



The Carers Social Action Support Fund

Final evaluation report: Appendices

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TSIP

The Social Innovation Partnership

APPENDICES

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Appendix A: Referral routes and volunteer numbers

Figure 11 below gives an outline of the routes through which carers are referred to the different grantees' services, and the number of volunteers recruited during the Fund timeframe (against the numbers projected at the outset of the Fund).

Figure 11: Referral routes and volunteer numbers

| Intervention type | Grantee | Referral routes | Projected number of volunteers | Actual number of volunteers |
|-------------------|-------------------|---|--------------------------------|-----------------------------|
| Peer support | Westbank | Self-referral through completion of initial questionnaire to join RCT | 382 | 144 |
| | Parkinson's UK | Mostly self-referrals, Parkinson's UK staff, specialist nurses, local charities | 5 | 2 |
| Respite | Thirsk | Self-referrals, health professionals, Health & Adult Services, family friends, other voluntary services, social workers | 215 | 248 |
| | Shared Lives Plus | Self-referral of the cared-for person or their social carer | 108 | 68 |
| Practical support | Age UK | Partner organisations and self-referral | 50 | 54 |
| | British Red Cross | Previous young carers who now have reached 18, self-referral, local colleges and health and voluntary services | 20 | 20 |
| Carer | Carers Trust | Partner organisations, health professionals and self-referrals | 345 | 713 |

| Intervention type | Grantee | Referral routes | Projected number of volunteers | Actual number of volunteers |
|-------------------|----------------|-----------------|--------------------------------|-----------------------------|
| identification | Cambridgeshire | | | |

Appendix B: Full literature review

We conducted a brief literature review on carer support interventions, to try and set the results of this evaluation into the context of the existing evidence base. A full literature review was outside the scope of this work, and so the following should not be seen as being representative of the existing literature on the subject. Full references are included at the end of this review.

Evidence-base for grantee interventions

The evidence on the effectiveness of they types of carer interventions supported by this Fund is largely inconclusive due to lack of high-quality evidence.

Maayan et al 2014 is a review of 4 RCTs, saying that **respite** care had no statistically significant results on any variables, but the quality of the evidence is poor, so the result needs to be interpreted with caution. Victor 2009 reviewed 25 studies on respite services (p. 98). Most do not use a robust research design, so they are classed as weak in terms of confidently attributing carer outcomes to the intervention. The studies indicate that respite services benefit carers in terms of having more time to themselves and feeling less socially isolated. The evidence for benefits to emotional wellbeing is mixed, indicating that other factors (such as the wellbeing of the cared-for) influence this outcome considerably. Similarly, the findings on benefits to the carer's ability to continue caring is mixed, suggesting that "breaks can be critical to maintaining caring situations", but "may also be the first step towards permanent use of residential care" (p. 104). In a few cases, expectations of a respite were not met because "the time spent was not enjoyable, involved other commitments or the carer was worrying about their situation" (p. 101).

Thompson et al 2007 reviewed 44 RCTs and found that **group-based supportive interventions** had a statistically significant impact on psychological morbidity, but not any other variables. Victor 2009 reviewed eight studies focusing on carer support groups. The studies indicate that the support groups were beneficial for the carer's emotional wellbeing. While none of these use a robust research design, meaning that the findings are indicative at best, the in-depth qualitative data offers valuable insights into potential mechanisms to benefit carers (p. 59). Charlesworth et al 2008 evaluated the effectiveness of a **befriending scheme**, but merely found a small improvement on depression (not statistically significant). The study may however underestimate the scheme's effectiveness, since take-up of the service has been very low.

Victor 2009 also reviewed five studies focusing on **information services**, designed to providing information specifically to enable carers to access services (p. 28). The studies focused mostly on knowledge-related outcomes, however, which have not been measured in this evaluation. Also, as with the other studies, the quality of the evidence is weak, so the studies' findings are inconclusive.

Wider evidence base for all types of carer interventions

The existing evidence-base on a considerable variety of carer support interventions is still relatively early stage and largely inconclusive in terms of effectiveness. Many studies found few to no statistically significant results, though in most cases this may be due to the relatively poor quality of the available data. There is thus a need for more rigorous research into all types of carer support interventions.

Existing intervention approaches include:

- Education, training and information
- Skills-building interventions
- Family and couple interventions
- Interventions to support carers to access services
- Interventions focused upon emotional and social support
- Employment-related interventions
- Respite-based interventions
- Carer's health interventions
- Cognitive reframing
- Telephone counselling
- Support / liaison workers
- Combination of several approaches

There are some practical evidence-based recommendations emerging from the literature that may be useful to projects similar to the CSASF project:

- **Personalised support:** Support provided to carers will be most effective when it is personalised and tailored to different individuals in different contexts, and self-directed – not prescribed from above (Department of Health, 2010).
- **Combining approaches:** if done well, multi-component interventions tend to offer the best chances of success through combining a variety of different support approaches. (National Collaborating Centre For Mental Health 2007, and Applebaum & Breitbart 2013). These should include the following components (recommended by NICE-SCIE):
 - Individual or group psychoeducation
 - Peer-support groups with other carers, tailored to the needs of individuals depending on the stage of dementia of the person being cared for and other characteristics
 - Support and information by telephone and through the internet
 - Training courses about dementia, services and benefits, and communication and problem solving in the care of people with dementia
 - Involvement of other family members as well as the primary carer in family meetings.
- **Most promising single approach:** One meta-review deemed approaches focusing on education, training and information for carers as 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).

- **Avoid 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 (National Collaborating Centre For Mental Health 2007).

References

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Appendix C: Fund Theory of Change

As part of setting up the CSASF, Cabinet Office created a draft Fund Theory of Change. The purpose of the Theory of Change was to clarify and communicate what the Fund was trying to achieve, and what kinds of interventions it expected to target in order to achieve them. Cabinet Office and TSIP made some changes to the Theory of Change once the chosen interventions had been selected, and the final version was used to drive the evaluation. The changes were minimal, and focused on a) more accurately reflecting the different interventions being funded, particularly Carers Trust Cambridgeshire's identification service; b) adding 'reduction of stress' as an outcome, to clarify the specific impact of practical support approaches;; c) adding some assumptions; and d) making some aesthetic and stylistic changes. The original and final versions of the Fund Theory of Change are below:

Figure 12: Original Fund Theory of Change

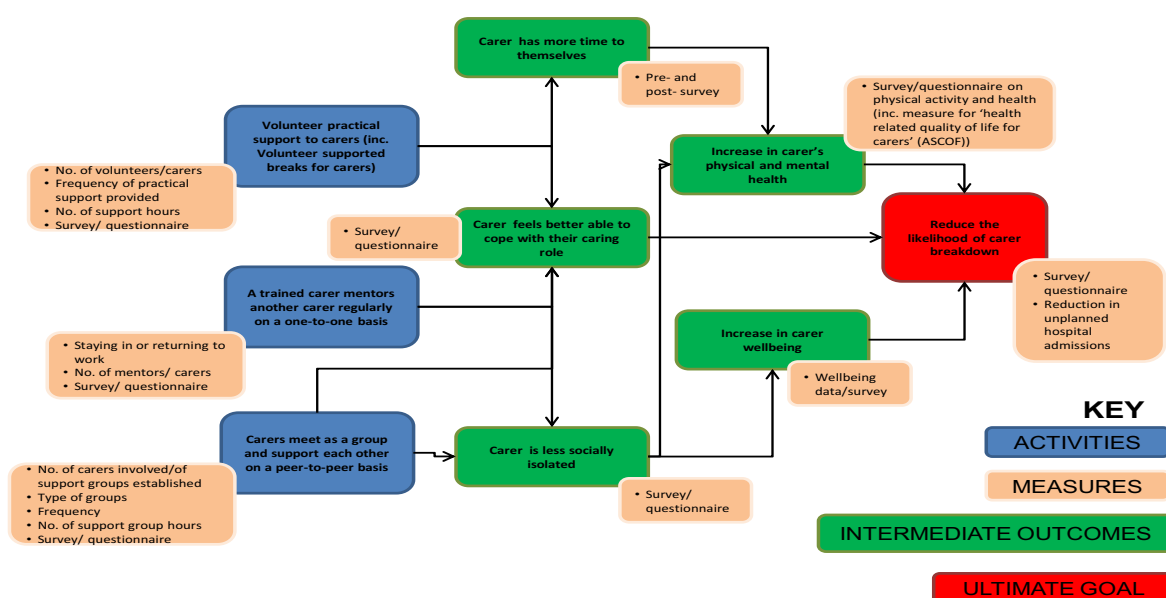
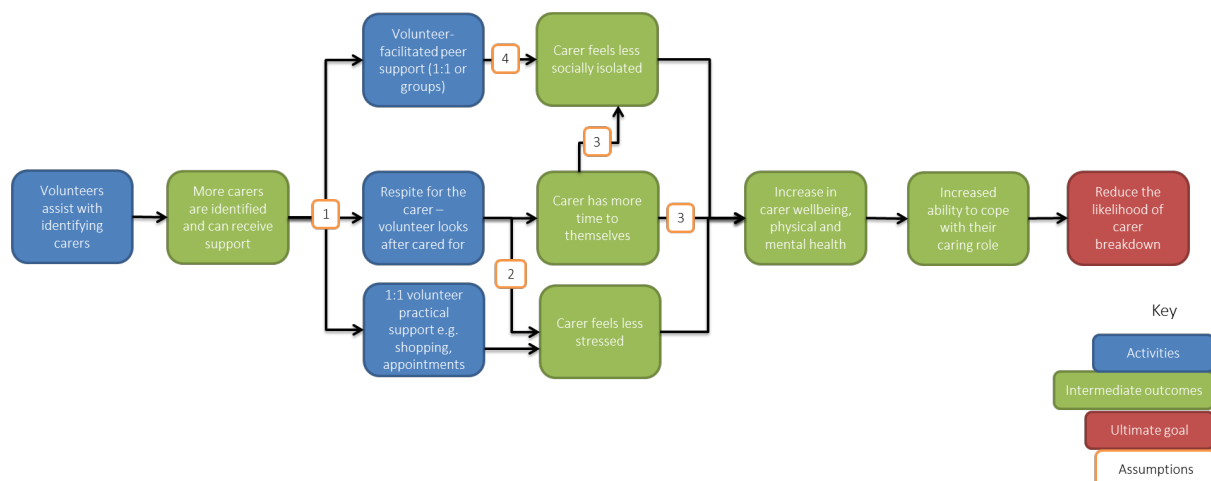


