to continue caring due to reasons beyond your control (e.g. becoming ill yourself, looking after very young children)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

### 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 <u>past 4 weeks</u> , <b>how concerned</b> were you about...         | A lot                    | Quite a bit              | A little                 | Not at all               |
|---------------------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 6. strains in your relationship with the person you care for?                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. the person you care for being too dependent on you <u>at the moment</u> ?    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. the person you care for becoming too dependent on you <u>in the future</u> ? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. the person you care for saying things that upset you?                        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. feeling irritable with the person you care for?                             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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 <u>past 4 weeks</u> , <b>how concerned</b> 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?                                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. "drifting apart" from family and friends, because your caring responsibilities limit the time available to keep in contact with them? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. feeling isolated and lonely because of the situation you are in?                                                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. not getting the support you need from family and friends?                                                                             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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

| During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...                     | A lot                    | Quite a bit              | A little                 | Not at all               |
|---------------------------------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 16. your own financial situation?                                                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. the financial situation of the person you care for?                                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 18. having to cover extra costs of caring (e.g. extra help in the home, trips to hospital)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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

| During the <u>past 4 weeks</u> , <b>how concerned</b> were you about... | A lot                    | Quite a bit              | A little                 | Not at all               |
|-------------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 19. your own physical health?                                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 20. your caring role making your physical health worse?                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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

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

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

☐☐☐☐

## Stigma and discrimination

(Please tick one box on each line.)

| During the <u>past 4 weeks</u> , <b>how concerned</b> 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? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

## Your own safety

(Please tick one box on each line.)

| During the <u>past 4 weeks</u> , <b>how concerned</b> 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)?                                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 29. being aggressive or threatening towards you (e.g. verbal threats, sexual aggression, physical intimidation)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

## The safety of the person you care for

(Please tick one box on each line.)

| During the <u>past 4 weeks</u> , <b>how concerned</b> were you about the person you care for... | A lot                    | Quite a bit              | A little                 | Not at all               |
|-------------------------------------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 30. harming themselves?                                                                         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 31. getting themselves into dangerous situations?                                               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 32. relapsing or deteriorating, such that it puts their safety at risk?                         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

## 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.)

| <u>In general</u> , <b>how satisfied</b> 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? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. that you have enough information about how their condition/illness is likely to develop in the longer-term?                                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. that you can get whatever information you need when you need it (e.g. through your doctor or on your own)                                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. with how easy it is to understand the information you have?                                                                                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. with the amount of advice available to you (e.g. from healthcare workers or other carers)?                                                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. that you are clear about who to go to for the information and advice you need?                                                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. that you are clear about who to contact if there is an emergency and you need help right away?                                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. that you are clear about who to call if you have a routine inquiry?                                                                         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

### Your involvement in treatment and care planning

(Please tick one box on each line.)

| <u>In general</u> , <b>how satisfied</b> are you with...                       | Very dissatisfied        | Somewhat dissatisfied    | Somewhat satisfied       | Very satisfied           |
|--------------------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 9. your involvement in important decisions (e.g. medication, hospitalisation)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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.)

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

## 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                                                             |                                                     |                                                                              |                            |                                 |
|                                                                                |                                                     |                                                                              |                            |                                 |
| <b>2. If you do not have any types of support, why might this be the case?</b> |                                                     |                                                                              |                            |                                 |
|                                                                                | 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.

## Appendix 7a: 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                | <u>ACTUAL</u><br><u>31 March</u><br><u>2025/26</u><br>£ | <u>Forecast</u><br><u>2025/26</u><br>£ |
|-----------------------------------------------|---------------------------------------------------------|----------------------------------------|
| <b>INCOME</b>                                 |                                                         |                                        |
| 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            |                                                         |                                        |
| <b>Total income</b>                           | <b>8,663</b>                                            | <b>13,250</b>                          |
| <b>EXPENDITURE</b>                            | £                                                       | £                                      |
| 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                                  |
| <b>Total expenditure</b>                      | <b>8,167</b>                                            | <b>14,760</b>                          |
| <b>Excess of Income over expenditure</b>      | <b>496</b>                                              |                                        |

