A Review

Regarding maintaining financial security for the Project's Core Activities and securing the funding and long-term survival of the support offered by the Respite Care Initiative.

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Executive Summary

This review considers how The Debenham Project can maintain the financial security of its established core activities while addressing the more challenging question of whether the Flexible Carer Respite Initiative can be funded and sustained in the longer term.

The Project's existing core activities, groups and services appear broadly financially secure. They have been sustained over many years by local goodwill, community fundraising, donations, careful financial management and the strong place the Project holds in Debenham and surrounding villages. However, the wider economic climate is likely to place increasing pressure on individual giving, local business support, charitable funds and public sector grants. It would therefore be prudent to strengthen and diversify income for core activities without allowing fundraising to displace the Project's central purpose of practical community-based dementia support.

The Flexible Carer Respite Initiative is different in scale and complexity. Its aim — to prevent or delay carer breakdown among families living with dementia — is strongly aligned with the Project's ethos and has the potential to deliver substantial benefits for carers, those they care for, and health and social care services. In the short to medium term, the priority should be to secure sufficient funding to complete the current two- to three-year development phase, drawing particularly on Suffolk Community Foundation opportunities, possible local sponsorship, Parish Council support and other Suffolk-linked charitable funding.

The review concludes that there is currently no realistic or reliable independent funding route that would allow The Debenham Project to operate the Respite Initiative as a permanent long-term service in its own right. The likely annual cost, potentially beginning at around £15,000 and increasing over time, would be beyond the Project's normal fundraising capacity. Options such as a long-term benefactor, individual sponsorship, direct debit giving, repeat charitable grants or statutory commissioning are all uncertain and insufficient as dependable standalone solutions.

There are also important ethical and operational issues that must be addressed before the Initiative could be treated as an ongoing service. These include whether support should be offered universally or targeted at families in greatest need, how eligibility should be assessed fairly, what authority the Project has to make allocation decisions, and whether professional social care and clinical expertise is required to support those judgements.

The recommended strategic direction is therefore not for The Debenham Project to attempt to fund the Respite Initiative indefinitely by itself. Instead, the Project should use its strong reputation, experience, community relationships and evidence from the current Initiative to influence the revised Suffolk Carers Strategy and make the case that flexible respite care should be recognised as an essential element of dementia support.

The strongest way forward is to work with statutory authorities, county dementia support organisations, academic partners and other community groups to develop Suffolk-wide pilot projects. These pilots should test the social, practical and financial benefits of integrated community-based dementia support, including flexible carer respite, in both rural and urban settings. This would allow The Debenham Project to contribute its experience and local model while avoiding the unsustainable burden of becoming the sole long-term funder and manager of the service.

Key recommendations:

- Protect and continue the Project's established core activities while developing a more regular local fundraising programme.
- Prioritise short- to medium-term funding for the current Respite Initiative phase, especially through Suffolk Community Foundation and potential local sponsorship.
- Prepare stronger future funding applications supported by clear evidence, realistic cost projections, independent assessment and a compelling prevention-based case.
- Recognise that The Debenham Project is unlikely to be able to finance flexible respite care as a permanent independent service.
- Use the Project's evidence and reputation to influence the revised Suffolk Carers Strategy and advocate for flexible respite care as part of statutory and community-based dementia support.
- Explore county-wide pilot projects with Adult Social Care, health partners, dementia support agencies, academic institutions and other community groups.

Introduction

This review has been prepared to consider how The Debenham Project can maintain the financial security of its established core activities whilst also addressing the more complex question of how the Flexible Carer Respite Initiative might be funded, sustained and developed in the longer term.

The Project has, over many years, built a strong reputation for community-based dementia support rooted in local goodwill, voluntary commitment and close relationships with families affected by dementia. This has enabled its core activities, groups and services to continue without major financial instability, despite relying largely on donations, fundraising and community support rather than guaranteed long-term revenue funding.

The Flexible Carer Respite Initiative presents a different and more demanding challenge. While its purpose is strongly aligned with the Project's ethos — helping families to cope with the impact of dementia and seeking to prevent or delay carer breakdown — its continuation

requires a level of predictable funding, assessment, partnership working and strategic support that may be beyond the Project's independent fundraising capacity.

This review therefore examines the current position, the funding options available in the short, medium and long term, the ethical and operational issues involved, and the possible strategic role The Debenham Project could play in influencing wider dementia and carers support across Suffolk. Its aim is to provide a realistic basis for discussion and decision-making about the future direction of both the Project's core work and the Respite Initiative.