Figure 13: Final Fund Theory of Change



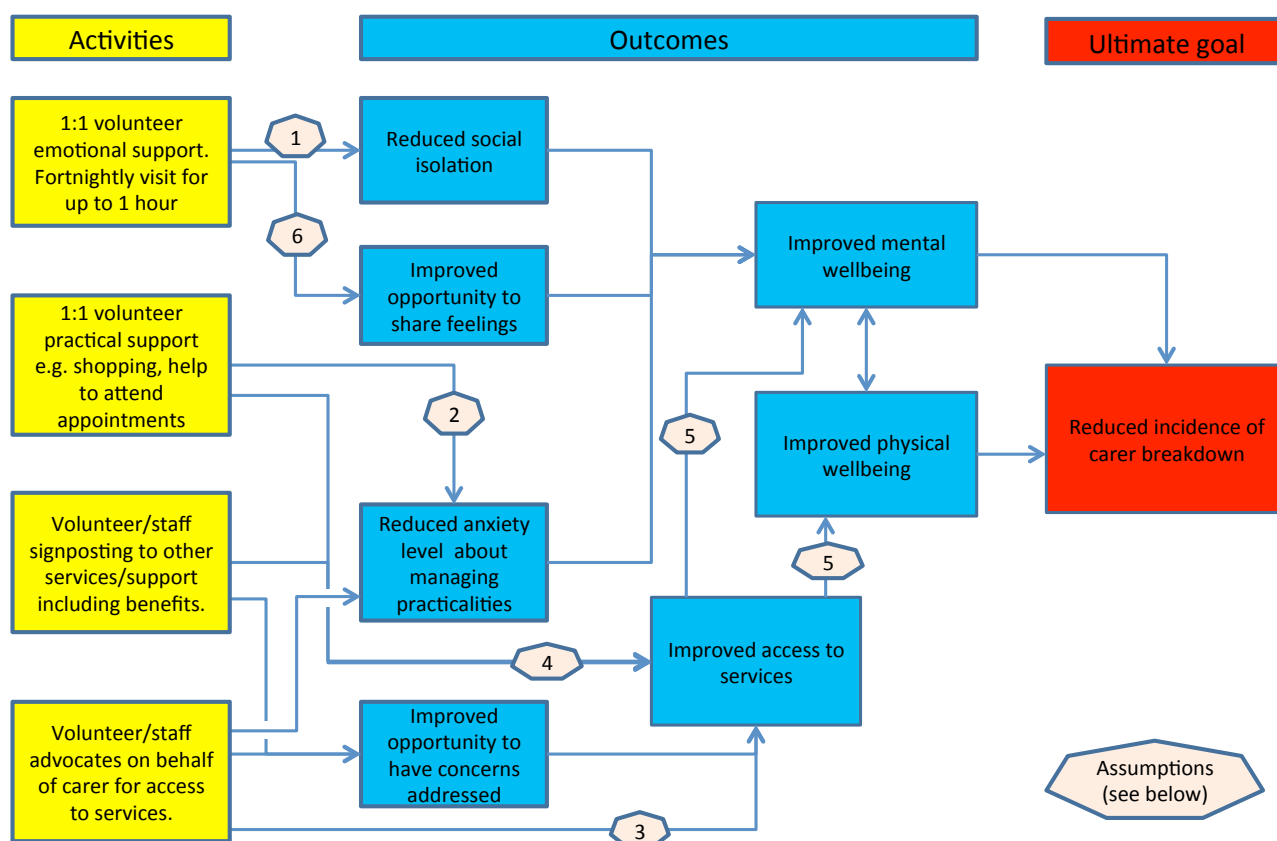
Assumptions:

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 – e.g. visiting friends/family, engaging in leisure activities or resting
4. Carers are willing to engage with other carers (despite being strangers), including sharing feelings and concerns

Appendix D: Grantee Theories of Change

Every grantee developed a Theory of Change for their own individual service, with support from TSIP and Cabinet Office. The purpose of these was to help select the right outcomes for each grantee's impact evaluation, and to identify some questions on service delivery as part of each grantee's light-touch process evaluation. Each Theory of Change is presented in turn below.

Figure 14: Age UK Theory of Change

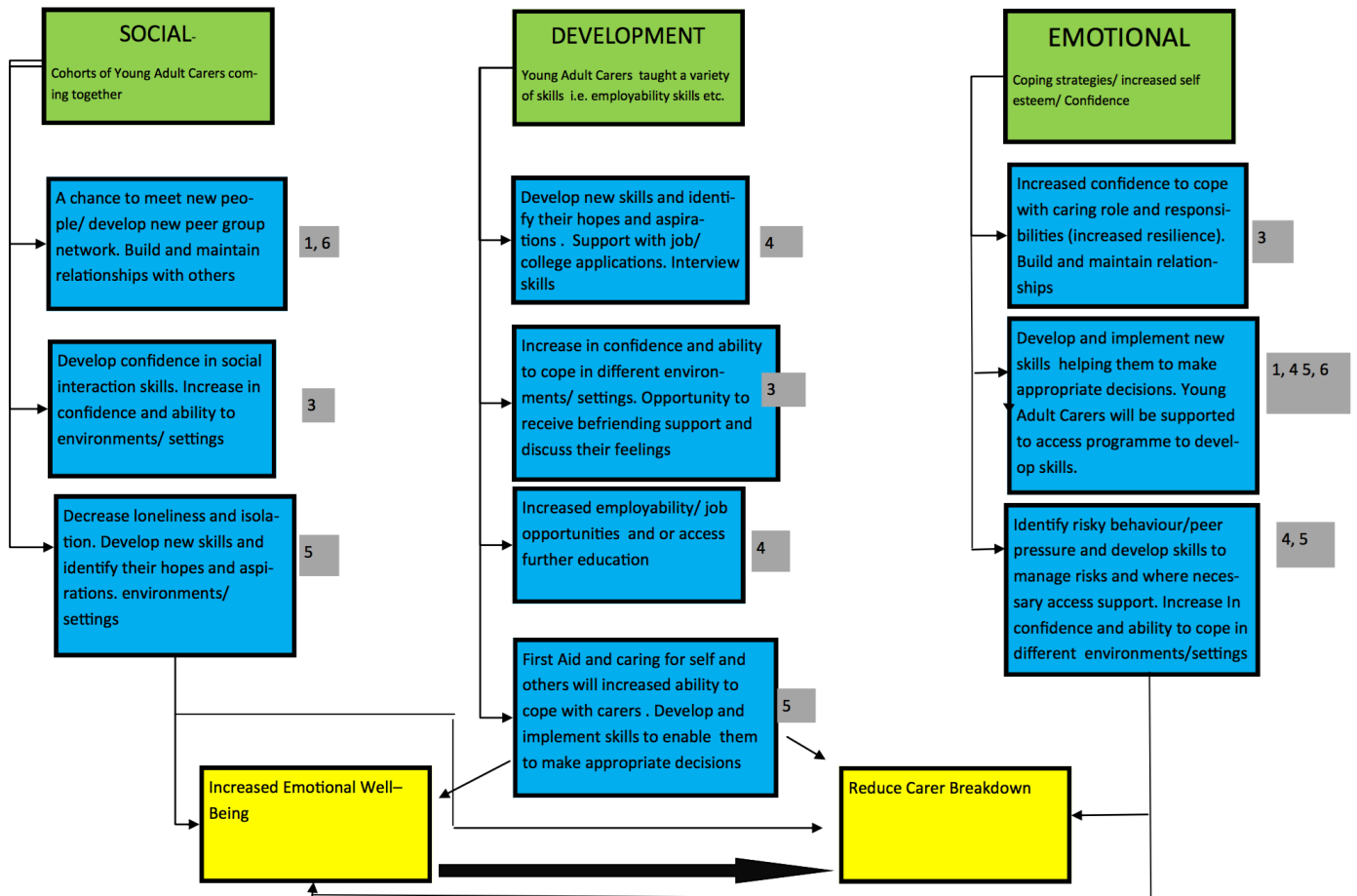


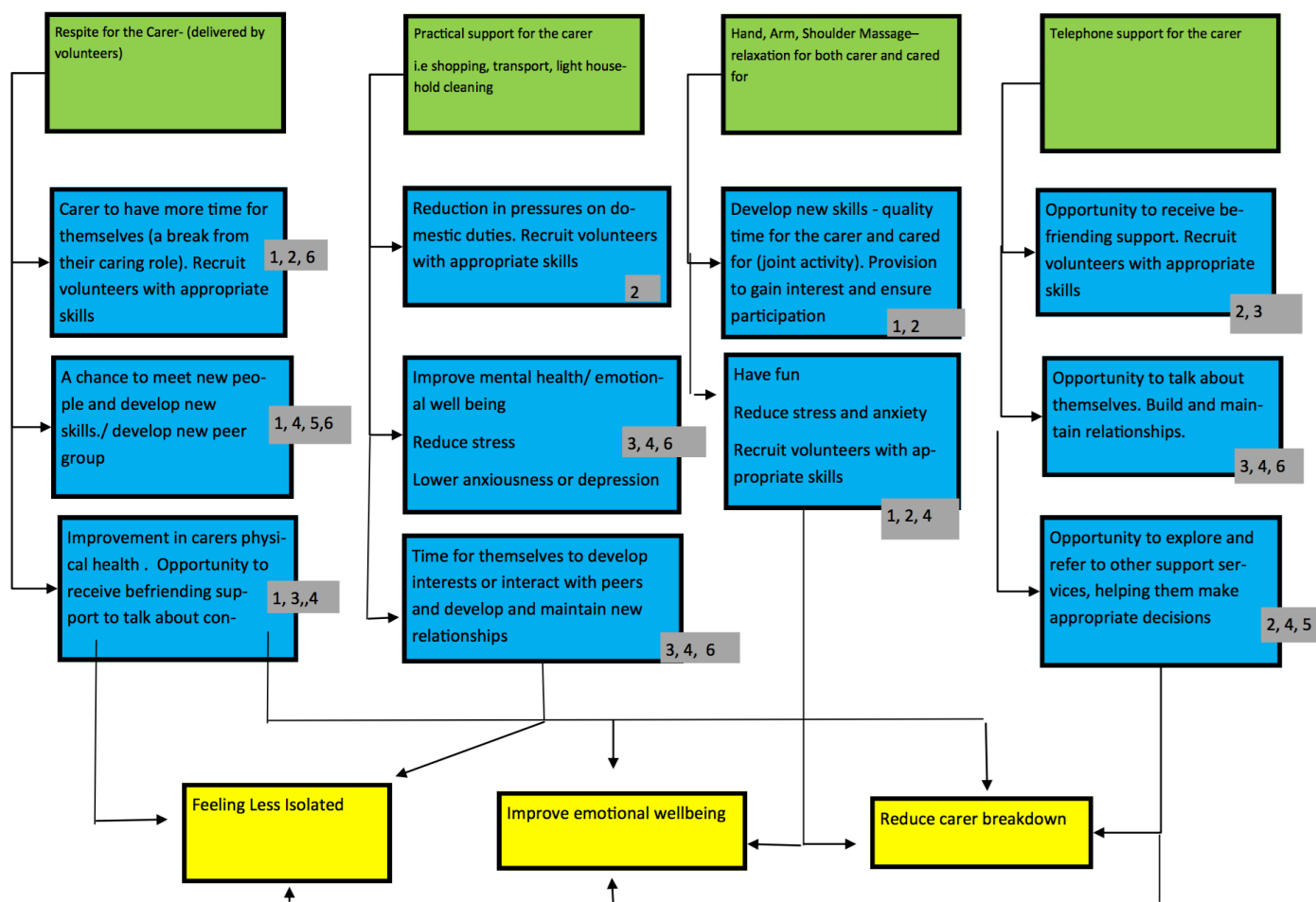
Assumptions:

1. Volunteer receives sufficient training to make them a good listener and empathetic
2. Volunteer is sufficiently flexible to meet carer's needs, and the processes for carers getting in touch with the service are sufficiently efficient
3. Advocacy is successful
4. Services required are available in their area
5. People actually take up the services they are referred to, and/or are eligible for them in the first place
6. One hour of contact a fortnight is enough to have a significant impact on feelings of isolation

Figure 15: British Red Cross Theory of Change

British Red Cross involves two slightly separate services. A Theory of Change was created for each service. The first Theory of Change refers to the 12-week Hive programme, the second to the 6-8 week volunteer support. The assumptions listed apply to both diagrams.

