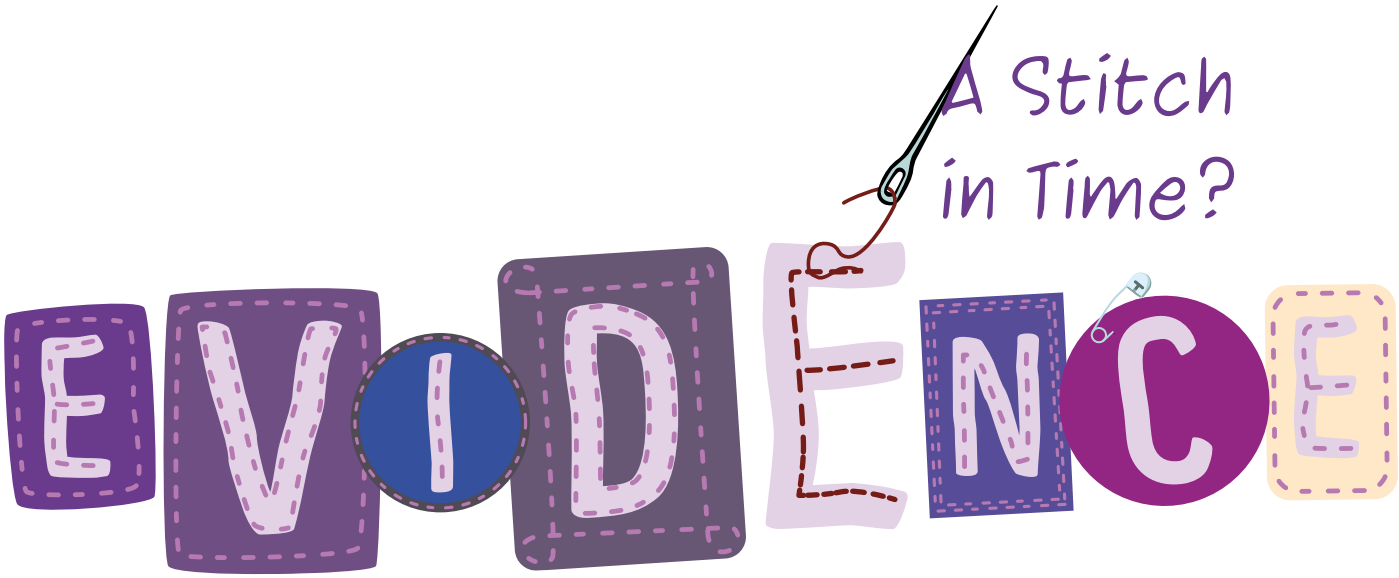


# "A good outcome" Evidencing how local carer organisations are supporting carers to achieve their personal outcomes

Evaluation Support Scotland
Coalition of carers in Scotland
University of Strathclyde Glasgow
jit joint improvement team
creativity, collaboration and continuous improvement
The Scottish Government

# "A good outcome"

# Evidencing how local carer organisations are supporting carers to achieve their personal outcomes

Author: Emma Miller

# Introduction

*A Stitch in Time?* is an action learning programme, supporting the third sector to collect and present evidence to explain, measure and prove how the third sector contributes to the agenda Reshaping Care for Older People (RCFOP), which is about refocusing on earlier intervention. Through 'A Stitch in Time?' practitioners and others identified unpaid carers as integral to the lives of older people who experience a decline in their health, supporting their relatives and friends to continue living in the community.

Carer organisations, in turn, play a critical role in supporting carers to continue in their role. They work to achieve personal outcomes important to carers of various ages. There is a challenge for these organisations to be able to evidence the preventative work that they do, as it is always difficult to prove that something didn't happen as a result of support. To address this, a project was developed in 2014 by Evaluation Support Scotland (ESS) and the Coalition of Carers in Scotland (COCIS) to develop a logic model as a framework for evaluation. That work also involved gathering evaluation materials and examples from participating carer organisations, which are available in the accompanying report. This part of this project involved a brief literature review.