**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 &amp; 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<br>Outturn<br>25/26 | Quarter 1<br>26/27 | Quarter 2<br>26/27 | Quarter 3<br>26/27 | Quarter 4<br>26/27 | Total 26/27 | Quarter 1<br>27/28 | Quarter 2<br>27/28 | Quarter 3<br>27/28 | Quarter 4<br>27/28 | Total 27/28 | Q<br>28/29 |
|-----------------------------------------|------------------------------|--------------------|--------------------|--------------------|--------------------|-------------|--------------------|--------------------|--------------------|--------------------|-------------|------------|
| Donations                               | 7,100                        | 1,800              | 1,800              | 1,800              | 1,800              | 7,200       | 1,500              | 1,800              | 1,800              | 1,800              | 7,200       |            |
| Legacy/in memoriam gifts                | 2,100                        | 400                | 400                | 400                | 400                | 1,600       | 400                | 400                | 400                | 400                | 1,600       |            |
| Travel scheme                           | 1,600                        | 400                | 400                | 500                | 500                | 1,500       | 550                | 550                | 550                | 550                | 2,200       |            |
| Fundraising                             | 879                          |                    |                    | 800                |                    | 800         |                    |                    |                    | 800                | 800         |            |
| Interest                                | 180                          | 45                 | 45                 | 40                 | 40                 | 170         | 40                 | 40                 | 35                 | 35                 | 150         |            |
| Carer respite contributions             | 1,320                        | 720                | 960                | 960                | 960                | 3,600       | 1,260              | 1,260              | 1,260              | 1,260              | 5,040       |            |
| Other                                   | 420                          |                    | 420                |                    |                    | 420         |                    | 480                |                    |                    | 480         |            |
|                                         | 13,599                       | 3,365              | 4,025              | 4,500              | 3,700              | 15,590      | 4,050              | 4,530              | 4,845              | 4,045              | 17,470      |            |
| <b>Charitable activities</b>            | 5,100                        | 1,350              | 1,350              | 1,350              | 1,350              | 5,400       | 1,400              | 1,400              | 1,400              | 1,400              | 5,600       |            |
| Volunteer drivers costs                 | 2,000                        | 550                | 550                | 550                | 550                | 2,200       | 600                | 600                | 600                | 600                | 2,400       |            |
| Insurances                              | 400                          | 100                | 100                | 100                | 100                | 400         | 100                | 100                | 100                | 100                | 400         |            |
| Fundraising                             |                              |                    |                    | 200                |                    | 200         |                    |                    |                    | 200                | 200         |            |
| Rent                                    | 1,600                        | 400                | 400                | 400                | 400                | 1,600       | 425                | 425                | 425                | 425                | 1,700       |            |
| Admin expenses                          | 3,300                        | 900                | 900                | 900                | 900                | 3,600       | 950                | 950                | 950                | 950                | 3,800       |            |
| Other                                   | 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      |            |
|                                         | 16,453                       | 5,482              | 6,360              | 6,410              | 6,210              | 24,462      | 7,239              | 7,239              | 7,589              | 7,239              | 29,306      |            |
| <b>Deficit</b>                          | (2,854)                      | (2,117)            | (2,335)            | (1,910)            | (2,510)            | (6,872)     | (3,189)            | (2,709)            | (2,744)            | (3,194)            | (11,835)    |            |
| <b>Deficit without respite</b>          | (271)                        | (655)              | (385)              | 40                 | (560)              | (1,560)     | (685)              | (205)              | (240)              | (690)              | (1,820)     |            |
| <b>Net cost of respite</b>              | 2,583                        | 1,462              | 1,950              | 1,950              | 1,950              | 7,312       | 2,504              | 2,504              | 2,504              | 2,504              | 10,016      |            |
| <b>No respite in subsequent periods</b> |                              |                    |                    |                    |                    |             |                    |                    |                    |                    |             |            |
| Opening reserve position                | 16,272                       | 16,272             | 15,617             | 15,232             | 15,272             | 16,272      | 14,712             | 14,027             | 13,822             | 13,562             | 14,712      |            |
| Closing reserve position                |                              | 15,617             | 15,232             | 15,272             | 14,712             | 14,712      | 14,027             | 13,822             | 13,562             | 12,692             | 12,892      |            |
| <b>With respite</b>                     |                              |                    |                    |                    |                    |             |                    |                    |                    |                    |             |            |
| 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      |
| Closing reserve position                |                              | 14,155             | 11,820             | 9,910              | 7,400              | 7,400       | 4,211              | 1,502              | (1,242)            | (4,436)            | (4,436)     |            |

