



# The Carers Social Action Support Fund

Final evaluation report

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**TSIP**

The Social Innovation Partnership



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# CONTENTS

<b>Executive summary</b>	<b>2</b>
<b>Introduction</b>	<b>7</b>
This report	7
The Carers Social Action Support Fund	7
Grantee interventions	8
Literature review	9
<b>Methodology</b>	<b>11</b>
CSASF Theory of Change	11
Research questions	12
Guiding principles	12
Evaluation design	13
Outcomes and tools	14
Data collection	15
Data analysis	15
Participants	16
Ethics	17
Limitations of the methodology	17
<b>Results</b>	<b>19</b>
Results across all grantees	19
Results of individual grantees	21
<b>Discussion</b>	<b>27</b>
Interpreting the results	27
Recommendations	37
<b>Conclusion</b>	<b>38</b>

# EXECUTIVE SUMMARY

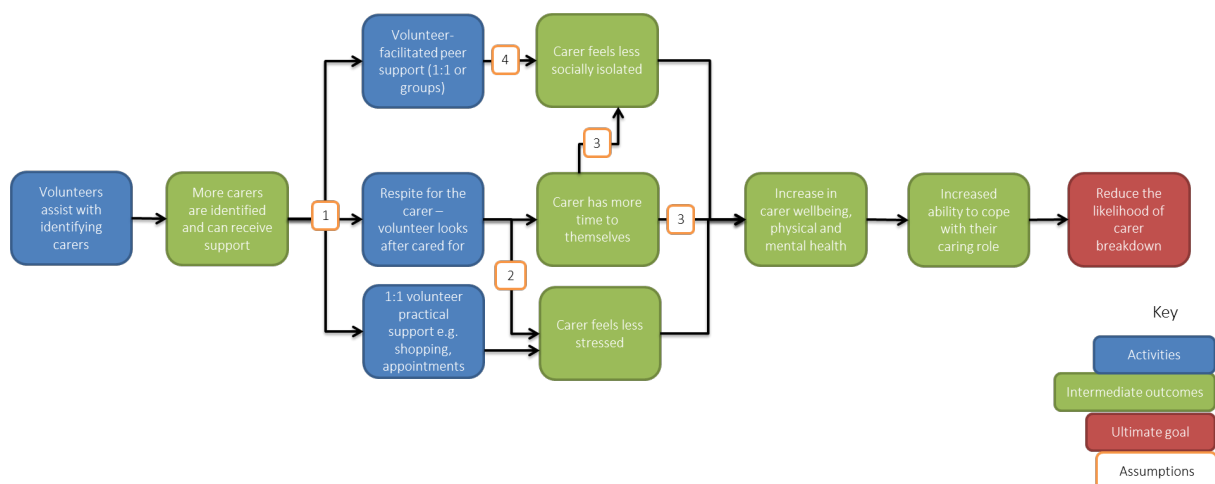
The Social Innovation Partnership carried out an evaluation of Cabinet Office's Carers Social Action Support Fund, including a randomised controlled trial. Here we summarise the evaluation and its findings.

## Key findings

- There is strong evidence that **peer support services** can slow, prevent or reverse a decline in carers' social isolation and carer-related stress.
- There is indicative evidence that **respite services** can reduce carer-related stress and reduce the likelihood of a carer breaking down.
- There is indicative evidence that **carer identification services** can help carers gain access to a range of well-integrated support.
- There is more limited evidence that **practical support services** can improve carers' well-being and/or reduce the likelihood of them breaking down.

## The Carers Social Action Support Fund

The Carers Social Action Support Fund (CSASF) is a £1 million Cabinet Office initiative commissioned in 2014 to invest in projects that use social action to support carers. The Theory of Change below outlines the outcomes it is trying to achieve, and the types of projects that it has funded to achieve them (see the full report for detail on the assumptions):



**A note on carer breakdown:** The Theory of Change infers that breakdown will occur when isolation, stress and a lack of time to oneself reach a point that is no longer manageable for the carer. This implies that it may be common for these things to deteriorate over time in the absence of any support, and that interventions may therefore not need to improve outcomes to be beneficial: it may be possible to prevent breakdown by halting a decline in those outcomes, keeping them steady at a level which the carer can cope with. This theory informs our interpretation of our findings.

**The CSASF grantees:** The CSASF funded seven grantees, all of which took part in the evaluation:

- Peer support services: **Parkinson's UK** and **Westbank** Community Health and Care
- Respite services: **Shared Lives Plus** and **Thirsk** Community Care and partners
- Practical support services: **Age UK** Buckinghamshire and **British Red Cross** & Hive Arts Ltd
- Carer identification services: **Carers Trust Cambridgeshire**

**The carers:** Aside from British Red Cross, which targeted just young carers, the carers were 66 years old on average. Carers were more likely to be female (68% on average) and White British (95% on average)

## The evaluation methodology

**Research questions:** Broadly speaking this evaluation aimed to measure the impact of the CSASF on its core outcomes, understand what factors affect the grantees' impact, and so deduce how effective social action approaches might be at supporting carers,

**Research design:** The design of the evaluation focused on measuring impact, but also included elements of process evaluation (to measure how the service was delivered in practice). It included both quantitative and qualitative approaches, broken down as follows:

- **Six pre-post designs:** Quantitative baseline and follow-up surveys given to all carers who started receiving the grantees' services during the data collection window.
- **One randomised controlled trial (RCT) design:** For Westbank, the same as above but with the addition of a randomised control group.
- **Four sets of interviews:** For four of the grantees, interviews with a small number of carers to explore the services and their impact in more detail.

## The results

The table below summarises the impact survey results across all seven grantees. **Green** cells represent a statistically significant positive change in outcome<sup>1</sup>, **amber** cells represent no change in outcome, and **grey** cells represent that outcome not being measured by that grantee. There were no statistically significant negative changes in outcome.

Outcome	Measurement tool	Peer support		Respite		Practical support		Identif-ication
		West-bank	PUK	SLP	Thirsk	Age UK	BRC	CTC
Reduced likelihood of carer breakdown	'Ability to Care' sub-scale of AC-QoL	NC	NC	PC**	PC*	PC**	NC	NC
	Questions 16 and 18 of Zarit Burden Interview	NC	NC	NC	NC	NC	NC	NC
Carer feels less socially isolated	De Jong Gierveld Scale	PC**	PC*	NC	NC	NC	NC	NC
Increased carer well-being/ mental and physical health	'Caring Stress' sub-scale of AC-QoL	PC**	PC**	PC*	PC**	NC	NC	PC*
	Short Warwick Edinburgh Mental Well-being Scale	NM	PC*	NC	NC	NM	PC**	NM
Carer has more time to themselves	'Caring Choice' sub-scale of AC-QoL	NM	NM	NC	NC	NM	NC	NM

Please see the full report and appendices for the qualitative and quantitative process results.

## What the results mean

Here we give brief answers to our paraphrased research questions, interpreting the results in the context of the natural limitations of the evaluation methodology:

### What is the impact of the CSASF grantees on carers?

The Westbank RCT produces this evaluation's strongest evidence, and shows that **Westbank's** peer support service slows and reverses a deterioration in carers' stress and social isolation, respectively. This is supported by the qualitative data.

The other grantees suffer from similar limitations to each other, which might overestimate or underestimate their impact. On balance these findings should only be seen as an indication of impact. **Parkinson's UK**, showed similar results to Westbank, the other peer support service: a reduction in social isolation, and an improvement in well-being. **Shared Lives Plus** and **Thirsk**, the two respite services, saw a reduction in caring stress and the likelihood of breakdown. **Age UK** and **British Red Cross**, the two practical support services, saw a reduction in likelihood of

<sup>1</sup> A double asterisk (\*\*) and darker green represents a change that is statistically significant at the 0.05 alpha level. A single asterisk (\*) and lighter green represents a change that is only statistically significant at the 0.10 alpha level.

breakdown (when measured by the more practically-focused of the two scales) and an improvement in well-being (when measured in its broader sense), respectively. **Carers Trust Cambridgeshire**, the only grantee focused on identifying and signposting carers, saw a reduction in caring stress. Qualitative data suggests that these carers felt particularly well-informed, with good access to a range of well-integrated services.

#### **What factors affect the grantees' impact?**

Carers' **level of need** seemed to be the biggest external influence on the services' impact, across all grantees – the greater the need, the greater the impact (and vice versa). The way each service was delivered could also influence the size of the impact – specifically the **length, frequency, flexibility** and **accessibility** of the social action sessions, and **how well-matched** the carers, people being cared for and volunteers are.

#### **How effective might social action approaches therefore be at supporting carers?**

Social action can, and likely regularly does, have a positive impact on carers, and can have a greater impact with the right combination of services, the right targeting and the right delivery. It should primarily be seen as a preventative approach for carers with a medium level of need, and should not be a substitute for more intensive services for those with the most acute and high needs.

## Our recommendations

The findings of this evaluation naturally lead to some recommendation for commissioners / policymakers, organisations delivering social action services, and researchers. Some of these recommendations should be considered in the context of the natural limitations of this evaluation's methodology.

- For commissioners / policymakers: **Invest in social action services** as a preventative approach for carers with a medium level of need, provided that those services can convincingly show their commitment to quality, learning and impact. But **also invest in evaluation** to continue to learn what works and how it can work even better, and continue to **invest in more intensive services for carers with the highest level of need**.
- For delivery organisations: **Take the learning from this evaluation**, where relevant, but **commit to further learning too** – delivery can always be improved, and there is an increasing evidence base from which to learn how. **Try to focus your services on carers who will benefit the most**, and refer more acute cases to more appropriate, intensive services.
- For researchers: **Use increasingly robust methods** to test our results, but **make sure those ambitions for robustness are realistic**, and aligned with services' context and stage of development. Where possible, **used mixed methods**. Finally, **carry out more literature reviews**, to collate research like this and distil the collective findings into clear recommendations.

## Our conclusion

Overall, this evaluation gives a solid indication that social action is a viable approach to effectively supporting carers, primarily through early identification and intervention in order to prevent deteriorating stress and social isolation for carers with a medium level of need.

All seven grantees saw some positive change in outcome among the carers they support, and although for all but Westbank we cannot confidently attribute that change to the interventions themselves, the qualitative data does support the quantitative findings where it is available.

We recommend that commissioners and policymakers recognise the potential of social action approaches and invest in appropriate support and evaluation accordingly, and that delivery organisations commit to continual learning on how to improve their services and maximise their impact.

# INTRODUCTION

In this section we provide an introduction to the Carers Social Action Support Fund (CSASF) and its aims; an overview of the intervention approaches employed by the Fund's grantees; and a brief literature review on carer breakdown and existing approaches to prevent it.