The literature review explores the evidence around carers outcomes and the impact of the caring role. This is far from a comprehensive review of the formal research evidence. Rather, examples have been selected to evidence short, medium and longer-term outcomes for carers, as outlined in the logic model for the project. This is partly an adaptation of a previous literature review for A Stitch in Time? A total of 18 studies were included, representing formal academic research as well as research by voluntary organisations, or both. Preference was given to UK examples, although there is also one study from Finland, one from Australia and one international review of the evidence. Priority was also given to studies where the full report is easily available online so that carer organisations can access the full documents. Some of the studies identify needs and outcomes important to carers (**section 1**), while the majority consider outcomes in relation to different types of support and interventions (**section 2**). Preference was given to the kinds of support usually provided by carer organisations. It should be noted that, given the brevity of this review, there's no attempt to assess the quality of the evidence presented.

Although the search for literature was brief, it was notable that there was limited research evidence on the importance of process outcomes. Evidence from recent research in Scotland highlighted the importance of good quality conversations to carers (Tsegai and Gamiz 2013). The process outcome highlighted here is being listened to, although there are other benefits such as feeling valued and having an opportunity to reflect. This helps carer organisations to evidence that the everyday conversations they have with carers already achieve positive outcomes.

# Summary of the literature included in this document

The first six studies in **section 1** of the grid below describe the needs of carers, mainly in the UK, and corresponding outcomes. The first two references are from the same research by Michael Hirst, emphasising the importance of psychological wellbeing for carers, the increased risks to wellbeing with the intensity of the caring role, and at the start and end of caregiving (1, 2).

Studies 3 and 4 demonstrate that carers felt unprepared or inexperienced for their new role, pointing to the importance of information and education. Study 3 relates to carers of older people being discharged home from hospital in Australia. It emphasises that inclusion in discharge planning and timely and appropriate education about the person's condition and support would have helped. Study 4, a UK academic study, highlights carers views that information and emotional and physical support would have helped them to overcome their sense of inexperience. The last two studies in section 1 (5, 6) are from Carers UK, based on their own state of caring survey. The first (5) considers how carers can end up in crisis, with emphasis on their own health breaking down or losing their employment. The second (6) highlights the risks of social isolation for carers. Both studies recommend key supports to address these issues.

**Section 2** focuses on the types of support which research shows are effective in achieving outcomes for carers. It is worth noting that several studies identify that carer support enables carers to maintain the relationship with the person they care for and continue in their caring role, and that this, in turn, supports the cared for person being able to remain in the community. Caution is required in considering the evidence, as in some cases there is a lack of evidence due to insufficient research being undertaken. References 7 and 8 both relate to research by Linda Packard, which considered the literature on the effectiveness and cost-effectiveness of a mix of services provided to older people and to carers. While institutional respite was effective in reducing carers' subjective burden, it could, in some cases, hasten the need for institutional care. While social work counseling was seen as effective and cost effective in improving carer outcomes, it was emphasised that most carers (in England and Wales) would not have access to social workers. This has implications for the role of carer organisations.

The next four studies (9-12) all relate to respite care of various kinds. The study from Finland (9) highlights the benefits to carers of institutional respite for older people. The other three studies highlight that home sitting services (10) and short breaks (11, 12) were valued by carers. Core outcomes identified are carers having a life of their own and being able to continue in the caring role, as well as improved relationships between the carer and cared for person.
Study 13 considers an expert carer training programme for people in intensive caring roles in Lothian, identifying a range of outcomes including improved confidence, knowledge and skills. Studies 14 and 15 focus on the importance of information and education emphasising the importance of information which is timely and targeted according to the individual carer's needs. These last two link back to studies 3 and 4 in **Section 1**, which highlighted the importance to carers of information and education.