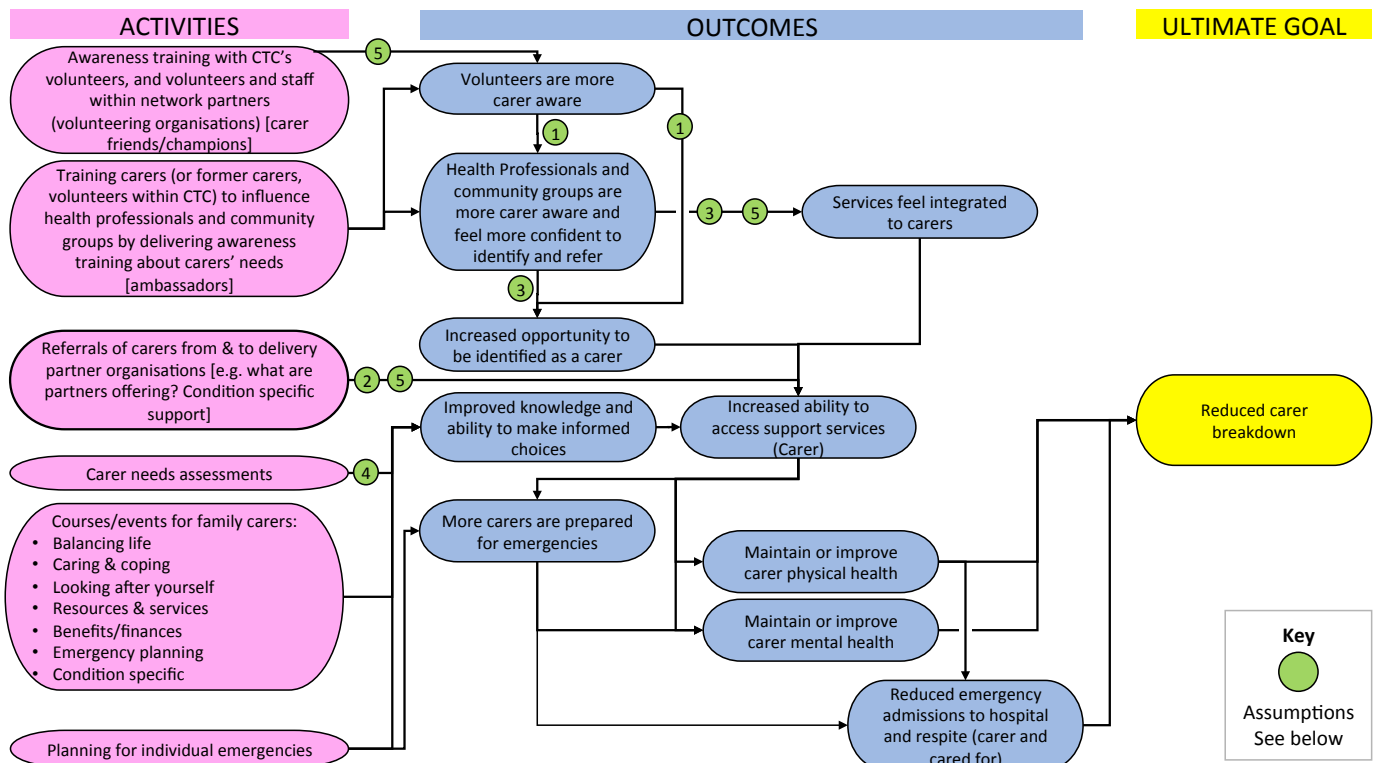




Assumptions:

1. Cohorts of young people will come together and commit to participate in 12 week training programme
2. Our support planning will enable us to support the carer
3. Carers' confidence and self esteem is lower than other young people of similar ages
4. Our volunteers will be of sufficient quality
5. Young Adult Carers are more vulnerable to risks
6. Our volunteers will be sufficiently flexible

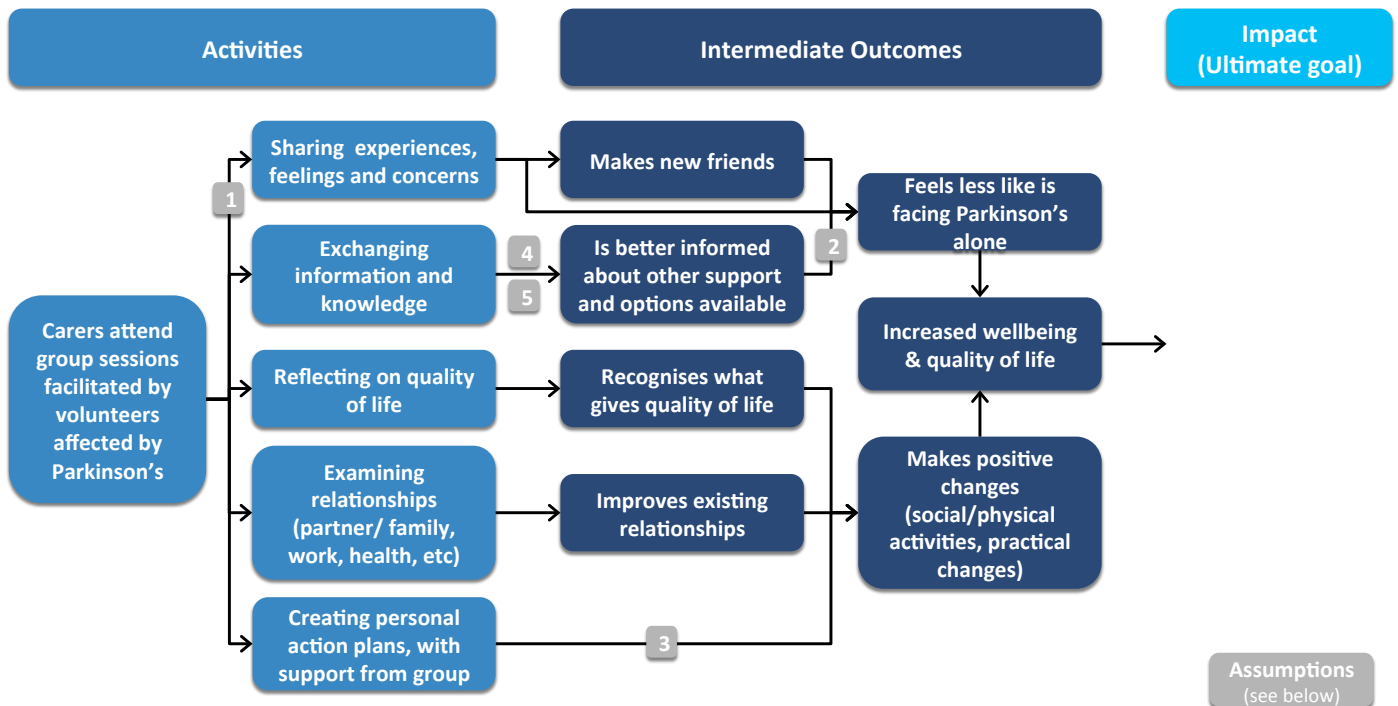
Figure 16: Carers Trust Cambridgeshire Theory of Change



Assumptions:

1. Volunteers will be willing & confident to engage beyond their existing volunteering role
2. Data will be shared efficiently with delivery partners to enable shared assessments
3. Health professionals are willing to refer carers and engage
4. The needs assessments need to be high quality (this is not always the case with statutory assessments)
5. Delivery partners fully engage with the project

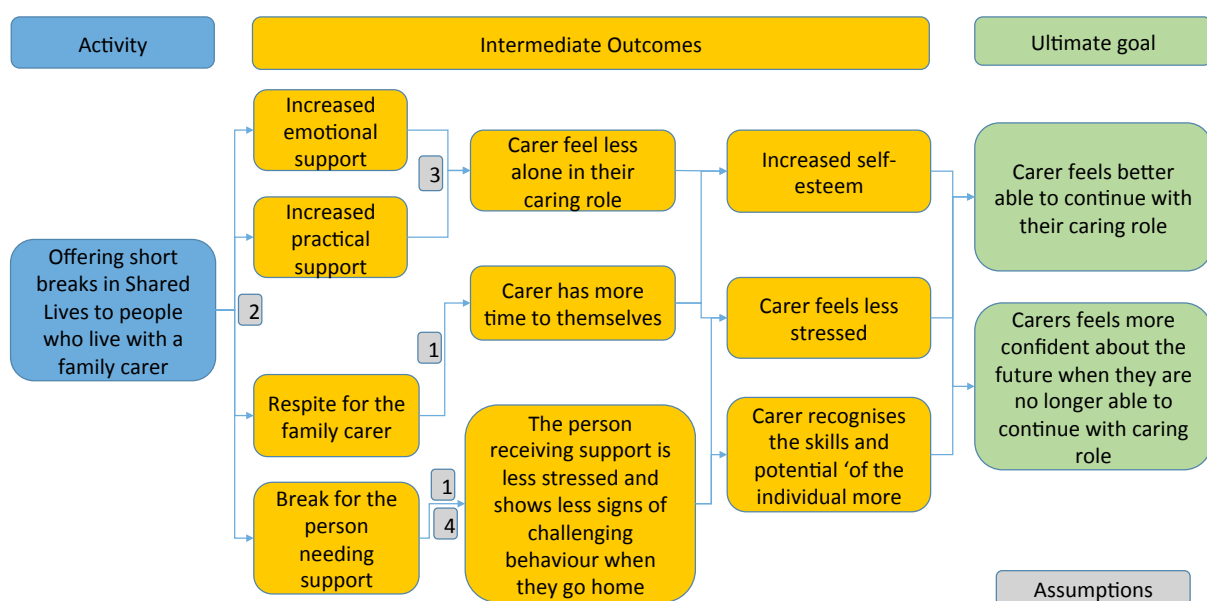
Figure 17: Parkinson's UK Theory of Change



Assumptions:

1. Carers are comfortable sharing feelings & concerns with the group
2. Other support/options are available and have capacity to meet demand
3. Carers are able & willing to implement action plans & action plan is appropriate for their needs
4. Information and knowledge produced & shared by Parkinson's UK's support groups is high quality
5. Participants and volunteers are willing & able to share local information