## THIS REPORT

This report is written by The Social Innovation Partnership (TSIP) following an evaluation of Cabinet Office's Carers Social Action Support Fund (CSASF). It places the CSASF in context, describing what it is and how it was set up to support a range of approaches seeking to address the problem of carer breakdown. The report then outlines the rationale behind our evaluation approach, and the tools and methodologies we employed, before sharing the actual evaluation results. The final section interprets this data and provides recommendations for both commissioners and policymakers, and delivery organisations. A number of appendices provide further detail on specific aspects of the evaluation.

Overall the report aims to:

- Provide a coherent narrative on whether social action can effectively support carers, using the evidence generated from the evaluation.
- Provide key recommendations for commissioners and policymakers, delivery organisations and researchers, on what should happen next with social action approaches that support carers.

Note that this report follows on from an interim report submitted to Cabinet Office in October 2015.

## THE CARERS SOCIAL ACTION SUPPORT FUND

Social action is all about people coming together to help improve one another's lives and solve the problems that are important in their communities. It can include volunteering, giving money, community action or simple everyday neighbourly acts. The Centre for Social Action, led by Cabinet Office, aims to identify and accelerate the development and spread of high impact social action initiatives. As such, the centre has invested tens of millions of pounds in hundreds of projects, through a number of funds, since its inception. The CSASF is one such fund - a £1 million initiative commissioned in 2014 to invest in projects that use social action to support carers.

### The problem: carer breakdown

The number of people with care needs is growing at a staggering rate. Demand has risen exponentially due to a rapidly ageing population and extended life-spans for people with long-term conditions or complex disabilities, with the result that there are currently 6.8 million carers in

England. If the state had to pay for all care provided by carers in the UK it would cost £132 billion per year, a sum almost as large as the annual NHS budget.<sup>2</sup>

Caring responsibilities can have an adverse effect on physical and mental health, education and employment. Studies show that 21 per cent of carers providing over 50 hours of care are in poor health, compared to 11 per cent of the wider population. Significantly poorer health and quality of life outcomes can, in turn, affect a carer's ability to care effectively and can even lead to admission of the cared for person to hospital or residential care. This creates costs for the wider economy, including businesses, due to the number of carers who have to give up work or reduce their hours to care for others. In a recent report as part of the Dementia Friends work, the cost to businesses was estimated at £1.6bn per year for dementia carers alone.

Some people who carry out caring responsibilities do not formally recognise themselves as carers, either because they see it as part of their family duty or they worry that, by identifying themselves, their ability to care will be subject to scrutiny. Under the Carers (Equal Opportunities) Act 2004, Local Authorities are obliged to inform carers of their right to receiving a carer's assessment, in the hope that this will result in more carers being identified and given the support that they are entitled to. However, a survey carried out by Carers Trust in 2012 found that 64 per cent of carers surveyed said they had never accessed any form of support outside their family and friends.<sup>3</sup>

## TSIP's role

Cabinet Office set up the CSASF to fund a small number of social action approaches seeking to support carers, in order to give those services a helping hand towards sustainability. Cabinet Office also wanted to strengthen the evidence base on the effectiveness of different social action approaches working in this area. With these two aims in mind, TSIP was commissioned to design and carry out an evaluation of the fund's grantees, to measure their social impact and identify how it could be improved. TSIP also played a part in the grantee application process, advising Cabinet Office on applicants' existing evidence of impact and capacity for further evaluation.

## GRANTEE INTERVENTIONS

The CSASF funded seven grantees in total, which deliver a range of different social action approaches to support carers. We provide the full names and details below, but for the rest of the report we will use the following shortened names for ease of reference: Age UK, British Red Cross, Carers Trust, Cambridgeshire, Parkinson's UK, Shared Lives Plus, Thirsk, and Westbank.

### Respite-based approaches

**Shared Lives Plus** works with local Shared Lives schemes to enable Shared Lives carers to provide breaks to unpaid family carers, generating and sharing learning UK-wide and raising awareness of how to tailor Shared Lives for family carers.

**Thirsk Community Care and its partners** support unpaid adult carers aged over 50 years, and/or those living in rural areas, through the respite sitting services established in North Yorkshire and York.

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<sup>2</sup> L. Buckner and S. Yeandle (2015) 'Valuing Carers 2015 – the rising value of carers' support', published by Carer's UK.

<sup>3</sup> Carers Trust (2012), 'Carers Trust Survey Briefing', published by Carer's UK.

## Peer support approaches

**Parkinson's UK** helps people with Parkinson's and their carers take control of their health and well-being through guided groups (A Path Through Parkinson's), supported by volunteer Self-Management Facilitators.

**Westbank Community Health & Care** mobilises carers and ex-carers as volunteers to support each other through informal social action that increases peer support – individually and in groups – enabling carers to achieve a better level of health and well-being and thus sustaining them in their caring role.<sup>4</sup>

## Practical support approaches

**Age UK Buckinghamshire's Carers Befriending Service (CBS)** provides trained volunteers to visit adult carers caring for people with memory problems and dementia in their own homes. The volunteer builds a meaningful relationship, becomes a listening ear or a shoulder to cry on, and gives information, advice, guidance and advocacy support.

**British Red Cross** and **Hive Arts Limited** offers a volunteer-led support service to vulnerable young adult carers aged 16-25 in Shropshire. Volunteers provide practical respite support to young adult carers to reduce the risk of carer breakdown and promote carer well-being and support through the transition to adulthood. (N.B. The service provides a mixture of respite, practical support and broader developmental support not relating to caring, but we have categorised it as 'practical support' for the purposes of this evaluation, as we felt this to be the closest fit.)<sup>5</sup>

## Carer identification approaches

**Carers Trust Cambridgeshire** increases carer identification by working with partners, delivering Carers Awareness training, and creating a network of Carers Friends, comprised of volunteers, paid professionals and Carers Ambassadors. Carers referred to the service are offered information, guidance and a range of services to support them in their caring role.<sup>6</sup>

Appendix A gives more detail on the grantees' referral routes, as well as the number of volunteers recruited as part of this fund.

# LITERATURE REVIEW

A full literature review was outside the scope of this work, and so what follows should not be seen as a representative summary of the research on carers. However, during the evaluation we did carry out a brief literature review on carer support interventions, to set the results of the evaluation in context, and below we share our core findings. For the full review, please see Appendix B. References have been included in the appendix rather than in footnotes here, for ease of reference.

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<sup>4</sup> For Westbank, the intention was that paid staff would be involved for a short period of time to help get individuals and groups up and running. In practice more indefinite input from staff was needed than anticipated, but the focus of the service was still peers supporting each other (see the 'limitations of the methodology' section for more details).

<sup>5</sup> The British Red Cross service closed down after data collection was completed, due to changing organisational priorities and challenges with the recruitment of volunteers. Indeed, it is our understanding that the service was delivered at times by staff rather than volunteers, and so its findings should be treated with caution – to some extent they may represent the impact of paid staff rather than social action (see the 'limitations of the methodology' section for more details).

<sup>6</sup> Carers Trust Cambridgeshire's service was delivered by some paid staff in addition to the volunteers, and the two are heavily intertwined. To some extent its results may therefore represent the impact of paid staff as well as volunteers (see the 'limitations of the methodology' section for more details).

## Evidence base for grantee interventions

The existing body of evidence on the effectiveness of carer interventions supported by this fund is largely inconclusive due to lack of high-quality evidence. This evaluation aims to strengthen the evidence base, in a way that could inform Cabinet Office and other commissioners' approach to funding carer support interventions in the future.

- **Respite care:** Studies indicate that respite services benefit carers by giving them more time to themselves and reducing feelings of social isolation. The evidence for benefits to emotional well-being and carers' ability to continue caring is mixed.
- **Group-based supportive interventions:** Past research finds that group-based supportive intervention can have a positive impact on psychological morbidity and emotional well-being, but not on other outcomes.
- **Befriending schemes:** One study indicates that befriending schemes result in small decreases in depression, though the result is not statistically significant.
- **Information services:** Studies show that information services can effectively improve knowledge-related outcomes, but little is known about their impact on other outcomes.

## Evidence-based recommendations around other types of carer interventions

The existing evidence base on a variety of carer support interventions is still relatively early stage and largely inconclusive. However, several practical, evidence-based recommendations do emerge from the literature that may be useful to Cabinet Office when designing similar funds in future:

- **Personalised support:** Support provided to carers is most effective when it is personalised and tailored to individuals in different contexts, and when it is also self-directed, not prescribed from above (Department of Health, 2010).
- **Combining approaches:** Carried out well, multi-component interventions that combine a variety of support tend to offer the best chances of success. See the full literature review for which components are particularly promising.
- **Most promising single approach:** One meta-review deems approaches focusing on education, training and information for carers to be the most effective, particularly when active and targeted, rather than passive and generic (Parker 2010). These are most beneficial in the early stages of caring (Victor 2009).
- **Avoiding harm:** Educational interventions for carers of people with dementia at an early stage after diagnosis may sometimes have an adverse effect on a carer's anxiety and should be supported with caution (National Collaborating Centre For Mental Health 2007).

# METHODOLOGY

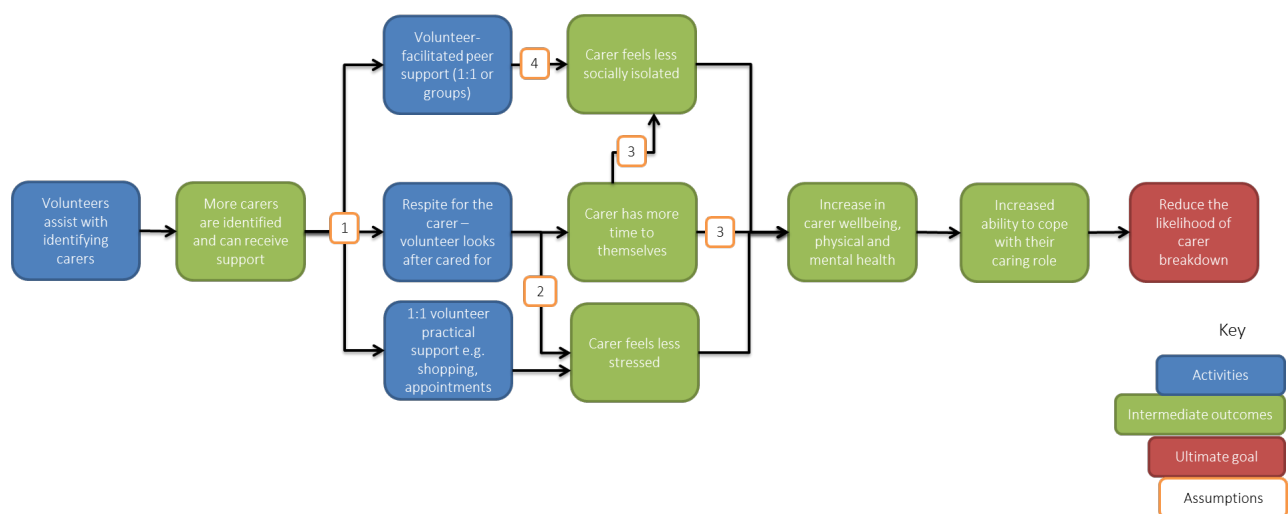
In this section we introduce the CSASF Theory of Change and the overall design of the evaluation, the processes for collecting and analysing the data, and the limitations of the methodology.