Study 16 is a systematic review of the literature undertaken jointly by carer organisations and a university. It provides a detailed review of 107 empirical studies, considering strengths and limitations of the evidence. It also provides useful detail on the type of mechanisms associated with improved outcomes.

Study 17 is authored by two carer organisations and makes the case for investing in carer's wellbeing to avoid spend on hospital admissions and residential care.

Finally, study 18 may be of interest to carer organisations in Scotland who are focusing on outcomes in assessment, as it highlights the value placed on good conversations between carers and staff.

# The outcomes identified in the logic model for this project

## Short term outcomes include:

- Outcomes for our service e.g. we reach people
- Outcomes for our carers e.g. better informed and being listened to
- Outcomes for the cared for person e.g. able to continue living where they want
- Outcomes for professionals e.g. increased awareness of the needs of carers

## Medium terms outcomes for carers include:

- Having a life outside caring
- Improved confidence in caring role
- Having a greater say/control over the support and services received
- Improve ability to manage and enjoy changing relationship with person cared for
- Positive relationship with practitioners
- Improved wellbeing
- Improved satisfaction with caring role

## Long term strategic outcomes include:

- Carers are able to continue in their caring role
- Carers are able to end caring role/move on when caring comes to an end
- Cares are able to achieve their personal outcomes
- Carers are treated as equal partners in care

# Evidence of carer organisations' role in supporting unpaid carers

| Section 1: Evidence of the needs and outcomes of carers | | | |
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| **Main Outcome(s)** | **Reference and link if available** | **Place of origin and methods** | **Evidence** |
| **1. Improved wellbeing** | Hearts & Minds: The health effects of caring, *Research summary*<br><br>Michael Hirst 2004<br><br>Carers Scotland, Glasgow | UK<br><br>Research uses data from British Household Panel Survey 1991 - 2000 | Carers often need additional support for health and wellbeing because of their caring responsibilities. The risk of psychological distress increases with the intensity of caring activities. Adverse effects on carers' psychological well-being are most pronounced around the start of care episodes and when care-giving ends. Ongoing health effects can persist beyond the end of caregiving. |
| **2. Improved wellbeing**<br><br>**Carers able to move on when caring role ends** | Carer distress: A prospective, population-based study<br><br>Michael Hirst 2005<br><br>Social Policy Research Unit, University of York, UK<br><br>Social Science & Medicine Volume 61, Issue 3, | UK<br><br>Based on data from the British Household Panel Survey covering 3000 would-be carers, 2900 former carers, and 11,100 non-carers during the 1990s; their psychological well-being was assessed at annual intervals using the General Health Questionnaire.<br><br>This academic journal article provides more detail on the research summary cited | Carers providing long hours of care over extended spells present raised levels of psychological distress, women more so than men. Compared with non-carers, risk for onset of distress increases progressively with the amount of time devoted to caregiving each week. Ongoing care increases their susceptibility to recurring distress, and adverse health effects are evident beyond the end of caregiving episodes.<br><br>The findings underline the importance for effective support and health promotion of early identification of carers, monitoring high-risk groups, timing appropriate interventions, and targeting resources. |