## Cashflow Forecast

|                                               | Forecast Outturn |         |         |         | Forecast |         |         |         | Forecast |          |         |         | Forecast |         |         |         | Forecast |         |         |          |
|-----------------------------------------------|------------------|---------|---------|---------|----------|---------|---------|---------|----------|----------|---------|---------|----------|---------|---------|---------|----------|---------|---------|----------|
|                                               | 25/26            | 26/27   | 26/27   | 26/27   | 26/27    | 26/27   | 26/27   | 26/27   | 26/27    | 26/27    | 26/27   | 26/27   | 26/27    | 26/27   | 26/27   | 26/27   | 26/27    | 26/27   | 26/27   | 26/27    |
| <b>Existing charitable activities inflows</b> |                  |         |         |         |          |         |         |         |          |          |         |         |          |         |         |         |          |         |         |          |
| Donations                                     | 3,000            | 1,800   | 1,800   | 1,300   | 7,900    | 1,800   | 1,800   | 1,800   | 1,300    | 8,700    | 1,850   | 1,850   | 1,350    | 1,850   | 1,850   | 1,350   | 1,850    | 1,850   | 1,350   | 6,900    |
| Legacy/memorial gifts                         | 400              | 400     | 400     | 400     | 1,600    | 400     | 400     | 400     | 400      | 1,600    | 400     | 400     | 400      | 400     | 400     | 400     | 400      | 400     | 400     | 1,600    |
| Travel scheme                                 | 400              | 400     | 400     | 500     | 1,800    | 500     | 500     | 500     | 500      | 2,200    | 575     | 575     | 575      | 575     | 575     | 575     | 575      | 575     | 575     | 2,300    |
| Fundraising                                   | 45               | 45      | 40      | 40      | 170      | 40      | 40      | 40      | 40       | 150      | 30      | 30      | 25       | 25      | 25      | 25      | 25       | 25      | 25      | 110      |
| Interest                                      | 150              | 150     | 150     | 150     | 600      | 150     | 150     | 150     | 150      | 2,400    | 150     | 150     | 150      | 150     | 150     | 150     | 150      | 150     | 150     | 600      |
| Other                                         | 3,845            | 2,755   | 3,540   | 2,240   | 12,420   | 2,790   | 2,790   | 3,735   | 2,285    | 11,600   | 2,855   | 2,855   | 3,300    | 2,850   | 2,850   | 3,300   | 2,850    | 2,850   | 3,300   | 11,860   |
| <b>Charitable activity inflows</b>            |                  |         |         |         |          |         |         |         |          |          |         |         |          |         |         |         |          |         |         |          |
| <b>Existing charitable activities</b>         |                  |         |         |         |          |         |         |         |          |          |         |         |          |         |         |         |          |         |         |          |
| 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   | 1,450   | 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     | 650     | 650     | 650      | 650     | 650     | 2,600    |
| Insurance                                     | 100              | 100     | 100     | 100     | 400      | 100     | 100     | 100     | 100      | 400      | 110     | 110     | 110      | 110     | 110     | 110     | 110      | 110     | 110     | 440      |
| Fundraising                                   | 200              | 200     | 200     | 200     | 800      | 200     | 200     | 200     | 200      | 800      | 200     | 200     | 200      | 200     | 200     | 200     | 200      | 200     | 200     | 800      |
| Rent                                          | 400              | 400     | 400     | 400     | 1,600    | 425     | 425     | 425     | 425      | 1,700    | 425     | 425     | 425      | 425     | 425     | 425     | 425      | 425     | 425     | 1,700    |
| Admin expenses                                | -                | 1,800   | -       | -       | 1,800    | 1,800   | -       | -       | 1,800    | 3,700    | 1,900   | -       | -        | 1,900   | -       | -       | 1,900    | -       | -       | 3,900    |
| Other                                         | 150              | 150     | 150     | 150     | 600      | 150     | 150     | 150     | 150      | 600      | 150     | 150     | 150      | 150     | 150     | 150     | 150      | 150     | 150     | 600      |