## CSASF THEORY OF CHANGE

The overall aim of the evaluation was to test the CSASF Theory of Change (Figure 1). This Theory of Change was developed by Cabinet Office during the fund's inception and then lightly edited in collaboration with TSIP.<sup>7</sup> Its purpose was to guide Cabinet Office's funding decisions and to create a framework for evaluation. It outlines:

- **Activities:** The types of intervention the fund supported.
- **Intermediate outcomes:** The main outcomes that these interventions were expected to achieve, in terms of the effect they have on lives of the carers they support.
- **Ultimate goal:** The impact that the fund was ultimately trying to achieve.
- **Assumptions:** The assumptions underpinning the Theory of Change that must hold true in order for the outcomes to be achieved in practice.

Figure 1: The CSASF Theory of Change



Assumptions:

1. There is good co-ordination and referral routes from being identified and receiving support.
2. The cared-for person feels comfortable with the volunteer who is providing respite, and the carer trusts them.
3. Carers spend their time gained from respite in a productive way; for example, visiting friends/family, engaging in leisure activities or resting.

<sup>7</sup> See Appendix C for the original Theory of Change.

4. Carers are willing to engage with other carers (despite being strangers), including sharing feelings and concerns.

It is important to emphasise that the fund ultimately aimed to prevent breakdown; in other words, to stop a negative outcome, rather than to achieve a positive one. The Theory of Change infers that breakdown will occur when isolation, stress and a lack of time to oneself reach a point that is no longer manageable for the carer. We theorised at the outset of this evaluation that it may be common for these things to deteriorate over time in the absence of any support, and that interventions may therefore not need to improve outcomes to be beneficial: **it may be possible to prevent breakdown by halting a decline in those outcomes**, keeping them steady at a level which the carer can cope with. This theory - deteriorating outcomes on the journey to eventual breakdown - is a key principle of the entire evaluation, and is something we will return to throughout the report.

## RESEARCH QUESTIONS

The aim to test the underlying logic of the Theory of Change can be broken down into four more specific research questions, which directed the evaluation design:

1. To what extent have the seven individual interventions achieved the core outcomes?
2. To what extent have carer characteristics and service implementation conditions acted as facilitators or barriers to the interventions' desired impacts?
3. How might the interventions be refined or improved based on the new evidence?
4. What can this tell us about the effectiveness of social action approaches to support carers?

It is important to emphasise here that the aim of this evaluation is not to provide definitive evidence on the effectiveness of these interventions; instead it has the more modest aim of providing an *indication* of effectiveness, which should be built on by further research with ever-increasing robustness.

## GUIDING PRINCIPLES

The overarching approach to the evaluation was underpinned by three key principles:



- **Collaboratively choosing relevant outcomes:** We employed a portfolio-level evaluation approach, whereby a common set of outcomes and measurement tools were used across all seven grantees, in order to produce a coherent set of findings. Cabinet Office's Theory of Change (Figure 1 above) served as a starting point for the choice of outcomes, but the evaluation was then tailored to individual grantees by selecting the outcomes most relevant to them, a process which was driven by the creation of individual Theories of Change for each grantee. See Appendix D for those Theories of Change.

- **Designing measurement tools with grantee feedback:** We identified a selection of appropriate measurement tools for these outcomes, which were combined into a single survey and then refined based on feedback from piloting the survey with the grantees and their service users. (This process of refinement may have had a minor impact on the validity of the tools – see the ‘limitations of the methodology’ section for more details.)
- **Grantee-led data collection:** Direct data collection by TSIP was not possible or planned for within the agreed budget, and was instead carried out by the grantees. To ensure successful data collection, grantees were given thorough hands-on support, including: initial one-to-one meetings to develop bespoke evaluation plans detailing the step-by-step process through which to collect data; help to embed data collection processes into their existing systems and delivery; and regular consultation to facilitate implementation of evaluation plans, solve data collection problems, and monitor data quality.

## EVALUATION DESIGN

The design of the evaluation focused on measuring impact, but also included elements of process evaluation (to measure how the service was delivered in practice). It included both quantitative and qualitative approaches, broken down as follows:

- **Six pre-post designs:** Age UK, British Red Cross, Carers Trust Cambridgeshire, Parkinson’s UK, Shared Lives Plus, and Thirsk employed quantitative pre-post designs. Baseline impact data was collected via survey between March and December 2015, and follow-up data was collected between June 2015 and March 2016. The length of follow-up periods varied between three and six months and depended on the type of intervention (see Appendix G for a breakdown by grantee). Initial sample sizes varied between approximately 25 and 157 carers. Some process evaluation questions were included in the follow-up survey (see the analysis section below for more details).
- **One randomised controlled trial design:** Westbank maintains a database of 17,000 carers and was therefore in a unique situation to conduct a randomised controlled trial (RCT). All carers from the database were invited to take part in the trial, and the carers who responded were randomly assigned to receive the service immediately (the intervention group) or from December 2015 (the control group). The total sample size was 652 carers at baseline. Impact and process data was collected via survey in the same way as the other six grantees. See Appendix E for more details on the RCT design.
- **Four sets of interviews:** For Westbank, Thirsk, Shared Lives Plus and Carers Trust Cambridgeshire, we carried out interviews with four carers receiving each service.<sup>8</sup> These were primarily focused on exploring impact and outcomes in more depth, but also covered the delivery of the service and how it might be improved.

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<sup>8</sup> The interviews were carried out as part of an extension to the Fund, which only four of the original seven grantees took part in. Only two interviews were carried out for Shared Lives Plus, as it was not possible to find more carers who were willing and able to be interviewed during the evaluation’s interview period.

## OUTCOMES AND TOOLS

Figure 2 below lists the outcomes measured across the portfolio, which grantee chose to measure what, and the quantitative tools they used to do so.<sup>9</sup>

**Figure 2: Outcomes and tools**

Outcomes	Measurement tools	Measured by
Reduced likelihood of carer breakdown	'Ability to Care' sub-scale of the 'Adult Carer Quality of Life tool' (AC-QoL) (5 items)	All seven grantees
	Questions 16 and 18 of Zarit Burden Interview	All seven grantees
Carer feels less socially isolated	De Jong Gierveld Scale (11 items)	All seven grantees
Increased carer well-being / Increased carer physical and mental health	'Caring Stress' sub-scale of AC-QoL (5 items)	All seven grantees
	Short Warwick-Edinburgh Mental Well-being Scale (7 items)	British Red Cross, Parkinson's UK, Shared Lives Plus, Thirsk Community Care & partners
Carer has more time to themselves	'Caring choice' sub-scale of AC-QoL (5 items)	British Red Cross, Shared Lives Plus, Thirsk Community Care & partners

We did not measure **carer breakdown** directly (for example, through hospital admissions) because instances of breakdown would be quite rare given the relatively short data collection timeframe. Instead, we measured the *risk* of breakdown using two separate tools: the first focused on an ability to cope with caring on a practical level; and the second focused on an ability to cope on a psychological level.

For **well-being, physical and mental health**, we chose to focus on well-being more than physical and mental health. Trying to cover all three concepts would require a survey that would be too long. More importantly, well-being was the quickest and most likely to be affected by the grantees' services. We used two different tools for well-being: the first asked questions that were specifically related to caring; whereas the second related to broader well-being and did not ask any questions specifically related to caring. We saw value in including both, where possible, because the first would be more sensitive to change, and the second would give an indication of how much the carers' caring situation affected their well-being as a whole.

To reduce the length of the survey, two other outcomes were not measured: '**carers less stressed**' and '**increased ability to cope with their caring role**'. These relate closely to 'increased carer well-being' and 'reduced likelihood of breakdown', respectively, which were already being measured.

<sup>9</sup> See Appendix F for full wording of the tools' questions, and details on their reliability.

For each grantee, the chosen tools were combined into a single survey, to which we added bespoke questions about the delivery of the service (as part of the light touch process evaluation).

The full survey was piloted by British Red Cross, Carers Trust Cambridgeshire, and Thirsk with a small number of carers prior to baseline data collection. TSIP incorporated their feedback into the survey as far as was possible. For example, the Warwick-Edinburgh Scale was included primarily because it includes positively-framed questions that counteracted the other negatively-framed tools, which may have made some carers feel uncomfortable.

## DATA COLLECTION

**Quantitative:** TSIP developed bespoke evaluation plans with each of the grantees, to ensure that each grantee was equipped to collect data effectively. Each evaluation plan outlines their chosen outcomes and measurement tools; target sample size and target population; baseline and follow-up(s) data collection time periods; staff responsible for data collection; and any practical details around survey administration.

The grantees reported to us on a regular basis so we could provide remote one-on-one support throughout the data collection period. This allowed us to troubleshoot any emerging issues and check in on the quality of their data in case tweaks needed to be made.

**Qualitative:** TSIP travelled to grantees' locations to carry out interviews with selected carers. Grantees were given a set of target demographics, to ensure a representative sample, and left to recruit the interviewees themselves. Carers were generally interviewed in a local community building or grantee office, and occasionally in the carer's own home.

The interviews were semi-structured, using tailored topic guides that covered four main questions:

- How was the service implemented?
- What was its impact?
- What were the barriers and facilitators to impact?
- What worked well and less well about the intervention?

Two members of TSIP staff attended the interviews – one carried out the interview, while the other took notes. Interviews were recorded so that we could refer back to the recordings where necessary, including for direct quotes.

## DATA ANALYSIS

At the end of the data collection period, grantees sent all quantitative data to TSIP, to be cleaned and analysed in-house primarily by our associate Zsolt Kiss of ZK Analytics. We held qualitative data from the interviews in the form of written notes and full recordings. We employed a variety of analysis approaches across these different types of data.

