Older Carers’ Voices and Stories: the Personal Impact of Funding
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Acknowledgements

Our wholehearted thanks go to all carers who gave up their precious free time and contributed to this report, Carers Trust Network Partners who continue to deliver excellent services meeting the needs of often marginalised, isolated and forgotten carers and to People’s Health Trust for recognising the need and supporting these vital projects.

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Introduction

This publication is all about older carers. Their voices. Their experiences. Their lives.

This report aims to bring together older carers’ thoughts and feelings about dedicated services and activities delivered by Carers Trust Network Partners under the Improving Health Outcomes programme and the positive impact it has had on their lives. Opinions have been gathered from 39 older carers who attended six focus groups held with Network Partners at Redbridge Carers Support Service, Derbyshire Carers Association, Helensburgh and Lomond Carers, Hillingdon Carers, North Argyll Carers Centre and Carer Support Wiltshire.

Older carer’s personal views about targeted services and activities, which would not have existed without the financial support of People’s Health Trust, are combined with five real life case studies. These provide a taste of the challenges older carers have to face on a daily basis and how just a little funding and support can have a significant and often life changing impact on carers’ health and wellbeing.

Through the Improving Health Outcomes programme, each Network Partner devised their own project made up of different activities and services based on identified local need and demand while addressing the key programme objectives. In different geographical areas older carers could access a range of services or activities including respite care, counselling, holistic therapies, arts and craft courses, weekend breaks, walking groups, support groups, training, legal and financial advice, gardening, benefits advice and day trips.

Feedback from the six focus groups, facilitated by Carers Trust staff, was predominantly from older carers who had accessed the Improving Health Outcomes programme. All of the case studies, from carers across the UK, tell the stories of the families who received support, from Network Partners, through the programme.

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Carers Trust is a major new charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with Network Partners – a unique network of 116 independent carers centres, 59 Crossroads Care schemes and 105 young carers services. Together we are united by a shared vision for carers – to make sure that information, advice and practical support are available to all carers across the UK.

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People’s Health Trust is an independent charity addressing health inequalities by investing in local organisations with great ideas to create fairer places to grow, live, work and age. People’s Health Trust is funded through 51 society lotteries, each designed to raise money to address health inequalities in a separate part of England, Scotland and Wales. The society lotteries operate through The Health Lottery. [www.peopleshealthtrust.org.uk](http://www.peopleshealthtrust.org.uk)
The funding

In 2011, The Princess Royal Trust for Carers and Crossroads Care were selected to coordinate the delivery of health related projects managed by carers centres, Crossroad Care schemes and young carers services across England, Scotland and Wales.¹ As part of its Healthy Places, Healthy People funding programme, carers centres and schemes in locations pre-determined by People’s Health Trust were invited to submit project proposals detailing how they would spend funding to develop effective services to improve health outcomes for either older carers (those aged 60 plus) or young adult carers (aged 16–24) from socio-economically disadvantaged communities. The project was called Improving Health Outcomes.

The first round of funding provided grants to 31 organisations in 30 different geographical areas across England, Scotland and Wales (see Appendix). Of the 31 organisations, 23 delivered projects targeted at older carers and eight at young adult carers. Each area received £40,000 to be spent in 2012/13.

The second round of funding provided continuation grants to 11 organisations (two were replacement organisations for Network Partners in the first round) across the three countries, nine received grants of £40,000 and two of £20,000 each (see Appendix).

The key objectives for the projects were:

- To improve the self-esteem, wellbeing and life chances of young adult carers aged 16–24, at a crucial transition stage of their life, helping them to make informed choices about every aspect of their own health (physical and mental) and supporting them to move from appropriate children’s services to adult services.

- To improve the emotional and physical health of older carers by helping them secure the benefits they are entitled to, making available appropriate health assessments and health related activities, offering support with emergency planning and planning for the future and facilitating access to breaks from their caring responsibilities in the way they choose.

The two key outcomes were to achieve:

- Empowered young adult carers, who will have increased self-esteem and the emotional strength and confidence to make the right life choices that will help them to achieve personal goals and aspirations in their adult life.

- Older carers better equipped for their caring role, feeling more confident to live fulfilled and healthier lives alongside their caring responsibilities and having an increased sense of wellbeing.

¹ Carers Trust is a new charity formed by the merger in 2012 of The Princess Royal Trust for Carers and Crossroads Care. Carers centres and schemes are now known as Network Partners.
The benefits of the Improving Health Outcomes programme in older carers’ own voices

This section of the report highlights some of the impact of the Improving Health Outcomes programme for older carers. It focuses on older carers who have overcome some of their daily challenges and accessed the diverse range of projects and activities provided by Carers Trust Network Partners.

A chance to be me again!

Many of the older carers, in different focus groups, highlighted that they felt they had lost themselves and had disappeared in their caring role. They emphasised that the activities offered through the Improving Health Outcomes programme gave them the opportunity to realise they are not alone and to re-engage with themselves, and as a consequence feel more able to fulfil their caring role.

Many commented on the fact that a carer’s life is not really their own. This is summed up by one carer:

“I have been in a caring situation for a long time. You don’t get to be the person you are inside; you don’t have the mental, emotional or physical energy.”

Other carers said:

“[Accessing services] made me realise I’m not on my own in a carer’s situation.”