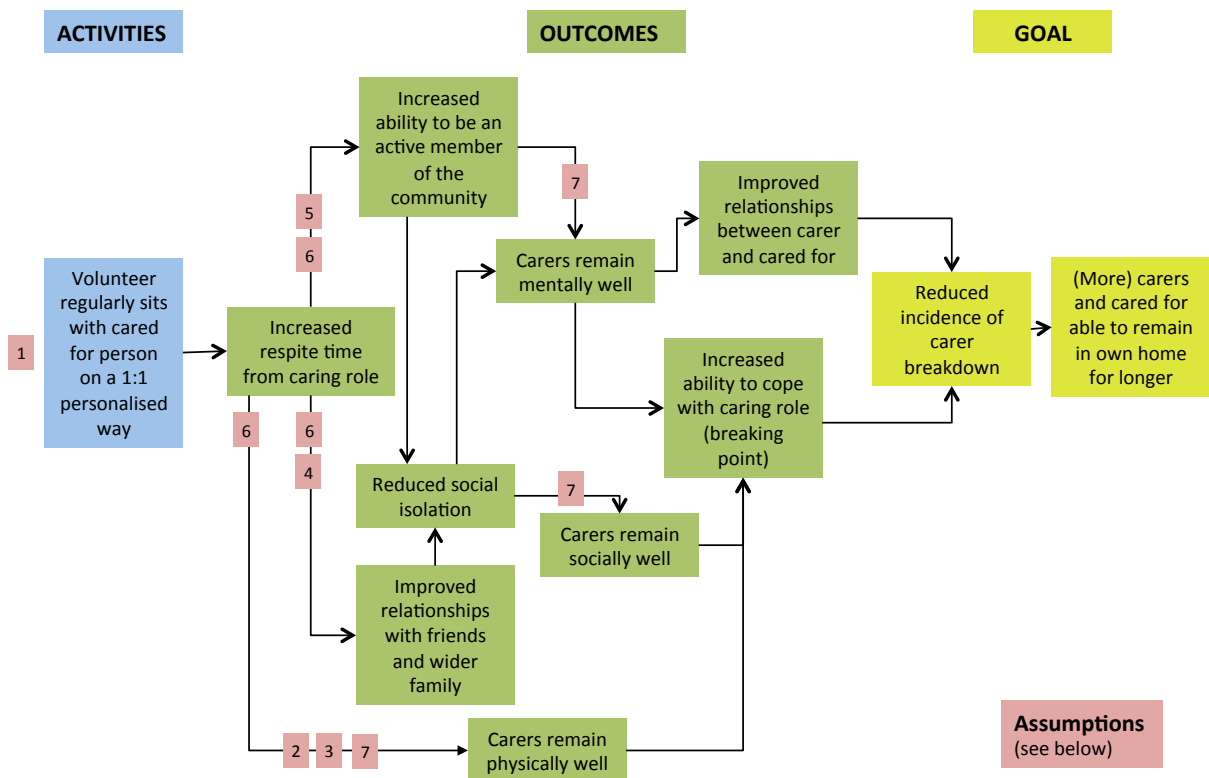
Figure 18: Shared Lives Plus Theory of Change



Assumptions:

1. The length of breaks is appropriate & helpful (rather than more stressful) to the carer and cared for
2. The Shared Lives carer builds a supportive relationship with the family carer
3. The family carer does not feel undermined in their role by the Shared Lives carer.
4. The person receiving support feels comfortable with the Shared Lives carer and enjoys the break

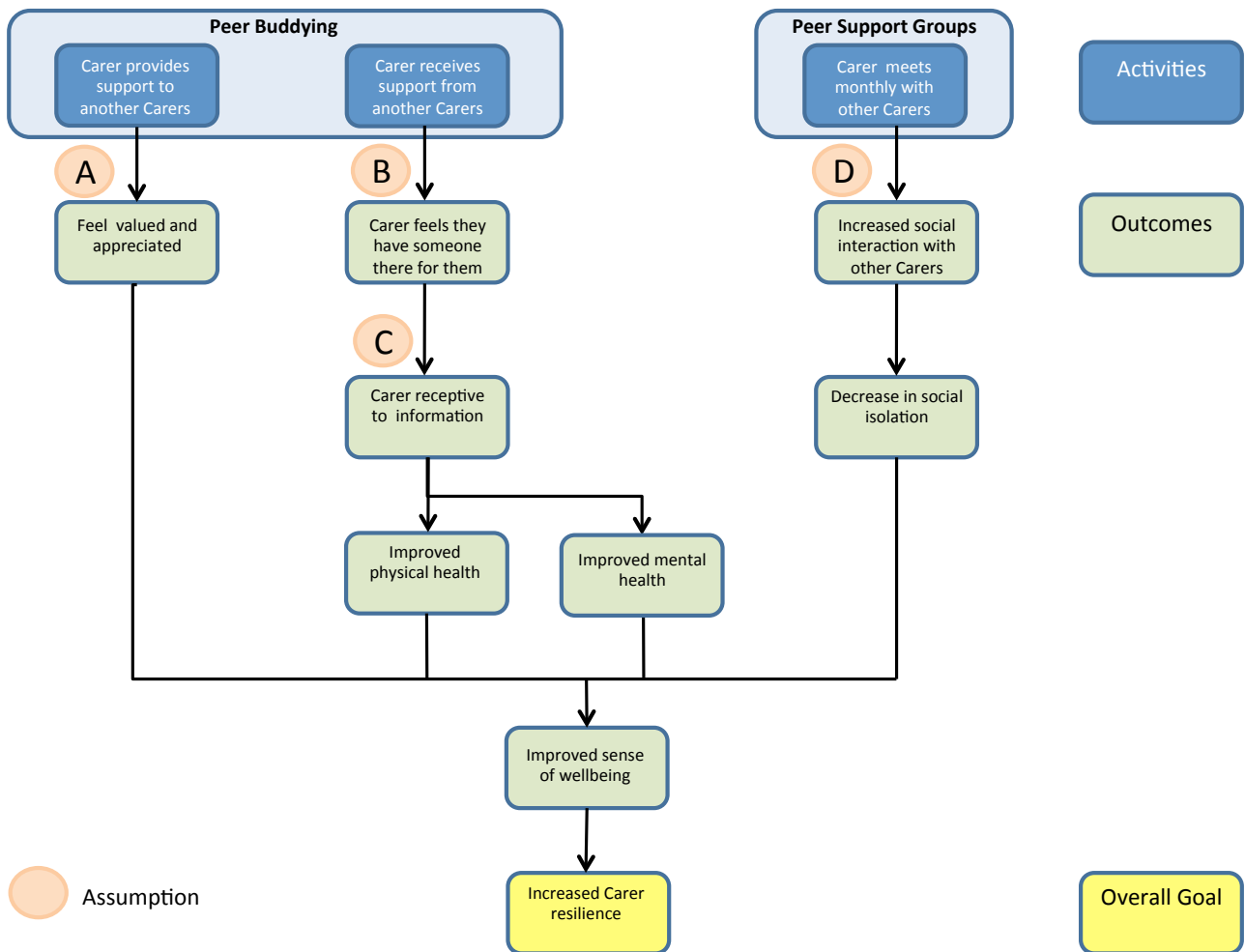
Figure 19: Thirsk Theory of Change



Assumptions:

1. Carer is anxious/stressed/depressed as a result of caring role
2. Carer's health issues are related to caring role
3. Carer goes to health appointments, engages in leisure activities, or sleeps
4. Carer spends respite time with family/friends
5. Carer spends time undertaking community activities
6. Breaks do not increase stress to carer or cared for
7. Wellbeing would deteriorate in absence of intervention

Figure 20: Westbank Theory of Change



Assumptions:

1. Positive feedback is communicated.
2. A bond of trust is established and that the support is available when needed.
3. As a result of improved sense of wellbeing, the Carer will be more receptive to respond advice and information from all sources.
4. Presupposes that the Carer will attend each month for the full session, and will 'gel' with the other attendees.

Appendix E: RCT methodology

The table below provides more thorough detail on the methodology for the Westbank RCT. It is compliant with the CONSORT checklist.

Figure 21: RCT methodology

| Heading | Detail |
|-------------------------|---|
| Trial design | Randomised controlled trial (individual randomisation) with a concurrent six month wait-list control group (1:1 group allocation ratio) |
| Eligibility criteria | The participants in the RCT consisted solely of carers on Westbank's 17,000-strong database at the time the trial recruitment started (February 2015). Any carers whose first contact with Westbank occurred after the trial recruitment started were not eligible. |
| Sample size | <p>Conflicting interests meant that a compromise was needed between maximising the sample size for research purposes and recognising what was feasible in terms of resourcing within the grantee's circumstances. TSIP's power calculation determined that a sample of 700 would be necessary in order to detect a minimum effect size of 0.26 (Cohen's d) with an estimated attrition rate of 67% (1:1 group allocation ratio).</p> <p>Westbank achieved a sample size of 652. Based on the same attrition rate and group allocation ratio, the minimum detectable effect size for this sample size would have been 0.27 (Significance level 0.05, 80% power, two-tailed).</p> |
| Participant recruitment | <p>Step 1: Via Westbank's March newsletter, with a deadline of 27/3.</p> <p>Step 2: Via an initial extension of the sign up deadline. This allowed some initial late signups to be recruited, and was driven by a follow-up e-mail to the 4,000 carers on the database who could be accessed by e-mail, encouraging further signups (digital survey).</p> |
| Participant allocation | <p>Randomisation: TSIP randomly allocated all participants into 1 of 2 groups - intervention or control – (intervention: control ratio is 1:1). Randomisation was conducted in two rounds using computer-generated random numbers (no stratification or other restriction), on 23 April and 8 May 2015, meaning allocation concealment was not necessary/applicable. The group allocations were then sent to Westbank using the carers' ID numbers. While Westbank enrolled participants, only TSIP was involved in the randomisation and allocation process.</p> <p>Blinding participants and service providers was not possible as the treatment condition differs substantially from the control condition, and TSIP is ethically compelled to fully brief potential participants on</p> |

| Heading | Detail |
|----------------------------|---|
| | the implications of participating in this trial. |
| Service type | <p>Participants could sign up to one or both of the two services offered – their choice was clarified as part of the signup process:</p> <p>Peer buddying (1-to-1 support)</p> <p>Peer support groups</p> <p>The RCT is treating both services as variations of the same service (rather than carrying out separate RCTS for each)</p> |
| Service delivery timelines | <p>Control group: Was not able to receive the service until November 2015 (safeguarding issues notwithstanding).</p> <p>Intervention group: Received the service as soon as Westbank was able to start delivering it to them.</p> |
| Ethics | <p>An ethics protocol for the wider project developed under the guidance of a London Metropolitan University professor ensures that proper ethics procedures were followed. Principally, this included collecting informed consent as a requirement for and prior to participation in the trial, as well as strict confidentiality guidelines communicated clearly to all parties involved. Access to confidential carer information was restricted within TSIP to one member of staff.</p> |

Appendix F: More detail on tools

This appendix provides more details on the measurement tools used in this evaluation. Figure 22 outlines the wording of each tool in full, figure 23 gives data on the internal consistency of the tools, and below that there is a more detailed summary of the piloting process carried out for the survey.