Our Current Existing Core Activities, Groups, and Services

Our core activities are characterised as items of expenditure which must be paid for from the Project's annual income i.e. revenue. Initially, the Project was funded to the point of launch by a gift and a loan provided by two of our trustees. Subsequently we were generously supported by Mid Suffolk DC over the following 3 years. Since then, we have been able to maintain and grow the Project without any significant financial concerns – the annual balance sometimes positive, sometimes negative but overall, always covering our costs. Achieving this has been entirely due to the unasked for goodwill of those we support and the community at large – for example, "Would it be OK to hold a garden party in aid of your project" : " We want to put on an event in support of your Project" : Ruth's second-hand bookstall : Donations in memoriam : Individuals doing a challenge on our behalf : Out of the blue donations : £50 added to payment for transport : Contents of collection boxes in local shops and businesses : Odd occasions at village fetes : Open Gardens: The Coopersfield bottle bank: But also Project organised events such as The Sixties Tea Dance and The Jukebox Party : Individual (occasional and regular) gifts : And, most precious of all, being asked to, "Just put that in your back pocket for the Project".

Provided we remain enjoying that special place in the heart our community, I see no reason why this informal giving should not continue. Nevertheless, we must recognise that over the next few years the economic climate will prove difficult for all charities to balance their expenditure against their revenue funding. Individual's real incomes, local business profits, and charitable funds will all be squeezed, and money available from central and local government will be even more limited.

So, in our minds, there is a need to be more proactive in raising funds to ensure that those activities, groups and services that we believe have been, and continue to be, central to the ethos of The Debenham Project are, not only protected, but also enabled to evolve and prosper. This is not a call to prioritise funding above delivery, it is only that we could and should do more.

The 1 year £6,000 MSDC revenue grant, provided explicitly to support our Core Activities, is more than welcome for two reasons:

1. It reflects the goodwill and importance that the District Council places upon The Debenham Project. It may be that they will be willing to consider further similar (probably smaller) grant(s) in the future. However, we suspect that achieving this will very much depend on delivering benefit in the wider geographical area currently served by the council. Perhaps, in terms of stimulating/working with/supporting other communities such as Stowmarket, Eye, Needham Market, Mendlesham, etc. in creating a "Collaborative Hub". Unfortunately, the Local Government Reorganisation might well lead to an impenetrable "hiatus of uncertainty".

2. It relieves our reserves to provide additional funding towards the Respite Initiative.

Summing up: We should not be overly concerned about financing the current Core Activities and overheads of the Project. But it would be prudent to think about how we might supplement our income, without depending upon our reserves, in order to safeguard against the expected downturn in individual giving and the increasing competition for grant funding. That said, sources of ongoing revenue funding are generally scarce, limited, and particularly difficult to obtain.

Ongoing Financing of the current Flexible Carer Respite Initiative

The nature of The Respite Initiative is complex. Currently, it is that of a partially funded Project of limited duration, but if it is to continue beyond the coming year or so, it must concurrently seek to; firstly, secure further reliable medium-term funding (2 to 3 years); and secondly, establish a long-term revenue funding stream.

Funding the former has had some success in enabling the initiative to continue for the time being, but it is by no means clear that The Debenham Project will be able to fully support it within our current financial resources, nor clear that any future funding application(s) will be successful.

Achieving the latter is a "whole new ballpark" – not just a matter of putting in applications and hoping, but by developing and maintaining ongoing relationships with one or more agencies/funders/sponsors/social and health care authorities/charitable funds, etc. to persuade them that respite care of the form we propose must be accepted as an essential element in the support of all families struggling to live with impact of dementia on their lives.

That said:

1. The first task is to secure such funding as may be available for the remainder of the 2 to 3-year timescale as described in a) the full Respite Initiative Project Proposal, b) the unsuccessful MSDC application, and c) the subsequently successful DPC application.

   Each has been reviewed in the light of the comments and feedback gleaned from both applications. It is clear that both councils were very keen to support The Debenham Project in its work, but MSDC felt that the application did not sufficiently meet their criteria for funding, whilst on the other hand DPC, despite some debate about the details, unanimously agreed to support The Debenham Project in our application. So, "Bad News" and "Good News". The net result is that any future applications, whilst demonstrating how important we feel about what we are seeking support for, must:

   Present the vision of the Flexible Care Respite Initiative as prevention and/or delay of family carers becoming physically and mentally unable to continue to care. The impact of Carer Breakdown – "I can't cope anymore" – is central to the increasing demand for Health and Social Care crisis intervention and subsequent long term rapid escalation of professional care involvement.