### The quantitative impact data

We conducted significance tests on all outcome data from the surveys, to assess whether any observed outcome changes were statistically significant or simply due to chance. In addition, we calculated the effect sizes for the statistically significant results, to describe the size of the outcome

change in a standardised way that could be somewhat compared to other research. The two types of research designs outlined previously required different significance testing approaches:

- **The RCT:** We used OLS linear regressions, taking into account baseline data, comparison group data and demographic data (including age, gender, ethnicity and disability). We carried out both intention-to-treat and treatment-on-the-treated analyses, though only report the former in this report (as both analyses produced statistically significant results for the same outcomes). The effect sizes were calculated using Eta-squared. As a rule of thumb, 0.02 is considered a small effect, 0.13 a medium effect, and 0.26 a large effect (though these thresholds should only be used as a very approximate indication of size of impact).
- **The pre-post designs:** We used dependent (paired sample) *t*-tests to assess whether outcomes changed significantly over time for carers. The effect sizes were calculated using an adjusted Cohen's *d*. It was adjusted for the correlation between baseline and follow-up outcome scores. As a rule of thumb, 0.2 is considered a small effect, 0.5 a medium effect, and 0.8 a large effect (though again, these thresholds should only be used as a very approximate indication of size of impact).

## The quantitative process data

We focused on analysing the process data with descriptive analyses:

- **Demographics:** We calculated the averages and frequencies for age, gender, ethnicity and disability.
- **Are carers still providing care at follow-up?** We calculated the percentage of carers still providing care at follow-up. In addition, for those carers who no longer provided care, we calculated the percentages of carers who stopped caring as a result of the cared for person's needs, the carer's health and ability to cope, and other reasons.
- **Actual dosage/attendance:** We calculated the average service 'dosage' that carers received, which depended on the type of service; for example, the average monthly number of sessions attended, the average monthly hours of service received, or the average number of services accessed.
- **Theory of Change assumption-related questions:** We calculated the averages and/or frequencies of additional bespoke survey questions, such as whether the volunteer was a good listener or whether peer support carers felt well-matched. These questions were designed to test how effectively the service was being delivered in practice.

## The qualitative impact and process data

All qualitative data was analysed thematically. One interviewer read through the interview transcriptions to identify potential themes, and these were then discussed with the second interviewer and a third team member, who had not attended the interviews, to try and minimise any bias or inaccuracy in interpretation.

# PARTICIPANTS

Every carer that came through the grantees' services for the first time during the evaluation's data collection period was invited to take part in the evaluation. Selection was not restricted by age, or

any other demographic or characteristic. See Appendix I for full details on the profile of the participating carers.

## ETHICS

Informed consent was collected from all carers who took part in the evaluation – separately for the quantitative surveys and qualitative interviews.

For the RCT, Westbank were advised to limit delivering the peer support service to any carers outside of the trial until it had finished, unless those other carers had a particularly high level of need. Carers in the control group were advised that they could leave the research and receive the service if they experienced an increase in need. They were also free to receive other services from Westbank or other organisations.

TSIP is not subject to any internal or external ethics committee, but we did consult with associates to confirm that we were operating as ethically as possible.

## LIMITATIONS OF THE METHODOLOGY

As is the case for virtually all research, this evaluation has a number of limitations that should be taken into account when interpreting the findings. We present these below, in approximate order of importance. Despite these limitations, we believe that the methodology is sufficiently robust for the findings of the evaluation to be considered a solid indication of the services' impact, which will require further research to explore in more depth and ever-increasing robustness (see discussion section for more details).

- **Lack of comparison group:** Apart from Westbank, the grantees' evaluations had no comparison group; therefore, we cannot be sure that any positive or negative changes were caused by the interventions themselves, rather than by other systematic factors. However, the Westbank comparison group means that we can confidently attribute any change in outcome for that grantee to the intervention itself. The Westbank comparison group can also be used tentatively as an informal reference point for some of the other grantees.
- **Low sample sizes for surveys:** Sample sizes were generally small, often driven by challenges with recruiting carers or volunteers. This made it harder to identify statistically significant findings, which means that the results may underestimate the impact of some grantees and some outcomes. On the other hand, where low sample size was driven by low response rates (which was primarily an issue at follow-up), the data might be unrepresentative. In particular, it may be skewed positively towards those who had the best experience and who were therefore more likely to fill in the survey, and so, in this instance, it may lead to an overestimation of impact.
- **Lack of full-scale process evaluation:** The CSASF specifically funded social action interventions. However, we have a degree of informal understanding that some of the services involved a higher number of paid staff than was originally anticipated (see footnotes 4, 5 and 6 in the 'introduction' for more specific details). The evaluation did not include a full process evaluation to explore the delivery of the services in depth, it has not therefore been possible to separate any impact of volunteers from the impact of paid staff. Still, overall the portfolio of funded services were very much primarily delivered by volunteers, and so the

evaluation findings should be interpreted as specifically reflecting the impact of social action (while bearing in mind the specific caveats for the aforementioned grantees).

- **Low sample size for interviews:** Interviews were carried out with four carers for each grantee who received extended funding (only two for Shared Lives Plus). While this was enough to raise a good number of interesting and useful themes, it was likely not enough to reach the point of saturation (when additional interviews do not identify any new themes), and so the qualitative findings cannot be seen as exhaustive or necessarily representative.
- **Validity of tools:** The tools for the evaluation were selected very carefully, and all were validated. However, to minimise survey length (particularly when trying to measure a range of outcomes), often only the sub-scales of some tools were used, and it was not always possible to match these sub-scales 100 per cent to the outcome in question (e.g. using the 'ability to care' sub-scale to measure likelihood of breakdown). Still, we have tried to be transparent about what kinds of question or statement each sub-scale contains, and in all but one case (Zarit Burden), the sub-scales themselves were validated in the same way as the scales in their entirety.
- **Non-comparability of interventions:** This evaluation covers seven separate grantees, each operating a different type of service in a different region of England with a different group of carers; therefore, the results cannot be directly compared or amalgamated across grantees, and cannot necessarily be extrapolated to other populations in other locations. However, the results can still be compared informally, to give an indication of the kind of impact different services might have, and we have no specific reason to think that these findings are particularly low in external validity. For example, aside from British Red Cross (which focused on young carers), all the carers are quite similar in terms of age, gender and ethnicity.

# RESULTS

In this section, we give an overview of the quantitative and qualitative results across all seven grantees, before providing more detailed quantitative data for each individual grantee.

## RESULTS ACROSS ALL GRANTEEES

### Quantitative data

Figure 3 below shows the outcomes measured across all grantees, the tools used to measure them, and an indication of how those outcomes have changed during each grantee's intervention. It uses the following key:

- Green (PC): Statistically significant positive change<sup>10</sup>
- Amber (NC): No statistically significant change, positive or negative
- Grey (NM): Not measured by that grantee

No outcomes showed a negative change that achieved or approached statistical significance.

**Figure 3: Changes in outcome across the portfolio of grantees**

		Peer support		Respite		Practical support		Identif-ication
Outcome	Measurement tool	Westbank	PUK	SLP	Thirsk	Age UK	BRC	CTC
Reduced likelihood of carer breakdown	'Ability to Care' sub-scale of AC-QoL	NC	NC	PC**	PC*	PC**	NC	NC
	Questions 16 and 18 of Zarit Burden Interview	NC	NC	NC	NC	NC	NC	NC
Carer feels less socially isolated	De Jong Gierveld Scale	PC**	PC*	NC	NC	NC	NC	NC
Increased carer well-being/ mental and physical health	'Caring Stress' sub-scale of AC-QoL	PC**	PC**	PC*	PC**	NC	NC	PC*
	Short Warwick Edinburgh Mental Well-being Scale	NM	PC*	NC	NC	NM	PC**	NM
Carer has more time to themselves	'Caring Choice' sub-scale of AC-QoL	NM	NM	NC	NC	NM	NC	NM

<sup>10</sup> Here and in the rest of the results section, a double asterisk (\*\*) and darker green represents a change that is statistically significant at the 0.05 alpha level, which means that we can be at least 95% sure the change was not purely due to chance. Setting the level at 0.05 is standard practice. A single asterisk (\*) and lighter green represents a change that is only statistically significant at the 0.10 alpha level, which means that we can be between 90% and 95% sure the change was not purely due to chance. Setting the level at 0.10 is more 'lenient' and less common, but we believe it is appropriate given the generally small sample sizes across most of the portfolio and the nature/stage of interventions being evaluated. See Appendix J for more detail.

The following bullet points highlight the key themes from the table (see the discussion section for more details):

- Westbank showed a statistically significant positive effect on two outcomes: reduced social isolation and improved well-being (measured by the 'caring stress' sub-scale). We can be extremely confident in attributing the changes in outcome to the intervention itself, due to Westbank's randomised controlled design.
- Every other grantee has at least one outcome showing statistically significant positive change, although we cannot be as confident in attributing these changes to the interventions themselves, due to a lack of comparison group.
- Overall the 'caring stress' sub-scale most frequently showed positive change, followed by the 'ability to care' sub-scale.
- The 'caring choice' and 'zarit burden' scales were the only two outcomes not to show any statistically significant positive change.

## Qualitative data

The following bullet points summarise the key qualitative themes across the four grantees for whom interviews were carried out. They are broken down first by intervention type, and then by the type of question they relate to - either exploring **impact** and any **barriers and facilitators** to impact, or identifying what about the service **worked well and less well**. Please see Appendices K to N for individual grantees' qualitative analyses in full.

### All approaches

- **Barriers and facilitators:** The impact of the services seemed clearly to depend on the carer's level of need: the higher the level of need, the greater the impact; and the lower the need, the lower the impact.

### Respite-based approaches

- **Impact:** Carers stated that respite triggered an immediate sense of relief, enabled them to rest, to restore a sense of normality and to improve their relationships. Carers felt able to enjoy this time off because they trusted those providing them respite.
- **Worked well:** The relationship between the volunteer and the person cared for was said to be very positive. The carers found the services easy to use and the volunteers and staff very friendly and helpful.
- **Worked less well:** The duration of shorter respite in some instances limited its impact.

### Peer support approaches

- **Impact:** The carers felt able to empathise with one another in a forum that was separate from their private lives, creating a space for emotional and practical peer support. This also provided an opportunity to realise how lucky they might be in comparison to other carers.
- **Barriers to impact:** The level of trust and desire to ignite a meaningful relationship varied, depending on how well the participants 'gelled'.
- **Barriers to participation:** Accessibility sometimes hindered carers' ability to participate, in terms of the rurality of locations or the carer's ability to leave their cared for person at home.

- **Worked well:** Programme coordinators (for groups) were said to be instrumental in getting the peer support groups going. Carers appreciated the flexibility that the peer buddy scheme offered.

#### Carer identification approaches

- **Impact:** Carers were able to access a wide range of carer support services, which they considered to be well-integrated. They also felt well-informed about the kinds of support they were eligible for.
- **Facilitators:** Referrals and signposting were particularly effective when the available services were high-quality, comprehensive and well-integrated.
- **Barriers:** There is a limit to what public services can achieve, however high quality and plentiful they might be.