Figure 22: Full wording of tools

| Outcome | Tool | Question / statement wording |
|---------------------------------------|--|--|
| Reduced likelihood of carer breakdown | 'Ability to Care' subscale of AC-QoL (5 items) | <ul style="list-style-type: none">• I am satisfied with my performance as a carer• I can take care of the needs of the person I am caring for• I feel I am able to make the life of the person I am looking after better• I can manage most situations with the person I care for• I am able to deal with the person I care for |
| | Questions 16 and 18 of Zarit Burden Interview | <ul style="list-style-type: none">• Do you feel that you will be unable to take care of your relative much longer?• Do you wish you could leave the care of your relative to someone else? |
| Carer feels less socially isolated | De Jong Gierveld Scale (11 items) | <ul style="list-style-type: none">• There is always someone I can talk to about my day-to-day problems• I miss having a really close friend• I experience a general sense of emptiness• There are plenty of people I can lean on when I have problems• I miss the pleasure of the company of others• I find my circle of friends and acquaintances too limited• There are many people I can trust completely• There are enough people I feel close to |

| Outcome | Tool | Question / statement wording |
|--|--|---|
| | | <ul style="list-style-type: none"> • I miss having people around me • I often feel rejected • I can call on my friends whenever I need them |
| Increased carer well-being / Increased carer physical and mental health | 'Caring Stress' subscale of AC-QoL (5 items) | <ul style="list-style-type: none"> • I feel depressed due to caring • I feel worn out as a result of caring • I am mentally exhausted by caring • I am physically exhausted by caring • I feel stressed as a result of caring |
| | Short Warwick-Edinburgh Mental Wellbeing Scale (7 items) | <ul style="list-style-type: none"> • I've been feeling optimistic about the future • I've been feeling useful • I've been feeling relaxed • I've been dealing with problems well • I've been thinking clearly • I've been feeling close to other people • I've been able to make up my own mind about things |
| Carer has more time to themselves | 'Caring choice' subscale of AC-QoL (5 items) | <ul style="list-style-type: none"> • I feel my life is on hold because of caring • My social life has suffered because of caring • I feel I have less choice about my future due to caring • I feel I have no control over my own life • Caring stops me from doing what I want to do |

Figure 23: Internal consistency of tools

| Outcome | Tool | Internal consistency as reported in the literature (Cronbach's alpha coefficient) | Actual internal consistency based on baseline data |
|--|--|---|--|
| Reduced likelihood of carer breakdown | 'Ability to Care' subscale of AC-QoL (5 items) | Subscales range from 0.78 to 0.89 (40-item version scores 0.94) | 0.879 (High) for 5-item subscale |
| | Questions 16 and 18 of Zarit Burden Interview | Full 22-item scale ranges from 0.85 to 0.94 | 0.709 (Good) for custom 2-item subscale |
| Carer feels less socially isolated | De Jong Gierveld Scale (11 items) | Ranges from 0.80 to 0.90 (6-item scale 0.70 to 0.76) | 0.905 (High) for 11-item scale |
| Increased carer wellbeing / Increased carer physical and mental health | 'Caring Stress' subscale of AC-QoL (5 items) | Subscales range from 0.78 to 0.89 (40-item version scores 0.94) | 0.898 (High) for 5-item subscale |
| | Short Warwick-Edinburgh Mental Wellbeing Scale (7 items) | Short 7-item scale scores 0.85 | 0.748 (Good) for 7-item scale |
| Carer has more time to themselves | 'Caring choice' subscale of AC-QoL (5 items) | Subscales range from 0.78 to 0.89 (40-item version scores 0.94) | 0.876 (High) for 5-item subscale |

Pilot of survey: With the help of British Red Cross, Carers Trust Cambridgeshire and Shared Lives Plus, TSIP piloted the survey with twelve carers and one service worker. Feedback aimed to investigate concerns around potentially upsetting questions and inappropriate length of the survey. The feedback was reassuring on both points, though there were some concerns in relation to the former, including feeling guilty about revealing personal information about their caring relationship and feeling depressed about their caring situation. We addressed the concerns as much as possible by carefully framing the survey and briefing grantees on how their staff should introduce the survey to carers. However, as these are validated scales, we were unable to change the wording of the questions. At baseline data collection, there were a few isolated cases where carers refused to fill in the survey or were tearful while filling in the survey. However, the majority of carers and workers did not report any concern.

Appendix G: Data collection processes and periods

Figure 24 below gives an outline of when and how data was collected by each of the grantees.

Figure 24: Data collection processes and periods

| Intervention type | Grantee | Collection process and period at baseline | Collection process and period at follow-up |
|----------------------|-----------------------------|---|---|
| Peer support | Westbank | Postal/email, to all 17,000 existing carers on Devon Carers database 23 Feb - 31 May | Postal/email, at 6 months after baseline |
| | Parkinson's UK | At first in-person or postal/email contact with staff 23 Feb - 23 Jun | Postal/email, at 3 months after baseline |
| Respite | Thirsk | At first in-person contact with staff 23 Feb - 31 Dec | In person, at 3 months or 8 visits after baseline |
| | Shared Lives Plus | At first in-person contact with staff 23 Feb - 31 Oct | Postal/email, at 3 or 5-6 months after baseline |
| Practical support | Age UK | At first in-person contact with staff 23 Feb - 31 Aug | In person, at 3 months after baseline |
| | British Red Cross | At first in-person contact with staff 23 Feb - 30 Sep | In person, at 3 months after baseline |
| Carer identification | Carers Trust Cambridgeshire | At first in-person or postal/email contact with staff 23 Feb - 31 Oct | Postal/email, at 5-6 months after baseline |

Appendix H: Carer numbers and response rates

This evaluation aimed to collect data for every carer that came through the grantees' for the first time services during the evaluation's data collection period. We tried to embed data collection tools and processes into the grantees' service delivery, to maximize response rates at baseline and follow-up.

Figure 25 below gives a grantee-by-grantee breakdown of a) the number of carers that came through the services during the data collection period, b) the number of those who filled in a baseline survey, c) the number of those who also filled in the follow-up survey (as a percentage in brackets), and d) the number of those who did not have any missing data at baseline or follow-up.

Figure 25: Carer numbers and response rates

| Intervention type | Grantee | Carers new to the service | Baseline surveys | Follow-up surveys | Without missing data |
|----------------------|-------------------|---------------------------|------------------|-------------------|----------------------|
| Peer support | Westbank | 652 | 652 | 378 (58%) | 308-359 |
| | Parkinson's UK | 77 | 61 | 53 (87%) | 36-39 |
| Respite | Thirsk | 212 | 151 | 91 (60%) | 75-84 |
| | Shared Lives Plus | 142 | 60 | 38 (63%) | 30-37 |
| Practical support | Age UK | 27 | 27 | 11 (41%) | 7-11 |
| | British Red Cross | 26 | 25 | 25 (100%) | 23-25 |
| Carer identification | Carers Trust | 138 | 119 | 91 (76%) | 71-85 |

| Intervention type | Grantee | Carers new to the service | Baseline surveys | Follow-up surveys | Without missing data |
|-------------------|----------------|---------------------------|------------------|-------------------|----------------------|
| | Cambridgeshire | | | | |

A few comments on the table:

- Numbers in the final column vary, as the extent of missing data varied by outcome.
- Because Westbank conducted an RCT, their process was slightly different – carers were invited to express their desire to take part in the service by filling in the baseline survey.
- Loss to follow-up (or attrition) did not differ considerably between Westbank's treatment and comparison groups. We received 315 baselines and 189 follow-ups (40% attrition) in the treatment group, and 304 baselines and 170 follow-ups (44% attrition) in the comparison group. The risk of bias from differential attrition (i.e. different attrition levels between the groups) is therefore considered low.
- Shared Lives Plus and Thirsk were operating their service across twelve semi-autonomous 'schemes' or partner organisations (respectively), which made collecting data more of a challenge.
- Other differences across grantees were largely driven by what data collection processes were possible in the context of their particular service – for example some were able to hand their survey to carers face-to-face, whereas others had to send them by post.

Appendix I: Quantitative process data

This evaluation was primarily an impact evaluation. However, we did also collect some quantitative process data, which can be split into four types:

1. **Demographics:** Data on carers' age, ethnicity, gender and disability.
2. **Dosage:** Data on the frequency and length of the services received, which was normally collected by grantees themselves and passes onto us.
3. **Carer status:** Data on whether or not the carer was still a carer when they completed their follow-up survey.
4. **Theory of Change assumptions:** Data that directly tests some of the grantees' Theory of Change assumptions, generally in relation to some quality of the service delivery.

A comprehensive overview of this data is presented below:

Figure 26: Overview of demographic data

| Intervention type | Grantee | Age (mean in years) | Gender (% female) | Ethnicity (% white British) | Disability (% yes) |
|-------------------|-------------------|---------------------|-------------------|-----------------------------|--------------------|
| Peer support | Westbank | 66 | 66 | 96 | 39 |
| | Parkinson's UK | 66 | 72 | 90 | 16 |
| Respite | Thirsk | 72 | 67 | 96 | 25 |
| | Shared Lives Plus | 56 | 87 | 95 | 17 |
| Practical support | Age UK | 72 | 74 | 89 | 22 |

| Intervention type | Grantee | Age (mean in years) | Gender (% female) | Ethnicity (% white British) | Disability (% yes) |
|----------------------|-----------------------------|---------------------|-------------------|-----------------------------|--------------------|
| | British Red Cross | 19 | 69 | 100 | 65 |
| Carer identification | Carers Trust Cambridgeshire | 66 | 71 | 89 | 67 |

A few comments on the table:

- The demographics across the seven grantees are relatively similar.
- Carers tend to be of older age (on average 66) except for BRC which specifically targets young carers.
- All carers are to some extent more likely to be female (68% on average), particularly for SLP (87 %).
- All carers are overwhelmingly likely to be White British (95% on average – significantly higher than the national average for carers).
- However, disabilities occur at varying degrees – while only 16% have disabilities at Parkinson's UK, the number is substantially higher at CTC with 67%. This may be due to the differing definitions of disability employed by different grantees.

Figure 27: Overview of dosage data

| Intervention type | Grantee | Average 'dosage' |
|----------------------|-----------------------------|---|
| Peer support | Westbank | Carers attended an average of 1.78 peer support sessions or buddy meetings between April and November 2015. ¹ |
| | Parkinson's UK | On average, carers attended 91% of their peer support groups. |
| Respite | Thirsk | On average, carers received 2.38 vists per month which lasted 3.9 hours in total . |
| | Shared Lives Plus | On average, carers received 2.17 vists per month which lasted 51.8 hours in total . |
| Practical support | Age UK | On average, carers received 3.15 hours of practical support per month. |
| | British Red Cross | On average, carers received 2.06 visits per month which lasted 4 hours in total . |
| Carer identification | Carers Trust Cambridgeshire | On average, carers attended 1.7 CTC-run services and 1 non-CTC-run service in the last 6 months. |

¹ This figure has been included for transparency, but it should not be interpreted as representing the typical 'dosage' of the service – the number is artificially low due to a number of carers in the intervention group not receiving the service at all (as explained in the discussion section of the main report), and many others not starting the service until late on in this period (due to the natural time taken to get hundreds of carers up and running with their groups and buddies).

Figure 28: Overview of carer status data

| Intervention type | Grantee | % no longer a carer |
|----------------------|-----------------------------|---------------------|
| Peer support | Westbank | 6% |
| | Parkinson's UK | 4% |
| Respite | Thirsk | 2% |
| | Shared Lives Plus | 7% |
| Practical support | Age UK | 9% |
| | British Red Cross | 4% |
| Carer identification | Carers Trust Cambridgeshire | 13% |

Overall, approximately 6% of carers who filled in follow-up surveys were no longer carers at that point. The most common reason was that the person they were caring for had passed away or moved into residential care; more rarely the reason was the poor health of the carer themselves. Carers who were no longer a carer were asked to fill in the survey based on how they were feeling just before they stopped being a carer. Though there are clear limitations to this data as a result, those limitation only affect 6% of the surveyed carers.