   Focus on the wider benefit and impact it will have in the eyes of the funding agencies. No source of sponsorship or charitable agency is likely to fund the

Initiative unless it not only satisfies their application criteria, but also, and more importantly, coincides with and supports their overlying vision, aims, and strategy.

Engage our very positive county and national reputation and cement our community roots. We are a small community project with a big name which has been achieved primarily by developing personal relationships with key organisations and individuals. Success depends much more on sharing and talking, than with a polished application.

Fully address how candidate families are assessed for eligibility for support by the Initiative. This is a critical issue that has significant ethical, and professional concerns for the Project that cannot be avoided or minimised.

Provide a realistic projection of the potential numbers, levels of support, and costs anticipated for the period of the requested funding (and beyond). Hitherto, the projections of the anticipated demand, and subsequent Project's financial commitment to the Initiative, beyond the short term have been well beyond our potential fundraising capability.

Provide credible statistical and anecdotal evidence of benefits already achieved. This requires the Final Report of the Trial to include access to all the evidence – statistical, anecdotal, and questionnaire responses. It will be a critical document in justifying further investment.

Involve collaboration with academic institutions, county dementia support agencies and other community-based groups. We must highlight our many years of experience and deep understanding in delivering community-based dementia support, and our close relationships with families struggling to cope with the impact of dementia on their lives, in order to assist other local communities in developing their own dementia support projects, and to work with Health, Social Services, and Academia in advancing their aims and strategy for improving dementia support.

Include independent assessment of appropriate Key Progress Indicators. We must show an openness to external critical analysis of our achievements, progress and data by an agency respected by the potential source of funding.

Provide a vision for the long-term continuation of the Respite Care Initiative and a viable strategy for its future funding. If the Respite Initiative is to continue beyond a year or 2 it will require a guaranteed source of funding on at least a further 3, 5, 10-year timescale. Whatever the source, it is very unlikely that any application will succeed unless there is confidence that it can be developed and financed as a long-term service.

We have explored the options for achieving sufficient medium-term (2 -3 years) funding for the completion of the current Respite Initiative objectives and believe these are limited to:

- A local sponsor e.g. Aspal Cyder (Coors)

- An application to Suffolk Community Foundation (SCF) Carers Fund
- Depleting our reserves
- A charitable fund with a Suffolk (preferably Mid-Suffolk) connection

As we will be looking for something, at least, in the region of £10K to £30K it suggests focusing on SCF and trying for help from Aspal Cyder. Both will likely be limited in terms of ongoing support for the Initiative beyond a couple of years. That said, SFC, by reason of its county-wide role and funding base, offers by far the best prospect and should be our priority. In practical terms this means:

- Consulting with Suffolk Community Foundation fund managers
- Being in a position to immediately submit a completed application whenever the Suffolk Community Foundation's "Carers Fund" opens again (hopefully at the beginning of July)
- Contacting Aspal Cyder to explore any possible sponsorship.
- Exploring the potential for a grant/sponsorship by a suitable Care Provider

It is critical to recognise that achieving funding requires identifying the opportunities that offer the best match to our aspirations and **acting now.** The general view is that funding for community and charitable organisations is going to continue becoming more difficult over the next few years e.g. The maximum Suffolk Carers Fund grant in January this year was £50K. It has now been reduced to £30K, and under the current Suffolk County Council leadership's plans to cut non-essential expenditure it is likely that the budget for the fund will be further reduced in the future. We cannot predict what funding for the Respite Initiative will be available in the future, but we can say that competition will be serious and it must be considered as an urgent priority.

Summing up: Achieving sufficient funding sufficient to complete, at least, the current 3 year timescale of the Respite Initiative Project is essential to its continuation in the longer term. To secure, even the medium-term, funds for the Respite Initiative will be a challenge.

Long-term Funding of the Flexible Carer Respite initiative.

So far, and for the next year or so, the Initiative has been / will be funded as a development project. However, if it is to become more than an experiment, and to be able to offer a measure of preventative respite carer support to all of our families in the long term, the Initiative will have to be considered as a "service" within the overall catalogue of the "core" activities, groups, and services provided by the Project, and financed as such i.e. by a reliable revenue stream. Broadly speaking, we must find additional annual income of, potentially in the region of £15,000[1] pa and significantly increasing over the 3 to 5 year+ timescale. This will far exceed our current fundraising capability.