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| | Pages 697–708 | above | |
| **3. Carers are better informed**<br><br>**Improved ability to manage and enjoy changing relationship with person cared for**<br><br>**Carers have increased confidence in caring role** | Becoming a carer for an Elderly Person after Discharge from an Acute Hospital Admission<br><br>Grimmer, K. Moss, J and Falco,J. 2004<br><br>The Internet Journal of Allied Health Sciences and Practice<br><br>VOL 2 No 4<br>ISSN 1540-580X | Australia<br><br>Design: Observational study collecting qualitative data monthly for 6 months following patient's discharge from hospital and attempted return to independent living in the community. Setting: 4 South Australian acute hospitals Subjects: 334 unpaid carers were nominated by 100 patients. 24 carers participated (17 elderly spouses, 3 younger family members, 4 neighbours/friends. | Highlights carers' perceptions of being unprepared for their role, and frustrations at the long-term and significant changes to their lives from the caring role. Many carers thought the role was imposed upon them without real choice, and their own fitness for their new role had not been considered during discharge planning. Carers said they were provided with little information about how to care for their relative.<br><br>Stress developed in many carer-patient relationships and patient and carer morale was often low for months post discharge.<br><br>Carers indicated that their tasks could have been easier by more timely, targeted education about the patient's condition and their role. They would have liked inclusion in discharge planning, and more timely and appropriate provision of post-discharge services |
| **4. Carers are better informed**<br><br>**Carers have increased confidence in caring role**<br><br>**Improved wellbeing** | Grounding Constructions of Carers: Exploring the Experiences of Carers through a Grounded Approach<br><br>Michael Burton 2008<br><br>Br J Soc Work 38 (3): 493- | UK<br><br>Small sample of 14 carers, individual interviews | Carers reported that they wanted to care, but that they felt their *inexperience* made day-to-day life more difficult as they adjusted to their new role. They were concerned that this was detrimental to the person. Some felt that this inexperience was compounded by a *lack of information* provided to them. Participants described difficulties understanding their new role, the role of health and social services and how to meet the care needs of the person they cared for. Many felt that information would have addressed their concerns and helped them through their inexperience |

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| | 506.doi: 10.1093/bjsw/bcl350 | | Other carers felt that a *lack of support*, both emotional and physical, aggravated this period. Carers highlighted that professionals did not understand or care about the difficulties they were facing or consider the circumstances that the carers faced at home. |
| **5. Improved wellbeing**<br><br>**Carers are able to continue in their caring role**<br><br>**Cared for person able to continue living where they want**<br><br>**Having a life outside caring** | Carers at Breaking Point<br><br>Carers UK 2014 | UK<br><br>Findings from Carers UK's State of Caring Survey 2014, examining the experiences of over 5,200 carers – asking if they have ever reached breaking point, the causes of crisis and what support would have prevented it. | The survey findings show that most carers have been pushed to breaking point, with a quarter requiring medical care as a result. 1 in 9 said that formal caring arrangements had to be put in place while the carer recovered and 1 in 5 were forced to give up their jobs because they were in crisis. Among the key recommendations of relevance to carer organisations are ending financial hardship, improved access to information and advice, flexible and affordable care which allows carers to continue working and to have a life outside caring |
| **6. Having a life outside caring** | Alone and Caring<br><br>Carers UK 2015 | UK<br><br>The findings are based on Carers' UK State of Caring Survey 2014 | The survey findings include that 8 in 10 carers have felt lonely or socially isolated as a result of their caring responsibilities, with many losing touch with friends and family, and almost half experiencing difficulties in their relationship with their partner because of caring.<br><br>Recommendations are to improve public |

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| | | | understanding of caring and disability, and to raise awareness of emotional and peer support. It is also identified as crucial that carers can access the practical and workplace support they need to spend time with other family and friends and to have a life outside caring. |
| **Section 2: Evidence of the role of support and services in improving outcomes for carers** | | | |
| **7. Improved wellbeing**<br><br>**Cared for person able to continue living where they want** | The effectiveness and cost-effectiveness of support and services to informal carers of older people<br><br>Linda Packard 2004<br><br>Personal Social services Research Unit, LSE<br>2004 | England and Wales<br><br>This literature review of the effectiveness and cost-effectiveness of support and services to carers of older people was one of three commissioned by the Audit Commission as part of its study of support for carers of older people in England. | One of the aims in providing support and services to carers is to reduce negative psychological effects. This review considered in-home respite care, institutional respite care, carer support groups, social work and counselling. It also considered daycare and home help/care services.<br><br>The evidence suggests that both services aimed at the older person, such as home help/care service, and services aimed at the carer, such as daycare/institutional respite care, can be effective in improving the welfare of carers and reducing the negative psychological effects of caring. Both types of service can also be effective in delaying the admission of the older person to institutional care and both are consequently in the interests of older people who wish to remain in the community.<br><br>It is recommended to read the summary of the evidence (starts p57) to get more detail on the outcomes of different forms of support. |
| **8. Improved wellbeing**<br><br>**Carers are** | The effectiveness and cost-effectiveness of support and services | England and Wales<br><br>(Literature review see Packard above) | In the international literature on interventions for carers, counselling is cited as an effective measure to relieve carer distress<br>In England and Wales, counselling/therapeutic |