Figure 29: Overview of Theory of Change assumption data

| Intervention type | Grantee | Survey question / statement | Score |
|----------------------|-----------------------------|---|---|
| Peer support | Westbank | Overall, my peer support group/buddy that I have been matched with are a good match for me | 2.19 (on a scale of 0-4, where 4 is 'strongly agree') |
| | | I feel like I have now made friends with other carers | 2.10 (on a scale of 0-4, where 4 is 'strongly agree') |
| | Parkinson's UK | How much progress have you made since attending the Parkinson's Self-Management Group towards completing the 3 actions you wrote on page 19 of your Log Book? | 1.31 (on a scale of 0-3, where 3 is 'I have completed all the actions') |
| Respite | Thirsk | How would you typically spend the time gained during the respite? | Family and friends: 49% Leisure: 27% Sleep/rest at home: 22% GP/health appointments: 20% Community activities: 15% |
| | Shared Lives Plus | [Shared Lives Plus' survey did not include any process evaluation questions] | - |
| Practical support | Age UK | How good a listener is the volunteer who is/was supporting you? | 2.64 (on a scale of 0-3, where 3 is 'very good') |
| | British Red Cross | The volunteer(s) have been sufficiently flexible in supporting me as and when I have needed it | 2.00 (on a scale of 0-3, where 3 is 'always') |
| Carer identification | Carers Trust Cambridgeshire | How helpful did you think Carers Trust Cambridgeshire's needs assessment was in | 2.34 (on a scale of 0-3, where 3 is 'very') |

| Intervention type | Grantee | Survey question / statement | Score |
|-------------------|---------|--|-------|
| | | identifying information and support that was well-suited to you? | |

Appendix J: A note on alpha levels and p-values

For this evaluation we set the alpha level at 0.10. Though not completely uncommon, this is different to the standard practice in research, which is to set it at 0.05. Setting it as 0.10 instead increases the risk of 'type 1 errors' – incorrectly rejecting the null hypothesis or, in other words, concluding that a change in outcome was caused by some systematic factor(s), when in fact it was purely due to chance.

However, setting the alpha level at 0.10 also has the opposite effect of decreasing the risk of 'type 2 errors' – incorrectly accepting the null hypothesis or, in other words, concluding that a change in outcome was purely due to chance when in fact it was caused by some systematic factor(s).

If the purpose of evidence is to guide funding decisions, setting the alpha level at 0.10 rather than 0.05 therefore a) increases the risk of funding ineffective services, but also b) decreases the risk of not funding effective services.

On balance, we believe this is a preferable tradeoff between the two risks, for the following reasons:

- There is a good chance that the lack of comparison group for six grantees leads to an underestimation of their impact. We theorised that carer outcomes are likely to worsen in the absence of services, and Westbank's comparison group gives strong (albeit not necessarily generalisable) evidence of this. Without a comparison group, the other six grantees' results do not take this into account.
- Sample sizes were generally quite small, largely driven by the current scale of the services being evaluated – outside of the RCT, the sample sizes ranged from 7 to 85 after removing missing data. Small sample sizes increase the risk of type 2 errors.
- The services being evaluated are generally at an early stage of development, and still have room for enhancing the quality and consistency of delivery – as the quantitative and qualitative data showed - and therefore increasing their impact.
- This evaluation does not aim or claim to produce definitive evidence on whether or not any of the six interventions are effective – it aims to give an indication of how effective they might be, to prompt further research with increasing levels of robustness (as per our recommendations).

In summary, the decision to set the alpha level at 0.10 was a practice-driven decision, based on our assessment that it produces the optimum tradeoff in risks given a) the early stage / small scale of the interventions being evaluated, and b) the aim of informing future research and funding decisions.

Appendix K: Qualitative analysis - Carers Trust Cambridgeshire

N.B. This analysis is based solely on the four interviews we carried out with carers. Its intention is to assess the impact of Carers Trust Cambridgeshire's (CTC) on some of the carers it supports; it should not be misinterpreted as an assessment of the broader state of carer support in Cambridgeshire.

How was the intervention implemented by the grantee?

CTC delivers a range of carer awareness training for different groups (health and social care professionals and volunteers) so that they can identify carers and refer them to relevant support services early on in their life as a carer. This is part of CTC's 'Caring Communities' approach, which aims to create an ecosystem of carer-aware, carer-friendly people who can identify, support and refer carers to appropriate services.

The CSASF funded some specific activities within this overall approach:

- Carer awareness training with CTC's volunteers, and volunteers and staff within network partners to produce 'carer friends and champions'. The majority of training is concentrated in this area.
- Training carers (or former carers, volunteers within CTC) to influence health professionals and community groups by delivering awareness training about carers' needs to produce 'carer ambassadors'.

These trained professionals and volunteers then make referrals of carers from and to delivery partner organisations. As much as possible we tried to focus solely on the particular impact that the CSASF-funded activities have had, but as it is closely intertwined with the broader approach and the many other services that CTC delivers, it has not always been possible to isolate this impact.

Carers do not come into direct contact with the Caring Communities approach

Carers are not necessarily aware that they experienced this Caring Communities approach per se; this is somewhat intentional, as the approach is designed to be smooth, natural and well-integrated. Sometimes carers had some recollection of how they heard about the support, but also sometimes only remembered the benefit of support they received rather than how they found out about it.

What was the impact, and how and why did it come about?

The service aims to identify carers at an earlier stage of their life as a carer so that they can access carer support to prevent breakdown. It predominantly acts as a trigger so that carers can access carer support services that they would not have been previously aware of. The service contributes to an ecosystem of carer awareness and support.

Carer identification

The process of being referred to carer support services differed from carer to carer, as follows. In many instances the carer could not recollect exactly how they had found out about their support services, in which case CTC provided us with some of this information.

Carer 1 journey: Carer 1 first identified as a carer from the time that his wife was first hospitalised; while she was in hospital he was asked whether he was willing and capable of being his wife's carer to which he replied yes. From that point onwards he was a full time carer. According to CTC records, he became aware of the Family Carers Prescription (which is provided through CTC) through an MDT coordinator a while after first being identifying as a carer.

When asked how he found out about the family carers prescription, the carer put forward two viable options. He stated that he may have heard about it either through carers magazine which he saw at the doctors (and subsequently subscribed to) or learnt about the prescription through a monthly carer peer to peer support group that he attends. The carer could not recollect which of these routes led him to access the prescription – both are plausible.

Carer 2 journey: Carer 2 was referred to the Shelford Dementia Support group through a partner organisation (Cambridgeshire and Peterborough NHS Foundation Trust – dementia carers support service). Once referred to Shelford Dementia support group (run by CTC), CTC referred her to a buddy scheme where she gained a buddy for emotional and practical support.

Carer 3 journey: For carer 3, they first identified as a carer when the people that she cares for (parents) visited the GP surgery where a member of staff from CTC was handing out leaflets as part of their carers drop-in service at GP surgeries. As a result, she was then pointed in various directions for support and proceeded to access required support thereafter. This was the first time that she identified as a carer and was made aware of support available, despite having been a carer for several years. This case demonstrates how valuable identification and signposting can be.

Carer 4 journey: Carer 4 was identified by a Multi-disciplinary Team (MDT) coordinator and was able to access a host of support services such as Family Prescription, a 'what if' emergency plan and a carers information pack as a result. She also had already been identified and accessed other support services.

Integrated services

Carers interviewed viewed the support services to be well-integrated because they all had someone that they could turn to as a first point of call. These individuals were CTC staff, health and social care professionals or volunteer buddies. Furthermore, carers were confident that these individuals had a good knowledge of the health and social care ecosystem to refer them to the appropriate service. One example given was when a carer was hospitalised, the hospital staff were able to notify other appropriate services that the carer had a relationship with.²

Peace of mind: due to being well informed

² CTC believe this is likely to have been an Individual Carer Emergency Respite (ICER). This is where the family of a carer registers a plan whereby they are contacted by medical staff if the carer is hospitalised. If the family is not available to support the cared-for person, the medical staff will contact CTC staff to arrange alternative support.

Interviews with carers made it apparent that these four carers felt much better informed than carers we interviewed for other grantees. These carers all had access to the carers magazine, which includes a comprehensive list of numbers to call if any support is needed.³ These carers also had access to a range of voluntary and health and social care organisations which kept them well informed (see ‘access to services’ below). Carers interviewed in other localities as part of this qualitative research strongly felt that information on carer support was difficult to access. This indicates that the service is working effectively in its aim to improve carers’ knowledge so that they can make informed choices, although we cannot be certain that this difference is not due to other factors.

Carers interviewed also all felt well prepared for emergencies. One carer has a pendant to use for emergencies and the other three have ‘what if’ emergency plans provided by CTC. This peace of mind should play some part in improving the mental health of the carers.

Peace of mind: due to being well supported

Carers stated that they feel well supported. CTC and healthcare professionals call carers regularly (every couple of months) to check in with the carers.

‘Knowing that I’m not on my own – that’s the main thing that helps me cope with caring.’

‘You need never be on your own if anything goes wrong.’

Access to services

Through a combination of services provided by the local council, different voluntary sector organisations and health and social care services, the four carers interviewed accessed the following types of support between them: 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, carers assessments and an information pack. This level and range of support was definitively greater than for the carers of other grantees that we interviewed. This is in line with CTC’s Theory of Change, whereby playing the role of ‘virtual integrator’ between different services in the area means that more of those services are offered to carers when they are first identified, via a single pathway organised and overseen by CTC.

What were the barriers and facilitators to impact?

Good services

A range of good quality services in the local area allowed referrals to be an effective route to access support.

Isolating impact

Some carers had already identified as carers and were receiving carer support from other services before coming into contact with CTC. Therefore, this can limit the impact achieved for the carer by the Caring Communities approach. Three of the carers had already self-identified or been

³ CTC stated that they also offer a tailored information pack and access to a Carers Support Directory.

identified as a carer, and had been accessing other carer support before being identified and referred on to access other services.

Limits to public services

Most of these four carers that we interviewed have most of their needs met that can be met through carer support services, yet the carers were still worried, lonely and stressed to some degree. There is potentially only so much that public services can do.

What worked well and less well in delivering the intervention?

Implicitly it seemed that the carers seemed happy with the service that they received: they were happy to find out about and access support. Carers were very satisfied with the support that they received (family carers prescription etc). However, they could often not make any explicit comment on the Caring Communities approach or signposting, as they did not recognise they were directly interacting with it nor were they explicitly made aware of it (as it would be of no benefit to them to do so).

Appendix L: Qualitative analysis – Shared Lives Plus

Unfortunately, the sample size for this qualitative research was half of that for other grantees as Shared Lives was only able to arrange for two family carers (FC) to be interviewed.

Of the two FCs interviewed, one cares for their 18 year old son with profound and multiple learning difficulties and physical disabilities, and the other FC cares for his wife with encephalitis and MS.

How was the intervention implemented by the grantee?

Frequency and duration

One cared-for person stays overnight at a Shared Lives carer's (SLC) home for one night every four to six weeks, and the other cared-for person stays at the SLC's home from 1pm on a Friday to 6pm on Monday (for three nights) every six weeks. Both FCs felt that the frequency and duration of respite was appropriate for their needs.

Who are the Shared Lives carers (SLC)?

For the 18 year old, his SLC was someone that he has known for most of his life: the SLC was his one-to-one learning support assistant during primary school. The FC has received the same respite service for the last six years from this carer. Respite was previously managed by Family Placement but recently moved over to Shared Lives when the cared-for person became an adult and turned 18 years old.

The other cared-for person has been matched with an elderly woman with common interests and background.

What was the impact, and how and why did it come about?

Relief

FCs spoke of an immediate sense of relief when their respite began. Carers felt that the cared-for was entirely dependent on them and the respite provided them with a sense of temporary

release from this dependency. Many carers we spoke to (including those using other services in the fund), speak of the weight they feel on their shoulders day to day due to being responsible for another person.

'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.'