- It is very unlikely that we will find a benefactor/sponsor to commit to an open-ended underwriting of the costs
- Direct commissioning by NHS and/or Social Services is unlikely unless it is as a core element of their current review of the Suffolk Carers Strategy for 2027

[1] Roughly estimated on the basis of averages of 10 families, 6 hrs pmth, and £20/hr

- A further request for support following a successful application for funding from Suffolk Community Foundation might be considered but only if the initial project successfully demonstrates the potential well-being and cost-benefits benefits to both families (carer and cared-for) and also the wider need e.g. Health and Social Care and other communities, and only following a year's break.
- Individual sponsorship of circa £150 p mth to cover the cost of supporting an individual family[2] possibly has some potential but requires finding a matching number[3] of well-off donors in an increasingly difficult economic climate. There are also the issues of anonymity, fairness, and long-term commitment to be addressed.
- A campaign to enlist regular direct debit donors committing, say, £25 p mth[4] may also have some potential.
- National charitable funds and business organisations generally either support charities with a potential national presence or donate relatively small sums to local community-based organisations. We would fall into the latter category. Matching funding is a common requirement.

Summing up: Unfortunately, we cannot see any of the above options leading to a sufficient and reliable long-term revenue stream. Reluctantly, we have concluded that the Flexible Carer Respite Initiative, as an independent service offering of The Debenham Project, cannot continue beyond the completion of its current phase as a project funded by the Parish Council grant and (possibly) a grant from the Suffolk Carers Fund (managed by Suffolk Community Foundation)[5]. This sets a realistic margin of between a minimum of 18 months and maximum of 3 years.

Difficult Issues

We also have serious concerns relating to the:

- Is the Initiative to be offered to:
    - all families as well-being support as in the Halesworth model
    - all families as a "taster" / "encouragement" leading towards their earlier investment in professional respite and/or other domiciliary support
    - only those families "close to the edge"
    - families for only a limited period
- Credibility and authority of the Project to make decisions over who gets support and who does not if probable demand exceeds availability
- Fact that, within the Project, we do not have the training and professional experience to interpret and assess the circumstances, needs, relationships, etc. of our families that would normally involve a senior social worker and a clinical psychologist
- Dependence on advice, collaboration, and commitment to a single professional service provider

Nevertheless, we believe that the fundamental concept of the Initiative to help prevent (or at least delay) "Carer Breakdown" - and with it, the importance of offering our families its

[2] As used by a number of overseas aid charities
[3] Ideally the number of sponsors should match the number of supported families
[4] This would roughly equate to 60 donors
[5] A maximum of £30,000 but can be spread over up to 3 years

continuing support and strength to cope with the impact of dementia on the lives of carers and those they care for, is without doubt. The question is - "How can this be achieved?" – on a long-term basis

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A Funding Strategy for The Debenham Project for the next Decade and Beyond

This is a matter of two concerns.

Firstly, that of ensuring that the core support that we have historically (and currently), provided to those families in our catchment who are living with the impact of dementia on their lives, continues and evolves.

We do not foresee any real risks if we continue to follow the current philosophy of maintaining the Project as belonging to, and supported by, the Debenham (and surrounding village) communities. We have been extraordinarily blessed in their donations and also fundraising events over the years (especial thanks to Joy and her team). Broadly, we have always managed to "balance the books". Nonetheless, due to the potentially increasing difficult economic situation, it would be wise to organise/encourage a programme of more regular local social occasions to supplement the income. It will be critical not to lose sight of the fact that Debenham (as the primary centre of local population) is the primary focus of the Project and the dominant source of its support.

And secondly, that those families we support should continue to be offered/receive the flexible respite care that we believe leads to the prevention and/or delay of "carer breakdown".

This is a much more serious worry. Without an ongoing independent injection of cash we cannot realistically see a way forward beyond a 3-year timescale. Therefore, we must seek a strategy which seeks to meet the needs of our families but, not necessarily, within the compass of the Project, i.e. we must try to persuade Adult Care Social Services that it is in their interests that they consider "Flexible Respite Care" as an essential element of their support service.

A Possible way Forward

It is our considered judgement that it is not financially practical for The Debenham Project to emulate the Halesworth model – we do not have, or are likely to have, such a generous benefactor. Nor do we believe it is possible to scale back on that model by limiting accessibility to a relatively few families i.e. those who are, in our judgement, "on the edge". Or by limiting our support for individual families to a limited period e.g. 12 months[6].