## RESULTS OF INDIVIDUAL GRANTEES

This sub-section provides further detail on each of the grantee's quantitative impact results. For each grantee there is: a) a **table outlining key data**; and b) a brief **summary and interpretation of that data**. These summaries aim to translate the 'outcome change' figure into something more meaningful – into the changes in survey responses that the figure could represent. They are not accurate translations based on individual-level data; they are hypothetical examples based on the value of the figure.

For quantitative process results see Appendix I, and for qualitative results for individual grantees see Appendices K to N.

The tables in this sub-section use a slightly different key to Figure 3 above. For the 'mean difference' column:

- **Green:** A positive change in outcome (for some scales an increase in score represents a positive change, for other scales an increase in score represents a negative change)
- **Red:** A negative change in outcome
- **Grey:** No change in outcome

For the 'p-value' column:

- **Green:** The change is statistically significant<sup>11</sup>
- **No colour:** The change is not statistically significant

It is important to note that where the p value is not highlighted (i.e. where there is no statistically significant change), the direction of outcome change should be largely ignored because we cannot be sufficiently confident that the change is due to anything more than chance. The reason we have colour-coded all 'outcome change' cells, even those which are not statistically significant, is simply for transparency.

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<sup>11</sup> As before, a double asterisk (\*\*) and darker green represents a change that is statistically significant at the 0.05 alpha level, which means that we can be at least 95% sure the change was not purely due to chance. Setting the level at 0.05 is standard practice. A single asterisk (\*) and lighter green represent a change that is only statistically significant at the 0.10 alpha level, which means that we can be between 90% and 95% sure the change was not purely due to chance. Setting the level at 0.10 is more 'lenient' and less common, but we believe it is appropriate for this evaluation - see Appendix J for more detail.

Figure 4: Westbank quantitative impact data

Outcome	Measurement tool	Sample size <sup>12</sup>	Mean at baseline	Mean at follow-up	Outcome change <sup>13</sup>	p-value	Effect size <sup>14</sup>
Reduced likelihood of carer breakdown	'Ability to Care' sub-scale of AC-QoL	T: 189 C: 170	T: 10.06 C: 9.86	T: 10.31 C: 9.84	0.23	0.32	-
	Questions 16 and 18 of Zarit Burden Interview	T: 185 C: 169	T: 1.21 C: 1.30	T: 1.34 C: 1.36	0.03	0.69	-
Carer feels less socially isolated	De Jong Gierveld Scale	T: 163 C: 145	T: 7.31 C: 7.26	T: 7.00 C: 7.70	-0.66	0.02**	0.02
Increased carer well-being / mental and physical health	'Caring Stress' sub-scale of AC-QoL	T: 169 C: 152	T: 9.15 C: 8.74	T: 9.01 C: 8.07	0.55	0.03**	0.02

As previously discussed, Westbank was able to include a randomised comparison group in their evaluation, which means we can be particularly confident in the findings – specifically, that any statistically significant change was caused by the intervention itself, rather than by other factors.

Figure 4 shows that carers supported by Westbank experienced a **statistically significant positive change** against the '**social isolation**' outcome, the scale for which covers statements like '*I miss the pleasure of the company of others*' and '*there are plenty of people I can lean on when I have problems*'. Here, the change of 0.66 could mean, for example, that more than half of the carers answered more positively to one of those statements after they had received the service. The effect size of 0.02 means this is a small effect, broadly speaking.

The carers also showed a **statistically significant positive change** against the '**caring stress**' sub-scale, which covers statements like '*I feel depressed due to caring*' and '*I feel worn out as a result of caring*'. Here, the change of 0.55 could represent, for example, that approximately half of carers changed their response to one of those statements from '*a lot of the time*' to '*some of the time*'. The effect size of 0.02 means this is a small effect, broadly speaking.

The two remaining outcomes showed a positive and negative change, respectively, but neither were statistically significant and therefore both should be viewed as 'no change'.

<sup>12</sup> Because Westbank were the only grantee able to include a comparison group, this table includes data for both 'treatment' and 'comparison' groups (denoted by 'T' and 'C' respectively).

<sup>13</sup> Because Westbank were the only grantee able to include a comparison group, the 'outcome change' column is slightly different to the 'mean difference' column of other grantees – it takes into account the comparison group data, the baseline data and the demographic data.

<sup>14</sup> See the 'analysis' sub-section for more detail on effect sizes

## Age UK

**Figure 5: Age UK quantitative impact data**

Outcome	Measurement tool	Sample size	Mean at baseline	Mean at 3- month follow-up	Mean difference	p-value	Effect size
Reduced likelihood of carer breakdown	'Ability to Care' sub-scale of AC-QoL	11	11.00	13.27	2.27	0.02**	0.84
	Questions 16 and 18 of Zarit Burden Interview	10	1.25	1.15	-0.10	0.64	-
Carer feels less socially isolated	De Jong Gierveld Scale	7	7.14	7.00	-0.14	0.88	-
Increased carer well-being/ mental and physical health	'Caring Stress' sub-scale of AC-QoL	11	9.27	9.27	0.00	1.00	-

Figure 5 shows that carers supported by Age UK experienced a **statistically significant positive change** against the **'ability to care'** sub-scale, which covers statements like *'I can take care of the needs of the person I am caring for'* and *'I am able to deal with a difficult situation'*. The change of 2.27 could represent, for example, that every carer changed their response to just over two of those statements from 'never' to 'some of the time'. The effect size of 0.84 means this is a large change, broadly speaking.

Other outcomes also showed a positive change, but were not statistically significant and should therefore be viewed as 'no change'.

## British Red Cross

**Figure 6: British Red Cross quantitative impact data**

Outcome	Measurement tool	Sample size	Mean at baseline	Mean at 3-month follow-up	Mean difference	p-value	Effect size
Reduced likelihood of carer breakdown	'Ability to Care' sub-scale of AC-QoL	25	9.36	9.64	0.28	0.68	-
	Questions 16 and 18 of Zarit Burden Interview	23	0.74	0.76	0.02	0.85	-
Carer feels less socially isolated	De Jong Gierveld Scale	23	5.52	5.83	0.30	0.28	-
Increased carer well-being / mental and physical health	'Caring Stress' sub-scale of AC-QoL	25	10.84	10.88	0.04	0.93	-
	Short Warwick Edinburgh Mental Well-being Scale	25	21.88	23.00	1.12	0.02**	0.49
Carer has more time to themselves	'Caring Choice' sub-scale of AC-QoL	24	11.08	10.88	-0.21	0.66	-

Figure 6 shows that carers supported by BRC experienced a **statistically significant positive** change against the '**Warwick Edinburgh**' scale, which covers statements like '*I've been feeling optimistic about the future*' and '*I've been feeling relaxed*'. The change of 1.12 could represent, for example, that every carer changed their response to just over one of those statements from 'some of the time' to 'often'. The effect size of 0.49 means this is a medium change, broadly speaking.

Other outcomes showed a mixture of positive and negative change, but none were statistically significant and should therefore be viewed as 'no change'.

## Carers Trust Cambridgeshire

**Figure 7: Carers Trust Cambridgeshire quantitative impact data**

Outcome	Measurement tool	Sample size	Mean at baseline	Mean at follow-up	Mean difference	p-value	Effect size
Reduced likelihood of carer breakdown	'Ability to Care' sub-scale of AC-QoL	83	10.17	10.78	0.61	0.16	-
	Questions 16 and 18 of Zarit Burden Interview	85	1.12	0.98	-0.14	0.37	-
Carer feels less socially isolated	De Jong Gierveld Scale	71	6.34	6.93	0.59	0.31	-
Increased carer well-being / mental and physical health	'Caring Stress' sub-scale of AC-QoL	81	9.46	9.99	0.53	0.09*	0.19

Figure 7 shows that carers supported by CTC experienced a positive change against the '**caring stress**' sub-scale, which was **statistically significant at the 0.10 level but not 0.05 level** (which means we cannot be quite as confident in the finding). This scale covers statements like '*I feel depressed due to caring*' and '*I feel worn out as a result of caring*'. The change of 0.53 could represent, for example, that approximately half of carers changed their response to one of those statements from 'a lot of the time' to 'some of the time'. The effect size of 0.19 means this is a small change, broadly speaking.

Other outcomes showed a mixture of positive and negative change, but none were statistically significant and should therefore be viewed as 'no change'.

## Parkinson's UK

**Figure 8: Parkinson's UK quantitative impact data**

Outcome	Measurement tool	Sample size	Mean at baseline	Mean at follow-up	Mean difference	p-value	Effect size
Reduced likelihood of carer breakdown	'Ability to Care' sub-scale of AC-QoL	39	9.97	10.64	0.67	0.18	-
	Questions 16 and 18 of Zarit Burden Interview	39	0.78	0.68	-0.10	0.44	-
Carer feels less socially isolated	De Jong Gierveld Scale	36	5.75	4.75	-1.00	0.06*	0.33

Outcome	Measurement tool	Sample size	Mean at baseline	Mean at follow-up	Mean difference	p-value	Effect size
Increased carer well-being / mental and physical health	'Caring Stress' sub-scale of AC-QoL	39	10.90	11.67	0.77	0.03**	0.36
	Short Warwick Edinburgh Mental Well-being Scale	38	24.39	25.66	1.26	0.10*	0.28

Figure 8 shows that carers supported by Parkinson's UK experienced a **statistically significant positive change** against the '**caring stress**' sub-scale, which covers statements like '*I feel depressed due to caring*' and '*I feel worn out as a result of caring*'. The change of 0.77 could represent, for example, that approximately three in four carers changed their response to one of those statements from 'a lot of the time' to 'some of the time'. The effect size of 0.36 means this is a small to medium change, broadly speaking.

Two other outcomes showed a positive change that was **statistically significant at the 0.10 level but not at the 0.05 level** (which means we cannot be quite as confident in these findings). These show that the carers may be feeling **less isolated** than before and may be feeling an **improved sense of well-being**. The effect sizes of 0.33 and 0.28 mean these are small changes, broadly speaking.

The two remaining outcomes showed positive change, but were not statistically significant and should therefore be viewed as 'no change'.

## Shared Lives Plus

**Figure 9: Shared Lives Plus quantitative impact data**

Outcome	Measurement tool	Sample size	Mean at baseline	Mean at follow-up	Mean difference	p-value	Effect size
Reduced likelihood of carer breakdown	'Ability to Care' sub-scale of AC-QoL	37	10.00	11.76	1.76	<0.01**	0.71
	Questions 16 and 18 of Zarit Burden Interview	37	1.08	1.16	0.08	0.59	-
Carer feels less socially isolated	De Jong Gierveld Scale	31	5.71	5.84	0.13	0.72	-
Increased carer well-being / mental and physical health	'Caring Stress' sub-scale of AC-QoL	37	9.19	9.86	0.68	0.08*	0.30
	Short Warwick Edinburgh Mental Well-being Scale	30	22.97	22.97	0.00	1.00	-
Carer has more time to themselves	'Caring Choice' sub-scale of AC-QoL	37	8.14	8.24	0.11	0.83	-

Figure x shows that carers supported by Shared Lives Plus experienced a **statistically significant positive change** against the '**ability to care**' sub-scale, which covers statements like '*I can take care of the needs of the person I am caring for*' and '*I am able to deal with a difficult situation*'. The change of 1.76 could represent, for example, that more than three in four carers changed their response to

two of those statements from ‘never’ to ‘some of the time’. The effect size of 0.71 means this is a medium to large change, broadly speaking.