| <b>Charitable activity outflows</b>           |                  |         |         |         |          |         |         |         |          |          |         |         |          |         |         |         |          |         |         |          |
|                                               | 2,400            | 4,350   | 2,600   | 2,400   | 11,750   | 4,325   | 2,525   | 2,875   | 4,425    | 14,150   | 4,535   | 2,835   | 2,935    | 4,635   | 2,935   | 4,635   | 2,935    | 4,635   | 2,935   | 14,790   |
| <b>Net charitable activity cashflows</b>      |                  |         |         |         |          |         |         |         |          |          |         |         |          |         |         |         |          |         |         |          |
|                                               | 1,445            | (1,555) | 940     | (760)   | 670      | (1,535) | 255     | 860     | (2,140)  | (2,560)  | (1,860) | 220     | 345      | (1,785) | 220     | 345     | (1,785)  | 220     | 345     | (2,930)  |
| <b>Cash balance b/d</b>                       |                  |         |         |         |          |         |         |         |          |          |         |         |          |         |         |         |          |         |         |          |
|                                               | 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  | 11,975  | 11,975  | 11,975   | 11,975  | 11,975  | 13,120   |
| <b>Cash balance c/d</b>                       |                  |         |         |         |          |         |         |         |          |          |         |         |          |         |         |         |          |         |         |          |
|                                               | 16,445           | 14,890  | 15,830  | 15,670  | 16,670   | 14,135  | 14,400  | 15,260  | 13,120   | 13,120   | 11,440  | 11,660  | 11,975   | 10,190  | 10,190  | 10,190  | 10,190   | 10,190  | 10,190  | 10,190   |
| <b>Career respite contributions inflow</b>    |                  |         |         |         |          |         |         |         |          |          |         |         |          |         |         |         |          |         |         |          |
|                                               | 720              | 960     | 960     | 960     | 3,600    | 1,260   | 1,260   | 1,260   | 1,260    | 5,040    | 1,290   | 1,290   | 1,290    | 1,290   | 1,290   | 1,290   | 1,290    | 1,290   | 1,290   | 5,160    |
| <b>Christie respite scheme outflow</b>        |                  |         |         |         |          |         |         |         |          |          |         |         |          |         |         |         |          |         |         |          |
|                                               | (2,182)          | (2,910) | (2,910) | (2,910) | (10,912) | (3,764) | (3,764) | (3,764) | (3,764)  | (15,066) | (3,896) | (3,896) | (3,896)  | (3,896) | (3,896) | (3,896) | (3,896)  | (3,896) | (3,896) | (15,584) |
| <b>Net outflow</b>                            |                  |         |         |         |          |         |         |         |          |          |         |         |          |         |         |         |          |         |         |          |
|                                               | (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) | (2,606) | (2,606) | (2,606)  | (2,606) | (2,606) | (10,424) |
| <b>Combined net cash position</b>             |                  |         |         |         |          |         |         |         |          |          |         |         |          |         |         |         |          |         |         |          |
|                                               | 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   | 7,584   | 7,584   | 7,584    | 7,584   | 7,584   | (234)    |

## Respite workings

|                      | <u>25/26</u>  | <u>26/27</u>  | <u>27/28</u>  | <u>28/29</u>  |
|----------------------|---------------|---------------|---------------|---------------|
| inflation factor     | 1             | 1.025         | 1.035         | 1.035         |
|                      | <u>Per hr</u> | <u>Per hr</u> | <u>Per hr</u> | <u>Per hr</u> |
| 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 | <u>26/27</u> | <u>27/28</u> |
|--------------|-----|-----|-----|--------|--------------|--------------|
| nos per week |     |     |     |        |              |              |
| 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.