Another care stated: *'The only thing I could say is respite is great, it's that break. It's like being in a pressure cooker and it's building and building and building, especially with the work situation.'*

Rest

As the duration of respite is for a substantial length of time (at least one night), FCs are able to truly relax. During respite, one FC often focuses on getting more sleep as it is his only opportunity to do so. *'It's the freedom to do what I want to do; at the very least I'm well rested. The fact is it's my choice. Sometimes I'm just too wrecked, too fed up with the whole thing, it's just that break to do whatever I want.'*

The other FC interviewed also has the chance to lie in which she does not have opportunity to do normally. She is also able to take a break from her son's behaviour which can at times be violent.

Normality

One FC spoke of how the respite enabled them to be 'normal'. *'It's a chance to be a normal every day family without any interruptions. It's broken, interrupted when [son's name] is there – [daughter's name] can show off without [son's name] taking the limelight.'* When the cared-for is with his SLC, the FC and her 11 year old daughter have a chance to do the things they can't do when the cared-for is present. They dine out, go to the pictures or just have a conversation without interruption. The FC otherwise has limited opportunity to spend quality time with her daughter. The daughter also benefits from the sense of normality deriving from the respite. She is able to invite friends to their house, whereas normally she would not want to invite friends as they feel intimidated by her brother.

Improved relationships

In one case, respite has improved the relationship between the FC and the cared-for. By providing time for relief and rest, the relationship between the cared-for and FC is said to have improved. *'It's [the respite] essential to us, I hate to think how we would manage without it. I'd be very doubtful that we would be together.'*

In the other case, we could also assume that the respite has improved the relationship between the FC and her daughter. The relationship between mother and daughter is already very strong but it may be fair to assume that by spending quality time together, it would further strengthen their relationship.

Trust

FCs were able to rest during their respite not just by being provided the time to do so, but also due to their trust in the SLCs. Being able to trust them fully to look after their loved-ones gave them piece of mind.' *To her, he is her surrogate grandson, it's just home from home, she's the only person that I trust with him to have him overnight.'*

Whilst the other FC similarly stated: *'It's great – we get out – it makes a massive difference that it's someone that you can trust, she follows your routine, home from your home.'*

The relationship with the SLC in both cases was strong. In one instance they text frequently during the respite to provide updates on the cared-for. In the other case, the FC had positive experiences of communicating any updates, such as change of medication for the cared-for.

Although not explicitly stated in these two interviews, it may be fair to assume that FCs feel less alone in their caring role as a result of having an SLC that also provides care to the cared-for.

Fund level outcomes

Through the two interviews conducted, this carer support service has demonstrably increased the time that carers have to themselves – this is the fund wide outcome that has been most clearly achieved. Some improvement in carer wellbeing and mental health due to the relief and rest that the respite provides has also been demonstrated. Carers do not however, appear to be any less socially isolated as a result of the service as they did not use the respite time to socialise.

Bespoke outcomes not evident in interviews

- The person receiving support is less stressed and shows less signs of challenging behaviour when they go home

Despite both cared-for people thoroughly enjoying their respite, they did not necessarily show less signs of challenging behaviour upon their return. In one case, this is due to the fact that the cared-for's behaviour is very unpredictable and does not follow any particular pattern. The other carer also stated that upon return the cared-for's behaviour is no different to usual.

- Carer recognises the skills and potential of the individual more

Interestingly, both FCs interviewed stated that they recognised the person that they cared for's skills most when they (the cared-for) are interacting with other people. *'Every time we go out I notice how lovely my wife is... Oh no, you don't notice it at home... I view her in a different light when she's out.'* The other carer thought her son was good at making people laugh and bringing people together but tends to take out any frustration or anger on his mother (the FC). However, the respite itself did not result in increased recognition of skills and potential.

- Increased emotional support

It was thought that by having a Shared Lives carer, they would also be a point of call for support outside of the dedicated respite time. However, out of the two interviewees; one had a close family and friends to call on when support was needed, and the other one tended not to discuss his emotional needs with family or the Shared Lives carer.

- Increased practical support

Shared Lives carer did not seem to provide practical support outside of the dedicated respite time.

It should be noted that the outcomes not being evident in these interviews may be due to the small sample size of two.

What were the barriers and facilitators to impact?

Fluctuating health conditions

One cared-for person was not able to go to respite for the first six months that it was available as she had health problems which resulted in her repeatedly falling over. Both the FC and cared-for would not have been comfortable in going to respite, particularly as the SLC was an elderly woman and would have not been able to help pick her up in the eventuality of a fall.

What worked well and less well in delivering the intervention?

Worked well

Both FCs had a very positive experience with the service and are very appreciative of SLCs and staff. Two themes in particular stood out:

Well-matched

Both cared-for people were well matched with SLCs. This is demonstrated by how much the cared-fors were said to have enjoyed spending time in the SLCs' homes. One cared-for was matched with a fellow Christian and former nurse of the same sex. The other cared-for was able to continue receiving respite from his respite carer of six years whom he has known for the majority of his life.

Length of stays

The lengths of stay were considered to be the appropriate length of time by both FCs.

Worked less well

Both FCs found it difficult to provide the schedule of prospective respite days in advance, as requested by Shared Lives. In practice, they found it difficult to plan far in advance as their circumstances and plans can change.

Appendix M: Qualitative analysis – Thirsk

How was the intervention implemented by the grantee?

Among all four carers interviewed, the person they cared for was matched with a volunteer of the same sex through a matching process. The volunteer sat with the person that they cared for in their home so that the carer could have respite. The volunteer chatted to them and kept the cared-for company. Precise activities depended on the wishes of the cared-for. The service provided differed from carer to carer: the duration of respite, frequency of respite, whether the time was regular or not and how the carer was referred to the service all differed. The service was provided by 12 different partner organisations. The differences in service provided will be explored further below.

What was the impact, and how and why did it come about?

We found that the impact on the carers as a result of the intervention varied significantly; therefore we have summarised the impact on each individual carer as no clear themes have emerged. Impact achieved depended on the need for respite, the service provided and what the carer did with the respite time. This will be discussed further in the barriers and facilitators section.

Carer 1: *'It's absolutely wonderful, it gives me something to look forward to.'*

Carer 1 cares for her husband who has dementia and other health problems. She is largely housebound as she cannot leave her husband in the home alone, cannot leave the home with him and does not have anyone nearby that she can rely on to provide regular respite (apart from the volunteer from the sitting service). The volunteer sits with the carer's partner regularly for two hours each week. These two hours is the only time that the carer has time for herself. During the break, the carer goes to a nearby town by bus to have a coffee.

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

The volunteer has also provided emergency respite which had enabled the carer to attend several family funerals last year which she would have not been able to attend to otherwise. The carer had been diagnosed with stress and anxiety but is now feeling better in herself.

The carer trusts the volunteer to look after her husband. *'It gives me piece of mind knowing that he's not going to be bleeding on the garage floor, that's wonderful. I can enjoy the two hours.'*

Fund level outcomes

Impact on this carer's wellbeing was the greatest out of the carers interviewed as the respite resulted in more time for herself, reduced social isolation and improved wellbeing as she had little other opportunity for respite and to leave her home. This carer also currently receives no other carer support.

Carer 2: *'It's a lifeline really'*

Carer 2 cares her for husband who has Parkinson's disease. She is able to leave her husband on his own for no more than an hour and is otherwise with him 24/7. The sitting service provides her with two volunteers who provide respite for a total of half a day a week. The carer is able to set dates to suit her in advance. The respite enables the carer to 'feel normal'. With the

respite time provided, she gets reflexology at a friend's house, goes to have her hair cut and spends time with her daughter.

'It enables you to live a more normal life – otherwise life is just centred around one person.'

Before beginning the respite service, the carer used to worry how she was going to cope: now she has peace of mind knowing that she's able to continue to have a normal life. *'Before I would think I've got to get back, I've got to rush back. I would be a bit of a nervous wreck really. Now it's more calm and relaxed in my life now.'* She did not have the time previously to do normal things as she had to take her husband everywhere if she were to leave the house.

As a result of the respite and accompanying peace of mind, she is now able to sleep better, feel more relaxed and happier. *'It feels now like his health problem is kind of shared so therefore there's not quite so much weight and stress on my shoulders. I know that there's some help there... I used to lay in bed worrying about my future thinking "oh my god, how am I going to cope".'*

The relationship between the carer and her daughter has also improved as they are now able to spend time together. Before respite began, she might not have seen her youngest daughter for two or three months, whereas now she is able to see her every week.

The carer believes that without the service, her husband would need to be in residential care.

Fund level outcomes

For this carer she has significantly more time to herself and has achieved some increase in carer wellbeing and mental health. It may be fair to assume the carer also feels less socially isolated as she is able to socialise more regularly.

Carer 3: 'Benefits are 50/50'

Carer 3 cares for her husband who has Parkinson's disease. She is not able to leave her husband at home alone, but can go out and about with him and has family nearby that can come to sit with him if she needs to leave the house. One volunteer comes for an hour on a weekly basis at a time that is convenient for the volunteer. During her respite she often goes to the shops and sometimes for a quick coffee; but also sometimes stays with them as by the time she has a quick chat with the volunteer there isn't enough time left to travel. The cared-for (husband) looks forward to the visits as the volunteer cheers him up.

Fund level outcomes

For this carer, the respite has provided some increase in time that the carer has to herself. The respite has not seemed to reduce any feelings of social isolation. This is as she does not tend to socialise during the respite (aside from with the volunteer) and already has family and friends nearby and does not feel socially isolated. The respite service has not appeared to have a great degree of impact upon carer mental health and wellbeing.

Carer 4: 'It's more for the wife; she gets a social life'

Carer 4 looks after his wife who has Parkinson's and several types of cancer. The carer is able to leave his wife on her own for prolonged periods of time and is very active in the community. A volunteer provided through the sitting service visits the wife of the carer roughly twice a month for an hour or so. The carer seemed to view the sitting service as more of a befriending

service than respite. The cared-for enjoys the volunteer's company and is cheered up by her. The impact on the carer is minimal, predominantly as according to the interviewee's self-assessment, the need for respite is currently low. *'It wouldn't affect me if the service didn't exist, but it's just a nice bonus.'*

Fund level outcomes

The carer does have some more time to himself, but the respite has seemed to have little impact on carer wellbeing, physical and mental health or level of social isolation.

We have also identified other benefits for the cared-for that have not been captured in the grantee's theory of change:

Social intercourse: Often the carer spoke of the direct benefit that the sitting service had on the person they cared for. The volunteer improved the cared-for's mood, and they enjoyed spending time with someone of the same sex so that they could talk about 'guy's' things or 'girl's' things.

The reduction in social isolation: In some cases, the reduction in social isolation appeared to be greater for the person being cared for as often they were the more socially isolated member of the partnership.

Fund level outcomes

Overall, the sitting service has contributed to significantly improving carer wellbeing in two of the four cases interviewed as part of our qualitative research. In the other cases, the carers did not appear to be at risk of breakdown and therefore the need was relatively low. The 'dosage' (i.e. length and frequency of the service) was also low in comparison to the other cases, so a higher dosage may have led to greater impact.

Bespoke outcomes not evident in interviews

- Increased ability to be an active member of the community

All interviewees spent their respite time either alone or with family and friends, not as an active community member. Two carers interviewed were already active in the community (playing roles on local committees etc). One was no longer as she could not leave her husband for the time required to attend, and the other carer was able to leave his wife and therefore attended local community events and meetings outside of respite time.

What were the barriers and facilitators to impact?