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| **able to continue in their caring role**<br><br>**Cared for person able to continue living where they want** | to informal carers of older people<br><br>Linda Packard 2004 Personal Social services Research Unit, LSE<br><br>Pages 41-43 | | social work has been found to be effective *and* cost-effective in reducing subjective carer burden However, only a minority of carers England and Wales are likely to come into contact with qualified social workers. |
| **9. Improved ability to manage and enjoy changing relationship with person cared for**<br><br>**Carers are able to continue in their caring role** | Informal carers of older family members: how they manage and what support they receive from respite care<br><br>Sirpa Salin, Marja Kaunonen, Päivi Åstedt-Kurki 2009<br><br>Journal of Clinical Nursing<br>Volume 18, Issue 4, pages 492–501 | Finland<br><br>Methods. The data were collected among informal carers who regularly use respite care services (*n* = 143). Two structured questionnaires were used: the Carers' Assessment of Managing Index (Nolan *et al.* 1995) and an index developed by the researchers. | Informal carers who provided care for younger individuals or people who needed less help had a better quality of life. Spouse carers and older carers were less satisfied with their quality of life. Periods of respite care had a major influence on informal carers' quality of life. Care periods remained rather isolated episodes in the lives of the older patients in that there was hardly any discussion at the institution about the family's situation, the objectives of respite care, or about how the informal carer was coping. The most useful coping strategies involved creating alternative perspectives in the caring relationship. |
| **10. Carers are able to** | Time and space : carers' views about | UK | Respite care was perceived as a service which, on balance, facilitated informal care and enabled care |

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| **continue in their caring role**<br><br>**Cared for person able to continue living where they want**<br><br>**Having a life outside caring** | respite care<br><br>Mark Ashworth<br>Anna H. Baker MA<br>2000<br><br>Health & Social Care in the Community<br>Volume 8, Issue 1, pages 50–56, January | Qualitative study involved 23 carers being interviewed about their experiences of respite care and qualitative themes were derived from the transcripts | to continue at home for longer than would otherwise have been possible. The particular component of this service that was most valued was the option of a home-sitting service. |
| **11. Improved wellbeing**<br><br>**Improve ability to manage and enjoy changing relationship with person cared for**<br><br>**Carers are able to continue in their caring role**<br><br>**Having a life** | Rest assured? A study of unpaid carers' experiences of short breaks<br><br>IRISS, Shared Cared Scotland, the Coalition of Carers in Scotland and MECOPP 2012 | Scotland<br><br>The study explored, from the carers' perspective, the benefits of short breaks (provided by formal services and family and friends), good practice in planning and provision, and areas for improvement. The research involved a Scotland-wide survey, focus groups and interviews. | Over half of survey respondents (57%) had not had a break from caring. Black and minority ethnic (BME) carers were less likely to have had a break than carers overall; 63% of BME respondents had not had a break from caring. However, short breaks were seen as fundamental to carers to help alleviate the physical and emotional demands of caring and to sustain the caring relationship, preventing admission to residential care<br><br>Those who experienced a short break were asked about the benefits. Common responses were 'recharging the batteries', having a chance to 'chill out', 'time to myself', a chance to catch up on quality sleep and a change from 'the routine' of caring.<br><br>Breaks from caring enabled carers to spend time on other relationships including partners, other |