The ‘caring stress’ sub-scale also showed a positive change, but this was only **statistically significant at the 0.10 level and not at the 0.05 level** (which means we cannot be quite as confident in the finding). The effect size of 0.30 means this is a small change, broadly speaking.

The three remaining outcomes showed negative change, but were not statistically significant and should therefore be viewed as ‘no change’.

## Thirsk

**Figure 10: Thirsk quantitative impact data**

Outcome	Measurement tool	Sample size	Mean at baseline	Mean at follow-up	Mean difference	p-value	Effect size
Reduced likelihood of carer breakdown	‘Ability to Care’ sub-scale of AC-QoL	84	9.86	10.38	0.52	0.08*	0.20
	Questions 16 and 18 of Zarit Burden Interview	84	1.30	1.38	0.08	0.35	-
Carer feels less socially isolated	De Jong Gierveld Scale	75	6.28	5.92	-0.36	0.17	-
Increased carer well-being / mental and physical health	‘Caring Stress’ sub-scale of AC-QoL	81	9.09	9.68	0.59	0.03**	0.26
	Short Warwick Edinburgh Mental Well-being Scale	79	23.68	23.63	-0.05	0.88	-
Carer has more time to themselves	‘Caring Choice’ sub-scale of AC-QoL	82	7.63	7.95	0.32	0.37	-

Figure 10 shows that carers supported by Thirsk experienced a **statistically significant positive change** against the ‘caring stress’ sub-scale, which covers statements like ‘*I feel depressed due to caring*’ and ‘*I feel worn out as a result of caring*’. The change of 0.59 could represent, for example, that approximately half of carers changed their response to one of those statements from ‘a lot of the time’ to ‘some of the time’. The effect size of 0.26 means this is a small change, broadly speaking.

The ‘ability to care’ sub-scale also showed a positive change, but this was only **statistically significant at the 0.10 level and not at the 0.05 level** (which means we cannot be quite as confident in the finding). The effect size of 0.20 means this is a small change, broadly speaking.

The four remaining outcomes showed a mixture of positive and negative change, but none were statistically significant and should therefore be viewed as ‘no change’.

# DISCUSSION

In this section we show how the results give a solid indication that a range of social action services can have a positive impact on carers, particularly on their levels of stress. Commissioners and policymakers should continue to support organisations to refine their social action services and scale their impact.

## INTERPRETING THE RESULTS

This evaluation aimed to answer four research questions, which are answered in turn below (questions two and three are combined into one). These answers take into account what the quantitative and qualitative data says, and how robust that data is. Broadly speaking, the quantitative data tells us what the impact is or might be, and the qualitative data tells us how or why that is the case. Each answer begins with a quick summary, before going into more detail. Outcomes and qualitative themes are bolded throughout. For ease of reference, we simply refer to grantees' organisational name when talking about the specific evaluated interventions.

To what extent have the seven individual interventions achieved the four core outcomes?

### Quick answer:

**Westbank** had a positive impact on well-being (proxied by caring stress) and social isolation, generally slowing or reversing a decline in these outcomes, rather than producing a large increase. We can very confidently identify what impact the service had, due to Westbank's randomised control design.

**Other grantees** did not have a randomised control design; therefore, we cannot be as confident in attributing any change in outcome to the interventions themselves. Still, their results do give an indication of what their impact might be, particularly when supported by qualitative data, and show that every grantee saw a positive change in at least one outcome.

**Parkinson's UK**, showed similar results to Westbank, the other peer support service: a reduction in social isolation, and an improvement in well-being. However, the size of the service's impact may have been bigger than Westbank's, and it also measured well-being on two different scales – one specific to caring, and the other more broad.

**Shared Lives Plus** and **Thirsk**, the two respite services, saw a reduction in caring stress and in the likelihood of breakdown (when measured by the more practically-focused of the two scales). They did not see a reduction in social isolation, and may not have seen an improvement in the carer having time to themselves (potentially due to the carers using their respite to rest or carry out other responsibilities).

**Age UK** and **British Red Cross**, the two practical support services, saw a reduction in likelihood of breakdown (measured by the more practically-focused of the two scales), and an improvement in well-being (measured in its broader sense), respectively.

**Carers Trust Cambridgeshire**, the only grantee focused on identifying and signposting carers, saw a reduction in caring stress. Qualitative data suggests that these carers felt particularly well-informed, with good access to a range of well-integrated services.

## Peer support: Westbank

This evaluation has produced its most robust findings for Westbank, due to its randomised controlled design. For Westbank, we can attribute any change in outcome to the intervention with a very good level of confidence, which we cannot do confidently for any other grantee.

**Quantitative findings:** Westbank's Theory of Change identified reduced **social isolation** and improved **well-being** as its two key outcomes (as well as identifying reduced likelihood of carer breakdown as its ultimate goal, as was the case for all seven grantees and the fund as a whole). Results from Westbank's RCT show that its peer support service had a definitively positive effect on both of these outcomes, though it should be noted that both effects are quite small in size.

It is also important to note that for both of these outcomes, scores in the control group worsen; for instance, the carers who did not receive the intervention felt more isolated and more stressed over time. This gives strong evidence for our theory that outcomes might worsen over time without support, and that for interventions to have a positive effect they do not necessarily need to improve outcomes: simply preventing or slowing their decline might represent a positive impact. Indeed, Westbank's data shows that carers who received the intervention did in fact feel more stressed, but this increase in stress was not as large as for those in the control group. So we can say that the intervention reduced isolation where it would otherwise have increased, but could only slow down or halt the rate of worsening carer stress.

There is one main caveat to these findings: attrition. Approximately half of the carers (spread equally between the intervention and control groups) who took part in the RCT did not complete the follow-up survey and therefore could not be included in the analysis. For this reason, we cannot be sure that these findings are representative of all carers who received the intervention; for example, they could be positively skewed, due to carers who had a positive experience being more likely to complete the survey than those who had a negative one. However, on the other hand, the results are almost certainly negatively skewed due to another factor; almost half of the carers in the intervention group did not actually receive the intervention,<sup>15</sup> but were still included in the analysis.<sup>16</sup> On balance, it is hard to say whether the results are therefore positively or negatively skewed, but these two factors are likely to have cancelled each other out to some degree.

**Qualitative findings:** The positive quantitative findings on social isolation and caring stress are also supported and enhanced by the qualitative data. In terms of reducing social isolation, **empathy** was a common theme to emerge from the interviews; each carer understood what the other was going through, and was able to provide emotional support that was reciprocated, therefore reducing feelings of guilt associated with being a burden on someone. For one of the two interviewees who received the one-on-one buddying service, the relationship moved beyond reciprocal support, developing into a real **friendship** where they contacted each other three or four times a week and socialised regularly.

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<sup>15</sup> The high number of carers not taking up the service is due to Westbank having to recruit via mail for the purposes of the RCT, rather than by phone as they normally would. It transpired that many carers had signed up to the RCT and filled in the baseline survey to be helpful, without necessarily having the intention or desire to actually receive the service. Differential attrition was however not an issue as attrition levels in each of the groups only differed by 4 per cent – see Appendix H for full details.

<sup>16</sup> As per the so called 'intention to treat' approach - see 'analysis' in the methodology section for more details.

*'I found out she was ill and so I called her up and said "I'm going shopping, do you need anything?" She said "no" but she said that nearly made her cry because she thought someone was thinking about her.'*

The quantitative process data gives a more representative indication of the extent to which friendships such as this can be called common. When asked, as part of the survey, if they felt they had made friends with other carers, responses were quite evenly spread across all options – from 'strongly disagree' to 'strongly agree' (though leaning slightly more towards the latter). Making friends is clearly far from a given. Interestingly, another common theme to emerge from the qualitative data expresses a characteristic almost opposite to those usually associated with friendship: **acquaintanceship**. Some carers felt able to open up with their peers because they were not a part of one other's lives outside the sessions, and therefore did not have to worry about feeling judged or running the risk of comments making their way back to the person they were caring for. This outlet seemed to reduce the stress of caring. Two other themes seemed likely to do the same: firstly, that carers were able to share genuinely useful **practical advice** and information; and secondly, that meeting other carers sometimes brought perspective, allowing them to see the positives of their own situation in **comparison to others** who were worse off.

**Carer breakdown:** While the intervention had a positive effect on isolation and stress, results show that it did not have an impact on the **likelihood of carer breakdown**. We used two different tools to measure this. The first, the 'ability to care' sub-scale of the AC-QoL survey, was more focused on the carers' ability to care for their loved one on a practical level (for example, *'I can take care of the needs of the person I am caring for'*). The second was a bespoke sub-scale of the 'Zarit Burden Interview' tool, created by extracting just two of the tool's 22 questions. This sub-scale was more focused on carers' ability to cope on a psychological level (for example, *'do you wish you could leave the care of your relative to someone else?'*).

Why did the intervention affect isolation and stress, but not the likelihood of breaking down (as the fund's Theory of Change predicted it would)? Perhaps because the path to breakdown is likely to be a lengthy one, taking longer than the six months during which data was collected. This is supported by the comparison group data, which shows that while carers who did not receive the intervention felt more stressed and isolated over six months, they did not feel more likely to break down. It may be, then, that the intervention was able to halt carers' deteriorating feelings of stress and isolation that, if left unchecked for longer than six months, would have eventually led to an increased risk of breaking down. This certainly seems a plausible theory that would benefit from further research.

Another contributing factor could be that the Zarit Burden sub-scale is simply not as sensitive to change as the other sub-scales, due to it including only two questions. Certainly we cannot be as confident in its validity (i.e. that it measures what it intends to measure), as the scale was only designed to be used in full (as opposed to the AC-QoL which was designed to have the option of using sub-scales). Similarly, the question *'do you wish you could leave the care of your relative to someone else?'* is a very personal and sensitive question, which carers may have felt guilty answering 'yes' to. The fact that none of the seven grantees saw a statistically significant change against this sub-scale may indicate that these explanations are valid.