Need: A reoccurring theme across grantees was the need of the carer. The higher the level of need to begin with, the greater the impact; conversely, the lower the level of the need to begin with, the lower the impact. Need can be segmented into several different themes:

- **Experience of being a carer:** Need for respite varied depending on how stressful they found their caring duties to be.
- **Quality and quantity of social connections:** This determines whether carers have other people to rely on to provide respite, and whether they have emotional support readily available.

- **Mobility:** Whether the carer could leave their home or not affected the impact of the programme. This was dependent on whether the cared-for could be left at home alone or leave the house with the carer, and whether they had someone else to rely on to sit with the person cared for.

Self – assessment of need: Many carers often thought someone else was needier than them and would hesitate to ask for help. It may be fair to assume that many people who could benefit from support do not put themselves forward and when offered support may downplay their need.

Duration of respite: The amount of time that the volunteers came for dictated what the carers could do with their time. For example, one carer would have liked to visit a friend in another town but the time allowed was not enough for her to do so.

What worked well and less well in delivering the intervention?

Worked well

Relationship between volunteer and person cared for

One theme that unites all four cases is the positive relationship between the volunteer and the person cared for. The cared-for looked forward to their visits and the carers felt assured that they would be safe and happy in the care of the volunteers. Reasons for this could be the effort that went into the matching process for volunteers and cared-fors, and an effective volunteer recruitment process.

The service

All carers that we spoke to had a highly positive experience of the service. The carers found the service easy to use and thought that the volunteers and staff were very friendly and helpful.

Worked less well

Duration of respite:

Longer respite sessions would allow carers to have more freedom to do what they choose with their respite.

Marketing

Better marketing of the service could allow more carers in need to access the service. Of the four interviewed, one heard through word of mouth, another dropped into the office to enquire what support they had on offer and two were referred by health and social care professionals.

Appendix N: Qualitative analysis – Westbank

How was the intervention implemented by the grantee?

Peer buddying

Carers were paired with another carer in the same locality to become peer support buddies. They were given each other's contact details and made their own arrangements to meet from there. Where possible, the buddy scheme tried to match carers with shared interests.

Peer support groups

Westbank invited carers to join peer support groups for conversation and coffee with other carers. A programme coordinator (member of Westbank staff) was present to help support carers and answer any questions.⁴ Carers had the opportunity to talk to other carers to share their experiences. The peer support groups for carers met for an hour either once a week or once a month. A programme coordinator organised and attended the meetings. In some locations, they met at a regular time and day, whilst in others they adapted the time to suit availability.⁵

Of the four carers interviewed: one carer took part only in peer buddying, two took part in only in the peer support group and one took part in both support programmes.

What was the impact, and how and why did it come about?

Peer buddying

Friendship

For one of the two carers who participated in peer buddying, the scheme was able engineer a lasting friendship. They are in contact three to four times a week, socialise with one another regularly and have been to the cinema, lunch and on walks together. As well as doing activities together, they also support one another as friends. One example of the friendship: *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.* As a result of the friendship they have someone to confide in and seek emotional support from.

Empathy

For many carers, talking to another carer is invaluable as another carer can truly empathise with their situation. Interviewees stated that it can be assuring that another carer understands them in a way that 'normal' people (i.e. someone who is not a carer) cannot, as they have a shared understanding of their experience. They can provide each other with emotional support without guilt of burdening them, as the relationship is reciprocal. *'We can offload to each other,*

⁴ Westbank explained that the intention of the project was for these members of staff to initially be present at the peer support sessions, but only for a short amount of time. They explained that in practice it took longer than expected for the carers to form relationships with one another, so most staff had to continue attending the sessions for longer than was planned.

⁵ Westbank explained that across all the groups, the expectation was that the length and frequency of the sessions would be decided by the carers based on their preferences (and that some chose to meet for two hours rather than one, for example).

she can talk about her position, I can talk about my position... it's just someone understanding how you actually feel. A normal person might not understand that whereas if you're a carer you do know how that other person is feeling.'

Acquaintanceship

Some interviewees also expressed a benefit in being able to talk about issues related to their caring role openly due to being acquaintances, rather than close friends. *'Sometimes it's easier to talk to people that you don't know about things because they're not judging you from a position of knowledge, they're taking it face value at what you're saying, they're seeing everything from your point of view, and they're not going to tell the person that you're talking about. So you can be fairly free with people that you don't know, freer than you would be with people that you do know.'*

Practical advice

Buddies help each other where possible by sharing their knowledge and providing advice. This can be about issues that specifically relate to their buddy. One example given was that a carer struggled to find socks that her partner was able to wear due to his condition and her buddy was able to solve this long standing problem. *'We were talking about socks and she said "oh, I know a site for socks on the internet that has special stockings", I've searched and searched and I couldn't find them but she knew about this site.'*

Self- regard

One carer noted that she learnt that she must think about her own wellbeing and happiness. *'This project taught me that you have to think about yourself – no one else is going to do it for you.'*

Bespoke outcomes not evident in interviews:

- Carer receptive to information

Carers that we spoke to all seemed to be very receptive to information in the first place, so the programme did not seem to make them any more receptive than they already were.

- Improved physical health

There were not any signs of improved physical health as a result of the programme apart from one buddy pair who sometimes go on walks together.

Groups

Comparison to others

Two of the three carers attending the peer support groups spoke of how attending the meetings made them realise how lucky they are in comparison to others, which made them feel more grateful for their own situation. *'I feel lucky that my family is my family as other people's situations seem difficult. It makes you feel grateful when you do meet people who are having a tougher time.'* This was the case when a carer had family and friends in the vicinity that they could rely on for emotional and practical support. This may have the opposite effect on carers in more difficult situations, although this was not alluded to in our research.

Legitimacy

Several carers stated that the people that they care for prefer not to be left at home alone, and that having a formal peer support group to attend provided them with a legitimate opportunity to leave the house and cared-for.

Practical information

Carers indicated that they were able to access practical information through other carers and the programme coordinator. For example, one carer learnt that there is an alert card in Devon and a carer should be getting a higher rate of attendance allowance, whilst another gained practical advice. *'I learnt from others how they deal with problems, it has been a great help.'* Carers attending the group sessions appear to receive more practical advice than the buddies as there are more people to consult, including a knowledgeable programme coordinator.

Acquaintanceship

Again, being acquaintances with other carers (rather than close friends) was seen as helpful. *'A lot of people are concerned that they don't want to express these things at home, their partner already feels guilty enough already that they're being a drain or a drab, to have it rubbed in by saying "ah another mess to clear up" is just not nice.'* Although this is was also mentioned by the buddies, the level of personal and open discussion in the groups was less than in the peer buddies.

Empathy

In a similar vein to the buddy scheme, some carers felt that other carers could empathise in a unique way that only other carers could. *'You can actually express the difficulties and frustrations that you're having. You don't have to explain "I love them really, but this is the problem." Everyone knows that you love or care for the person that you're caring for. What you're expressing is the frustrations are the, possibly joint frustrations that are frustrating everyone in their situation. You can just let that all hang out.'*

Social interaction

All carers increased their social interaction with other carers. For one carer who was socially isolated the programme decreased their social isolation. *'I'm delighted with the programme, I don't feel so socially isolated anymore.'*

Fund level outcomes

On the whole, the programme had more impact on carers' wellbeing and mental health and less impact on physical health and feeling less isolated. It contributed to wellbeing and mental health as it provided emotional and practical support to carers. It had less of an impact physical health as the programme did not too carry out any activities that directly targeted this and not all carers felt socially isolated.

What were the barriers and facilitators to impact?

There were a number of barrier and facilitators that enabled or impeded impact and participation.

Need

A reoccurring theme across grantees is the need of the carer. The higher the level of need to begin with, the greater the impact; conversely, the lower the level of the need to begin with, the lower the impact.

Need can be segmented into:

- **Quality, quantity and geographical location of social connections:** This can determine whether carers have other people to rely on for social interaction, and whether they have emotional and practical support readily available. If carers have rich social connections, then their need for emotional and practical support from other carers diminishes; whereas if social connections are poor, need is increased and therefore the programme has more potential for impact on carers.
- **Carer wellbeing:** whether carers are emotionally, mentally and socially well and have financial means to entertain oneself can influence their need for peer support. If their wellbeing is high, impact is minimal; whereas if their wellbeing is initially low, greater impact can be seen.

Compatibility

Depending on how well participants 'gel', the level of trust and desire to ignite a meaningful relationship varies. One carer stated that he did not 'gel' with other participants so often has small talk about topics such as their pets. As such, the carer has no intention of staying in touch with any of the other carers once the peer support group ceases to exist. Another carer shared that although she had collected a few contact details, most of the group was unwilling to share theirs. It may be fair to assume that some carers may decide not to continue attending the support group, once they have judged that there are not any carers that they click with. Similarly, some buddies are highly compatible and some are not. We would assume that this is fairly normal, as in any newly formed group of unknown individuals, not everyone would find someone that they naturally gel with.

Barriers and facilitators to participation

Accessibility

Interviewees stated that accessibility hinders their ability to participate. Accessibility is determined by how long they can leave the person that they care for on their own and whether there is someone else that can look after them or not. If a carer is able to access the programme with ease then this facilitates participation, whereas if it is difficult to access, participation is impeded.

It should be noted that many cared-for people have conditions which decline (in many cases sparked by a fall), so that accessibility diminishes in tandem with the cared-for's conditions and eventually carers cannot leave them. One carer stated: *It's not that people didn't want to come but it's difficult when you're leaving someone behind.*

Needs of those cared-for have prevented many carers from attending the peer support groups. In one group there were only three regular attendees. According to one of the regular

attendees interviewed, most of the other carers did not come regularly as they could not leave the person that they care for for the duration of the meeting without being worried.

Self –assessment

Many carers tend to think that someone else is more in need than them so hesitate to ask for support. If a carer self-assesses as in need of support, then they are more likely to put themselves forward to participate in carer support programmes. If they self-assess as not needy enough for support, then this is a barrier to participation. *'I should have been going out and asking for help. I thought other people are more needy.'*

Perceived benefit

Carers decide to participate in peer support partly depending on perceived benefit that they see in the programme. If they anticipate benefiting from the programme, then they are more likely to participate, whereas if they envisage there to be little benefit to them, then they are less likely to participate in carer support programmes.

What worked well and less well in delivering the intervention?

Worked well

Flexibility (for buddies)

Buddies liked how the scheme was very flexible to suit their wants and needs.

Programme coordinator (for groups)

According to interviewees, the programme coordinator was instrumental in making the peer support groups happen. Coordinators checked to see if the carer could attend and sometimes arranged the meetings around carers' schedules. They also helped to 'gently spark' conversation during meetings. Carers believed that without the programme coordinators the group would not continue.

Worked less well

Accessibility (for groups)

The geographical location of the meetings made it difficult for carers that live in rural locations to attend. It should be noted that a group meeting in one rural location was organised, yet it only succeeded in attracting two attendees that had already been paired up as buddies.

Comparison between the two peer support programmes

One carer who attended both peer support programmes provided useful insight into comparing them.

With the buddy programme, the carer felt that the relationship was deeper so that they could discuss personal issues and contact when in need of emotional support. The buddy programme was said to be more convenient as they could decide to meet on their own terms. For example, the carer went to visit her buddy as her buddy could not leave the person she cares for home alone. They also email each regularly which creates more of a lasting bond and they can communicate however frequently they wish. There is also no need for a coordinator; there is

only a need for the buddies to be matched. *'I think the meetings are great but for sustainability I think the buddy relationship thing is more likely to prove really useful.'*

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