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| **outside caring** | | | children and friends. Breaks helped carers to top up vital reserves of patience and tolerance. The anticipation of having breaks was part of the positive impact. |
| **12. Improved wellbeing**<br><br>**Carers are able to continue in their caring role**<br><br>**Improved ability to manage and enjoy changing relationship with person cared for** | Creative Breaks 2012-13: Evaluation of Time to Live Projects<br><br>Adele Laing 2014<br><br>Shared Care Scotland | Scotland<br><br>This evaluation examines The Time to Live short breaks projects running from October 2012 through to September 2013. Shared Care Scotland monitored and evaluated each project using Mid-term and End of Grant Reports. The evaluation was based on these reports and telephone interviews with the projects | The Time to Live strand is part of the Creative Breaks programme and awards grants directly to individual carers so that they can arrange and pay for the short break that suits them best. The evaluation found improved physical, mental and emotional wellbeing for carers. Carers were better supported and more informed about sources of help. Enhanced relationships between carers and those they care for was identified as of benefit to both parties. |
| **13. Carers are better informed**<br><br>**Carers have increased confidence in caring role**<br><br>**Improved wellbeing** | Caring with Confidence Lothian 'Expert Carer' Training Pilot *Summary Report*<br><br>Dr David Watson & Janice West<br>School of Health<br>Glasgow Caledonian University<br>Professor Timothy B | Scotland<br><br>Mixed methodological approach incorporating a quasi-experimental pre-test/post-test design with qualitative focus groups and interviews. | The aim of the Caring with Confidence project was to develop a comprehensive programme of 'expert carer' training determined and delivered locally. The project was targeted at those caring 50 or more hours a week or carers whose health was being adversely affected by their caring situation, enabling them to build on their own expertise and gain further knowledge and confidence from health professionals and peer support. Carers reported improved outcomes including:<br>• More positive about their caring situation;<br>• More confident in their caring role; |

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| | Kelly<br>University of Dundee School of Education, Social Work and Community Education<br>2009 | | • Caring had less of a negative impact on their physical health;<br>• More able to manage the caring situation;<br>• Less isolated;<br>• More supported;<br>• More confident talking with care professionals about what they needed;<br>• More positive about their financial situation;<br>• More knowledgeable and skilled |
| **14. Carers are better informed**<br><br>**Improved wellbeing**<br><br>**Carers are able to continue in their caring role** | A Road Less Rocky – Supporting Carers of People with Dementia<br>*Executive Summary*<br><br>Liz Newbronner, Ruth Chamberlain, Rachel Borthwick, Martin Baxter, Caroline Glendinning<br>2013<br><br>Carers Trust | UK<br><br>The report brings together the findings from the research, which had three stages:<br><br>A limited literature review of recent research with carers of people with dementia.<br><br>Interviews and focus groups with a total of 46 carers in four locations across the UK (two in England, one in Scotland and one in Wales).<br><br>A national survey of carers of people with dementia, which elicited 325 responses | The review found a reasonable number of papers on the experiences of carers of people with dementia, but a dearth of empirical research on interventions to support carers of people with dementia.<br><br>There were critical points along the journey where carers most value information and where support is most needed. However, they are not necessarily neatly sequential, and may be affected by many other factors. Professionals and service providers need to check that carers have the information and advice appropriate for current challenges and that carers know where to go for further information and advice when future difficulties arise. Failure to recognise carers' needs at these points risks the breakdown of care-giving and the carer's health and other costs for carers and wider society. |
| **15. Carers are better informed** | Meta-review of international evidence on | International review | The strongest evidence of effectiveness of any sort from the meta-review was in relation to education, training and information. Interventions of this |