Therefore, if the Debenham Project, as currently envisaged, will not be able to continue to finance the Respite Initiative, beyond the next 2 or 3 years, an alternative approach must be considered. If we are unable to offer Flexible Carer Respite in the long term ourselves, can we persuade Social Services that it should become an essential element of the support they provide? There is every chance!

[6] This would create an impossibly difficult situation if the family actually was "on the edge" when our support was due to end.

- The existing Suffolk Carers Strategy is currently being revised and there is an opportunity to influence the future of social care for several years ahead.
- As a recognised exemplar of good community-based involvement we would be a preferred candidate for any future pilot projects to explore the benefits of "Flexible Carer Respite".
- We are/will be able to provide the initial evidence that early intervention can substantially reduce the risks of carer breakdown and, with it, the costs to Social Services (Adult Care) and individual families.
- Based upon our experience, we can readily advise/mentor other communities Iin developing their own community-based dementia support.
- There is the potential for influencing the future Carers Strategy to include, long-term investment in collaboration between voluntary community-based support and the professional services and agencies.

Whether we are listened to depends totally on having a practical, cost beneficial, social, and politically attractive proposal coupled with being involved in the debate about the future of dementia care throughout the County

Fundamentally, this means arguing for the Statutory Authorities (Health and Social Services) to seriously buy into community-based support as the key to substantial reductions in the demand for crisis intervention and the potential benefits of savings in domiciliary and residential social care costs, reduced hospitalisations and subsequent delayed discharges, and overall improvements in the well-being and quality of life of both carers and those they care for.

By working with other community groups and agencies, it should be possible to develop a proposal for a number of 3-year pilot projects across Suffolk[7] to demonstrate the benefits and cost-effectiveness of integrated community-based support, and particularly Flexible Carer Respite in both rural and urban settings. This would provide the opportunity to explore (and quantify) them in terms of improved physical and mental well-being, crisis avoidance, reduced hospitalisations, quicker discharge, delayed need for residential/nursing care, etc.

It is imagined that the pilots would be overall managed, preferably, by Shaftesbury Suffolk Memory and Dementia Support but alternatively Suffolk Family Carers. Our role would be to work with their advisors and Christies to offer families a fully integrated team approach. It would overcome most, if not all, the concerns that have been identified as well as freeing us from the need for fundraising and financial management.

However, we are aware that, STILL!!, in terms of "The Care Act", the dominant emphasis on providing dementia support lies in funding personal care for the cared-for and largely ignores the needs of the family carer[8]

Conclusion

[7] We would initially suggest Ipswich collaborating with Bury, Woodbridge with Felixstowe, Hadleigh with Stowmarket, and Debenham with Eye.

[8] Financial support is only based upon an assessment of the needs of the person with dementia.

The review concludes that The Debenham Project's existing core activities remain broadly financially secure, largely because of strong local goodwill, community fundraising, donations and careful management. However, the expected pressure on household incomes, local businesses, charitable giving and public funding means the Project should become more proactive in developing supplementary income streams, while continuing to preserve its community-led ethos.

The Flexible Carer Respite Initiative is recognised as highly valuable because it aims to prevent or delay carer breakdown among families affected by dementia. Short- to medium-term continuation may be possible through existing Parish Council support, a potential Suffolk Community Foundation Carers Fund application, sponsorship, or other Suffolk-linked charitable funding. The immediate priority is therefore to secure enough funding to complete the current two- to three-year development phase.

For the long term, the review finds no realistic or reliable independent funding route that would allow The Debenham Project to operate the Respite Initiative as a permanent service on its own. The likely annual cost, potentially starting at around £15,000 and increasing over time, would exceed the Project's normal fundraising capacity. Options such as ongoing benefactors, direct debit campaigns, individual sponsorship, national charitable funds, or statutory commissioning are all considered uncertain or insufficient.

The review also identifies significant ethical and operational issues, including how families should be selected for support, whether the service should be universal or targeted, how eligibility decisions can be made fairly, and whether the Project has the professional expertise required to assess complex family circumstances without external clinical and social care input.

The proposed way forward is to use the Project's reputation, experience and evidence from the current Initiative to influence the revised Suffolk Carers Strategy and encourage Adult Social Care and health partners to recognise flexible respite care as an essential part of dementia support. Rather than trying to fund the service indefinitely itself, The Debenham Project should seek to help shape county-wide pilot projects that test the benefits and cost-effectiveness of integrated community-based dementia support, including flexible respite care.