## Remaining grantees

The rest of the answer to this first research question covers the remaining grantees. All six of these grantees had the same evaluation design and therefore shared similar limitations to their quantitative data, so we will discuss these limitations and their implications together at the end of

this sub-section. Rather than repeating the same limitations each time we discuss the grantees' results individually below. Overall, based on these limitations, the quantitative results discussed below could be underestimating or overestimating the interventions' impact. We recommend viewing them only as an indication of each grantee's potential impact. We would need further research to confirm or deny this with more accuracy and confidence.

### Peer support: Parkinson's UK

The results for Parkinson's UK were very similar to Westbank, the other peer support intervention, as its Theory of Change would predict. They show a statistically significant reduction in **social isolation** and improvement in **well-being** (with larger effect sizes than Westbank), but no change in **likelihood of carer breakdown**. However, whereas Westbank only used the 'carer stress' sub-scale to measure well-being, Parkinson's UK also used the Warwick Edinburgh scale (a broader measure of well-being) and found a statistically significant positive change in both. This evidence gives an indication that these carers' caring responsibilities are a large enough part of their life that a reduction in stress that was solely related to their caring also had an impact on their well-being as a whole. Interestingly, Parkinson's UK was the only grantee to also see a change in both measures of well-being – the other three to use both only saw a change in one or the other. A full explanation of this is outside the scope of this research, due to the aforementioned limitations of the quantitative data and not all grantees having qualitative data; but this is a solid indication that Parkinson's UK is having a meaningful impact on the carers it supports.

### Respite: Shared Lives Plus and Thirsk

The portfolio's two respite services, Shared Lives Plus and Thirsk, share almost identical findings. Like the two peer support interventions they both saw an improvement in **well-being** (proxied by a reduction in caring stress). This is supported by the qualitative data, where carers commonly expressed how the service gave them an immediate sense of **relief**, the chance to **rest** and return to **normality**, which in turn helped to **improve their relationships**:

*'Just to have that break, the relief is amazing, honestly it is. It's like someone saying that you've got a massive meeting tomorrow, or a massive presentation to do, that you're really stressed out about and someone says that it's cancelled. It's like ahh [sigh of relief], that's what it feels like honestly. Especially when it's someone that you trust.'*

*'It's a chance to be a normal every day family without any interruptions. It's broken, interrupted when [son] is there – [daughter] can show off without [son] taking the limelight.'*

However, unlike Westbank and Parkinson's UK, the two respite services did not see a reduction in **social isolation**, despite this belonging to both their Theories of Change. This could be explained by the theory, supported by the Westbank comparison group, that without support, carers' social isolation will actually worsen over time. Taking that into account, Shared Lives Plus and Thirsk carers' statistically *insignificant* small increase and sizable decrease, respectively, in social isolation could actually represent a positive impact, for Thirsk particularly. There could be some truth to this, but we cannot be sure – it is risky to use Westbank's comparison group as a comparison for other grantees, as it may not be representative of those other grantees' carers.

Furthermore, the qualitative data may shed some light on why the respite services may in fact not be having an impact on isolation. As highlighted above, one common theme from the Shared Lives Plus interviews was **rest**; rather than using their respite time to socialise with different people, some carers are using that time to relax or catch up on sleep, which would understandably reduce stress,

but would not have any effect on social isolation. Similarly, some carers interviewed for Thirsk also chose (or were only able) to spend that time alone; for example, by going for a walk or getting a bus into town to have a coffee:

*‘When I’m walking by the river, I’m singing to myself. It’s wonderful just to have a break.’*

However, quantitative process data for Thirsk does show that seeing family and friends was the single most common activity for the carers to do during their respite (49% reported doing so), which supports the argument that the lack of a comparison group is underestimating the service’s impact on social isolation.

Another outcome that did not change for Shared Lives Plus and Thirsk was **carers having more time to themselves**. This is particularly surprising, given that by definition respite aims to give the carers more time to themselves, and good qualitative evidence shows this happening. We propose two competing explanations for this specific finding:

- The carers *do* have more time to themselves, but the ‘carer choice’ sub-scale measures more than simply having free time (e.g. statements like *‘I feel I have less choice about my future due to caring’*).
- Many carers do *not* have more free time to themselves because, as the qualitative data shows, some use their time to sleep, look after their family, to do other things or to meet other commitments that do not constitute free time to themselves.

Both of these explanations are plausible, and would benefit from further research.

Finally, unlike the peer support services, both Shared Lives Plus and Thirsk did see a reduction in the **likelihood of carer breakdown**, as measured by the more practical ‘ability to care’ sub-scale (but not the more psychological ‘zarit burden’ sub-scale). Why might the respite services be more likely to reduce the risk of breakdown, when all four services seemed to positively affect level of stress / well-being? The answer may lie in the *size* of the change in carer stress. As previously discussed, Westbank’s carers actually became slightly more stressed over time, but less stressed than they would have been without any support (as measured by the comparison group). Thirsk and Shared Lives Plus’ carers, on the other hand, saw a sizable reduction in stress levels. It could therefore be that reduced stress levels lead to a reduced likelihood of breaking down, whereas slowing the rate of worsening stress simply stalls the likelihood of breaking down. This also suggests that Shared Lives Plus and Thirsk’s reduction of stress might be particularly impressive, using Westbank’s comparison group as a proxy for their own (which, however, requires strong caveats).

### **Practical support: Age UK and British Red Cross**

The results of Age UK and British Red Cross, the two grantees offering practical support interventions, bore less resemblance to each other than the peer support and respite services did. This could be, in part, because the services are far less alike than those within other intervention types, particularly as British Red Cross provides a service that goes beyond pure practical support.

Like the respite services, Age UK saw a reduction in **likelihood of breakdown** (when proxied by the ‘ability to care’ sub-scale), despite not seeing a change in any other outcome. It could be that, while there was no change in stress relating to caring, there was a reduction in stress or anxiety relating to things outside of caring, as Age UK’s Theory of Change predicts (e.g. chores around the home, accessing other services), and that this reduced the likelihood of breakdown. Unfortunately, we could not explore this further through interviews, as there were none. This would have been

particularly interesting given that Age UK's change in the 'ability to care' sub-scale was bigger than any other change across the portfolio (though the size of the change could be driven by Age UK's very low sample size, which increases the risk of the data being affected by chance).

Similarly, British Red Cross saw an improvement in **well-being**, when measured by the Warwick Edinburgh scale, despite not seeing a change in any other outcome. Again, this change may have been driven by other unmeasured outcomes; as the only intervention targeting young people, British Red Cross was perhaps the most focused on personal development outside of caring, and so may have affected broader well-being by, for example, increasing employment aspiration and opportunities.

#### **Carer identification: Carers Trust Cambridgeshire**

Carers Trust Cambridgeshire is somewhat different to the rest of the portfolio, as it did not deliver a direct service to carers but rather aimed, through its 'Caring Communities' approach, to: a) increase and bring forward the initial 'identification' of carers by other parties; and b) signpost those carers to other services effectively (as well as delivering a small number of services in-house). Its quantitative results, therefore, which show an improvement in **well-being** (proxied by carer-related stress), may relate to part or all of that journey: identification, signposting to services, and/or receiving those services. The qualitative data from the interviews with carers suggest some key themes in unpacking that journey.

The carers had **access to a wide range of services**. Through a combination of local council, voluntary sector organisations, and health and social care services, the four interviewed carers accessed: respite (breaks, day centres and sitting services), buddy schemes, peer support groups, social activities such as dancing and singing, financial support, financial advice, emergency planning and information booklets.

The carers also felt that the various services they used were **well-integrated**. They all had someone that they could turn to as a first point of call - whether a CTC member of staff, health and social care professional or volunteer buddy – and they were confident that these individuals had a good knowledge of the health and social care eco-system and could therefore refer them to the appropriate service. For example, when one of the carers was hospitalised, the hospital staff were able to notify other appropriate services that the carer had a relationship with.

The four interviewed carers also seemed to feel much better **informed** than other interviewed carers. For example, they all had access to the carers magazine which includes a comprehensive list of numbers to call if any support is needed, and to a range of voluntary and health and social care organisations that kept them well-informed. Carers interviewed for other grantees strongly felt that information on carer support was difficult to access, which gives an indication that the Caring Communities is working effectively. This is supported by the quantitative process data, which shows that surveyed carers thought CTC's needs assessment was helpful in identifying relevant information and support (the relevant question had a score of 2.34 out of 3).

#### **Limitations across all six grantees**

As previously mentioned, each of these grantees faced similar limitations to their quantitative methodology, which on balance mean that their quantitative results could be underestimating or overestimating their impact:

- **Attrition:** Most grantees suffered from attrition to some degree (31% on average), whereby – for example – carers complete a baseline survey but not the follow-up, meaning that their

data cannot be included in the analysis. The more carers left out of the analysis, the less representative the results are; they may, for example, be positively skewed, due to the surveys being less likely to be filled out by carers who had a less positive experience of the intervention.<sup>17</sup>

- **Sample size:** As many of the grantees have quite low sample sizes, it is harder to detect statistically significant findings (i.e. it is harder to confidently rule out that an observed change in outcome is caused purely by chance). To some extent, attrition and low sample sizes may counteract each other, with the former potentially increasing the risk that we overestimate positive impact, and the latter potentially increasing the risk that we underestimate impact.
- **No comparison group:** The largest limitation is the lack of comparison group, which means that, even when we can confidently rule out a change in outcome being purely down to chance (i.e. when it is statistically significant), we cannot rule out the possibility that this change has been caused by some other *systematic* factor (e.g. carers attending other services available in that geographical area). It also means that we cannot be sure whether a lack of outcome change means the intervention has had no effect, or that it has had the positive effect of halting deterioration in those outcomes (as the Westbank comparison group shows is the case for those carers).

On balance, the quantitative results discussed above could therefore be underestimating or overestimating the interventions' impact. We recommend viewing them only as an indication of each grantee's potential impact. We would need to carry out further research to confirm or deny this with more accuracy and confidence.

**To what extent have carer characteristics and service implementation conditions acted as facilitators or barriers to the interventions' desired impacts? How might the interventions be refined or improved based on the new evidence?**

#### Quick answer

Carers' level of need seemed to be the biggest external influence on the services' impact, across all grantees. The way each service was delivered could also influence the size of the impact – specifically the length, frequency, flexibility and accessibility of the sessions, and how well-matched the carers, the people being cared for and the volunteers were. The 'recommendations' sub-section later gives suggestions on refining interventions based on this evidence.

The interviews brought to light a number of themes that might have helped or hindered the interventions' impact on the carers they support. As the number of interviews per grantee was small (two to four), we cannot draw firm conclusions as to how much these themes affected the results across all carers, though in some cases the quantitative process data gives us a stronger indication of how representative the qualitative findings might be.