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| **Carers have increased confidence in caring role** | interventions to support carers. Working Paper No. DH 2394<br><br>Gillian Parker<br>Hilary Arksey<br>Melissa Harden<br>2010 | | type, particularly when active and targeted rather than passive and generic, increase carers' knowledge and abilities as carers. There is some suggestion that this might also improve carers' mental health or their coping. However, this latter conclusion remains to be tested rigorously.<br><br>Beyond this, there is little secure evidence about the interventions cited. These authors emphasise this is not the same as saying that these interventions have no positive impact, but that better research is needed. |
| **16. Improved wellbeing**<br><br>**Carers are better Informed**<br><br>**Carers have increased confidence in caring role**<br><br>**Having a life outside caring** | A Systematic Review of Interventions for Carers in the UK: Outcomes and Explanatory Evidence<br><br>Elizabeth Victor<br>2009<br><br>PRTC, Young Carers International and the University of Nottingham | UK<br><br>The review is restricted to the specific context of the UK since the introduction of community care reforms in 1990. 107 studies based upon empirical research were included | There was a reasonable amount of evidence identified about interventions offering: access to support; emotional and social support; education and training; and carer breaks. There was little evidence about: personalised support such as direct payments; interventions targeted at carers' physical health; interventions aimed at supporting carers employment; befriending schemes; and complementary therapies.<br><br>Potential mechanisms underlying the achievement of outcomes by information services, as suggested by the evidence, included helping carers to feel less alone and that back up support was available if necessary, as well as providing access to the resources offered by services<br>The review found some evidence that support workers could support emotional wellbeing of carers, but this was not definitive. There was tentative evidence of the role of Carer Support |

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| | | | groups in improving emotional wellbeing. There was evidence of improved knowledge in relation to stress management and counselling, with mixed evidence on emotional wellbeing. Carer training could validate existing expertise and provide new knowledge and understanding leading to new skills<br><br>The potential value of flexibility, tailoring and personalisation of services was apparent for a number of types of intervention.<br><br>The exec summary provides useful details |
| **17. Improved wellbeing**<br><br>**Cared for person able to continue living where they want** | Supporting Carers: The Case For Change<br><br>PRTC and Crossroads | Reviews evidence from Randomised Control Trials and peer reviewed journals and draws on the resources of the two organisations involved the report for evidence | Makes the case that spending more on breaks, training, information, advice and emotional support for carers reduces overall spending on care by more than £1bn per year on unwanted admissions, delayed discharged and residential stays. Highlights examples of breaks, counseling and training that have shown success in helping carers to maintain their health and quality of life and that of the person cared for. The examples are from the Carers Hub created by PRTC and Crossroads |
| **18. Carers are listened to** | Carers' assessment and outcomes focused approaches to working with carers<br><br>Abenet Tsegai and Rebecca Gamiz 2013 | Scotland<br><br>Included focus groups (4) with carers and practitioners and analysis of documents including blank and completed carers assessments | It was found that the conversation between carer and staff can in itself lead to positive outcomes. However it was also seen that outcomes-focused conversations require considerable skill at an individual level, as well as support at an organisational level, to create an environment for individuals to develop their practice. |

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# A Stitch in Time?

**A Stitch in Time? is a partnership project to support the third sector to collect and present evidence about its contribution to Reshaping Care for Older People (RCOP). The programme runs from April 2013 to March 2015 and focuses on third sector organisations working with older people and carers in Lothian.**

## A Stitch in Time? publications

**A model to explain the third sector contribution to Reshaping Care for Older People**

**Indicator Bank for third sector outcomes for older people**

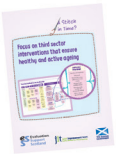
**Focus on third sector interventions that make the physical and social environment more age friendly**

**Focus on third sector interventions to enable older people to keep or be more socially connected**

**Focus on third sector interventions that allow older people to stay positive and in control**

**Focus on third sector interventions to enable older people to keep or be more financially and materially secure**

**Focus on third sector interventions that make the system work better for older people**



**Focus on third sector interventions that ensure healthy and active ageing**

To accompany this series there are **evaluation case studies** and a number of **evidence reviews**.
To see all publications associated with A Stitch in Time please see Evaluation Support Scotland website.

**Evaluation Support Scotland (ESS) works with voluntary organisations and funders so that they can measure and report on their impact.**

Evaluation Support Scotland

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