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<sup>17</sup> See Appendix H for full details of each grantee's response rate and sample size

**Level of need:** By far the most consistent theme across grantees and carers was that higher the carer's level of need, the greater the impact of the intervention. The level of need seemed to be driven by at least three different things:

- **Difficulty of caring situation:** For example, one carer looked after her son who was sometimes violent towards her; whereas other carers looked after their partners who were physically unwell, but unaffected mentally and not physically violent.
- **Mobility:** While some carers were completely unable to leave their home, others were able to if they brought the person they were caring for with them, while others still were able to leave home by themselves.
- **Support network:** While some carers had friends or family nearby who were able to provide practical and emotional support, others had no one nearby who could help them.

The carers' level of need had a huge impact on how they viewed their service, leading to statements about the same intervention as diverse as:

*'It's a lifeline really.'*

*'It wouldn't affect me if the service didn't exist, but it's just a nice bonus ... it's more for the wife, she gets a social life.'*

**Self-assessment of need:** While some carers accessing services do not necessarily have a high level of need, there is also evidence that some carers who do have a high level of need do not access services that they could be or should be receiving. Some carers reported thinking that someone else probably needed more support than they did, and so they felt hesitant about asking for help themselves.

*'I should have been going out and asking for help. I thought other people are more needy.'*

This evidence supports the importance of services like Carers Trust Cambridgeshire's, which aim to make carers more aware of the support that they are entitled to.

**Relationships:** The quality of relationships was another consistent theme. For the respite services, the important relationship was the one between the volunteer and the person being cared for. Across both Shared Lives Plus and Thirsk, all interviewees felt that the person they cared for was well matched with and had a good relationship with their volunteer, which brought peace of mind and allowed them to rest and relax during their respite. For Westbank's peer support service, the important relationship was the one between the carers. It was mentioned earlier that one carer built a strong friendship with their buddy, which reduced feelings of isolation. On the other hand, another carer said that they did not particularly gel with the other carers in their peer support group, which meant they may not have experienced that same reduction in isolation. This may not be an issue if the focus of the peer support groups is to reduce the stress of caring through somewhat detached emotional and practical support, rather than friendship. However, the quantitative process data shows that carers supported by Westbank gave a mixed response to a question about how well-matched they felt to their peers (2.19 out of 4); whether friendship is important or not, being well-matched seems undoubtedly important, so this seems like a key area for potential improvement.

**Duration, frequency and flexibility of respite:** For the respite services, the key themes were the duration, frequency and flexibility of the visits. These varied quite significantly across carers. At times, the evidence shows that this was to suit carers' needs; whereas at other times it implies this was driven by alternative factors (e.g. availability of volunteers, which partner organisation was

delivering the respite etc). The quantitative process data shows that Shared Lives Plus provided an average of 51.8 hours of respite per month (for example, one three-night stay), while Thirsk provided an average of 3.9 hours per month (for example, two two-hour stays). Some Thirsk carers may have preferred more time, with one saying that she would like to visit a friend in another town but does not have the time. Shared Lives Plus carers on the other hand seemed to be happy with the duration and frequency of support, though they sometimes found it difficult to schedule their visits in advance as requested, as it reduced their flexibility. Improvements in outcome were greater for Shared Lives Plus than for Thirsk, which may be driven by the higher length of breaks.

**Accessibility, frequency and flexibility of peer support:** Flexibility was less of an issue for Westbank's peer support service: the one-to-one buddies appreciated the flexibility to meet whenever and wherever they wanted, and the regularity of the group sessions seemed not to be an issue for the carers interviewed. The frequency of these sessions did not come up as an issue either, as they varied from weekly to monthly depending on the geographical location and the carers' preferences. However, accessibility was sometimes a significant challenge – both in terms of sessions based in rural locations being difficult to travel to, and some carers struggling to attend because they were unable to leave the person they care for.

**Overall:** Overall, the qualitative data makes it clear that the same service can have a very different impact on different carers. Though we were only able to interview four carers at most for each grantee, these interviews gave a solid indication that if each service is delivered in the right way to the right person, it is likely to have a very positive impact. Equally, however, if it is delivered in the wrong way to the wrong person, it is unlikely to have much impact at all.

## What can this tell us about the effectiveness of social action approaches to support carers?

### Quick answer

Social action can, and likely regularly does, have a positive impact on carers, and can have a greater impact with the right combination of services, the right targeting and the right delivery. It should primarily be seen as a preventative approach for carers with a medium level of need, and should not be a substitute for more intensive services for those with the most acute and high level of need.

It is difficult, and almost certainly inadvisable, to try and answer this question with definitive statements. The methods used for this evaluation have their natural limitations, and the evaluation only covers seven interventions (and only one or two of each type), each operating in their own context and with their own limitations as they grow, develop and learn. Further research should be carried out to corroborate or contradict the findings of this evaluation. However, overall this evaluation is robust enough to justify seeing its results as a solid indication of what the effectiveness of social action approaches might be, and how that effectiveness might be increased even further.

The results indicate the following:

**Impact of social action approaches:** Social action can, and likely regularly does, have a positive impact on carers' lives. Depending on a carer's level of need, many are likely to be on a journey of increasing stress and social isolation, which might eventually lead to breakdown – to being hospitalised themselves, or having the person they look after go into residential care. Sometimes social action might only be able to halt or slow deteriorating feelings of stress and isolation, which

might indefinitely prevent the carer from eventually breaking down. This would still be a positive outcome. In even more positive cases, social action might be able to reverse this decline, improving carers' well-being and actually pushing them further away from breaking point, perhaps permanently.

It is likely that combining multiple social action approaches would be the most effective way of supporting carers – as the fund's Theory of Change predicts. Qualitative evidence for Carers Trust Cambridgeshire suggests that identifying carers with the support of volunteers can lead to them accessing a particularly wide range of services, and feeling particularly well informed. Quantitative evidence across the grantees also suggests that different types of service are then likely to be complementary - that peer support may be particularly effective at reducing social isolation (albeit also helping with stress), whereas respite may be particularly effective at reducing stress and the likelihood of eventual breakdown. The picture is less clear for practical support, though there is some limited evidence that it too could improve well-being and reduce the likelihood of breakdown, and that this could be driven by different pathways to the other intervention types and so be cumulative rather than duplicative.

**Improving social action approaches:** The research also indicates that all of these social action approaches can continue to refine and enhance their support, in order to increase their impact further. Respite services could increase the frequency, length and flexibility of their breaks; peer support services could make their sessions more accessible, in part through partnering with respite services to look after the person being cared for; and both types of service could take steps to ensure that the carers, volunteers and people being cared for are as well-matched as possible.

**Targeting social action:** The final piece of the puzzle is level of need. If a carer's level of need is very low, with no risk of worsening stress and isolation, social action approaches (or indeed any other approaches) to supporting them may have little meaningful benefit. If the level of need is too high, social action may be insufficient – any negative momentum may be harder to reverse, and may need more acute, intensive intervention. It seems that social action has the chance to be most effective in between those two extremes; where the carer has a medium level of need, which leaves them at risk of worsening stress and social isolation over time, and that may eventually lead to breakdown in the future.

**Limitations of social action:** Having said all of that, it is important to emphasise that social action approaches are not a panacea. No single intervention saw an improvement in all outcomes, and none of the interventions showed carers having more time to themselves (as measured by the 'caring choice' sub-scale) or being less likely to psychologically break down (as measured by the Zarit Burden sub-scale). While both of these tools had potential flaws, this does not mean we can dismiss their findings out of hand. Furthermore, the magnitude of the positive changes are generally not large – effect sizes, though not definitive, do indicate that for all but two outcomes the changes were small to medium. Indeed, these services are unlikely to revolutionise a carer's daily life, which is understandable given that caring can be 24/7, while the interventions are short and sometimes infrequent. For the carers who are most in need and closest to breaking down, social action is very unlikely to be sufficient; these carers will likely need more intensive, professional support, at the very least in the short term.

**Overall:** Still, overall this research does give a solid indication that social action has the potential to be an effective approach to supporting carers, primarily as a preventative measure for carers with a medium level of need.

# RECOMMENDATIONS

The findings of this evaluation lead to some recommendations for commissioners and policymakers, and to organisations delivering social action services. Some of these recommendations should be considered in the context of the previously discussed limitations of the methodology. The strengths and limitations of this evaluation also naturally lead to some recommendations for further research.

Overall, we have ten main recommendations:

## **For commissioners and policymakers**

1. Invest in social action services as a preventative approach, identifying carers early and focusing support on those with a medium level of need - provided that those services can convincingly show their commitment to quality, learning and impact. Where possible, invest in different types of services in the same geographical region, to maximise collective impact.
2. At the same time, invest heavily in evaluation, to continue to learn what works and how it can work even better (see recommendations for research below).
3. Continue to invest in more intensive, acute services for carers with the highest level of need and who are closest to breaking down – these should not be replaced by social action.

## **For delivery organisations**

4. Take the learning from this research, where relevant – focus as much as you can on effective matching, and ensure that your services are sufficiently accessible, lengthy, frequent and flexible to meet your carers' needs.
5. Try to focus your services on carers who will benefit the most (i.e. those with a medium level of need), and ensure there are mechanisms in place to refer more acute cases to more appropriate, intensive services.
6. Commit to further learning – delivery can always be improved, and there is an increasing evidence base from which to learn how. Push funders to invest in evaluation where you can, search for relevant research online, get feedback from your carers, brainstorm ideas for improvement among staff and volunteers, and speak to your peers to learn from each other.

## **For research**

7. Where possible, use mixed methods – quantitative data to produce a representative view of what the services' impact is, and qualitative data to produce an in-depth view of how and why the impact is what it is.
8. Gradually increase robustness - this research has given an indication of social action's potential impact, so a useful next step would be to try and replicate the results with even more robust designs, including comparison groups.
9. On the other hand, make sure ambitions for robustness are realistic, and aligned with services' context and stage of development. It is likely not a good use of resources to try to conduct an RCT with a sample size of 30 carers, with no clear referral route through which to randomise, or with a brand new service that is still going through teething problems that will substantially limit its impact.
10. Carry out more literature reviews, to collate research like this and distil the collective findings into clear recommendations. Make the research and recommendations digestible, and take proactive steps to share it with the right commissioners, policymakers and delivery organisations.

# CONCLUSION

Overall, this evaluation gives a solid indication that social action is a viable approach to effectively supporting carers, primarily through early identification and intervention in order to prevent deteriorating stress and social isolation for carers with a medium level of need.

All seven grantees saw some positive change in outcome among the carers they support, and although for all but Westbank we cannot confidently attribute that change to the interventions themselves, the qualitative data does support the quantitative findings where it is available.

We recommend that commissioners and policymakers recognise the potential of social action approaches and invest in appropriate support and evaluation accordingly, and that delivery organisations commit to continual learning on how to improve their services and maximise their impact.

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