“[At] group sessions … I unload … talk things through … recognise other people have the same problems.”

“[Home] would be a prison if I didn’t have an outlet … the carers centre … for problems.”

“You meet other people, that’s very important, it gets you out a bit more.”

“Something to look forward to.”
“An opportunity to share concerns and gain support from other carers in similar situations.”

“You can forget about the responsibilities of caring for a while.”

“In terms of friendships made … it doesn’t stop here … contact continues outside of the classes and you have a sense of being part of a ‘family’.”

“Good to be able to plan things outside of caring and to be able to do something for yourself and fit it around the caring role.”

“Gives hope that you can have a life outside of caring.”

“Recharges your batteries and keeps you energised.”

**Weekend breaks**

Through the Improving Health Outcomes programme, some of the projects funded older carers to have weekend breaks. The opportunity to access time away which someone else had organised had a huge impact on carers including their emotional wellbeing – one had not had a holiday for over ten years. Heartfelt comments included:

“A release for the whole weekend, not a carer, I can be a person again.”

“Played stupid games carrying on like teenagers.”

“Formed friendships that never had.”

“Gives you the strength to carry on.”

“Can’t put a monetary value on it, can’t function without it [time away].”
Therapies and counselling

A range of holistic therapies were also provided including massage and aromatherapy. These had an enormous impact, not just the therapy itself but also the break it gave carers, giving them an increased sense of wellbeing.

“Me time I don’t get, the first me time was a bit strange.”

“Would have gone to the doctors, massage helped me relax and feel better.”

“Takes you away from stress.”

The provision of counselling sessions was a crucial lifeline for some:

“I benefitted from the counselling. Helped to focus on ‘what do you want, what do you need?’ rather than what the cared for person wants and needs.”

“Incredibly valuable.”

“Nervous breakdown on the way without the counselling.”

Social events

Other more social events included local walks in Scotland and visits to local gardens – a welcome break from the usual routine increasing the confidence of sometimes demoralised carers:

“Wouldn’t go out on my own but because being organised and friendly folk going …”

“All chat and relaxing, really good outings.”

“Walking … group … was very good.”
Training courses

A number of Network Partners delivered a wide range of training courses including dealing with stress, power of attorney and accessing benefits. These proved to be important interventions. For example, most older carers found the techniques they had learned in meditation classes helpful to use at home. They were given a guided meditation CD which they use to help relax, enabling them to cope better with the challenges they face. This has a positive impact on their emotional wellbeing and better equips them to fulfil their caring role.

“Sometimes you don't have time to think about things ... happiness, stress etc ... Mindfulness course ... makes you think about yourself.”

“Stress management course ... lot of nervousness coming in to meet people you don't know. But it got people talking ... good to work through stress ... learning techniques ... to deal with stress.”

“I got more out of that than anything, loved it, very therapeutic [the art class].”

Impact of Improving Health Outcomes projects on physical health

Of the 21 carers asked, who had specifically accessed the Improving Health Outcomes programme, 12 (57%) felt that the project had had a beneficial impact on their physical health (not all Network Partners delivered projects specifically focussed on improving physical abilities).

“You don’t always hear about these things ... the carers service ... Caring ... It’s what you do, it’s not an issue until the strain tells on you mentally and physically.”

“Poor mobility at first, but much improved now.”

“Joint stiffness had decreased and the exercises get easier over time.”
“Exercises are challenging, but everyone can take things in their own stride and the group are very supportive.”

“Feeling able to do more generally.”

“Being able to relax.”

“Improved flexibility and joint control.”

“There are social as well as physical benefits and you can really enjoy having a laugh with others.”

“Everyone involved in the activities have ‘gelled’ as a group.”

“There is a real sense of achievement in being able to do the activities which seem quite challenging at first.”

One couple, who are co-carers, felt that taking part in activities brought them closer together, they had lost 2st between them and were taking less medication as a result.

Impact of Improving Health Outcomes projects on emotional wellbeing

Of the 21 carers asked, who had specifically accessed the Improving Health Outcomes programme, 18 (85.7%) felt that the project had had a beneficial impact on their emotional wellbeing.

“If it wasn’t here … the organisation … lots of people would have breakdowns.”

“Combats depression.”

“Boosts confidence and morale.”

“There is a positive impact on the person being cared for in that you feel happier and better able to cope and this improves relationships at home.”
“The activities make you feel calmer and allow you to de-stress.”

Some older carers found a card making project an enjoyable creative process which gave them a sense of pride when taking their cards home to show their families.

Positive unexpected outcomes from the Improving Health Outcomes projects

Participants from two of the focus groups highlighted that as a result of the project they have now formed their own strong social networks and organise their own informal social activities including celebrating each other’s birthdays and meeting for coffee.

For another group there were spin off activities including an intergenerational choir involving older carers and school children. For some carers, it was the opportunity to access social events:

“The first time I have been out properly for years.”

“We cannot underestimate the difference that making new friends has made to our lives.”

“Weekends away allowed the breakdown of social and financial barriers as we were all treated the same.”

One carer noted that without the activities and support of her Network Partner she would be more isolated and less able to cope but also that:

“It stops you being a burden to the health services. My husband would have to go into care without the support.”
Challenges for older carers accessing services/activities

In the focus groups we asked older carers what they thought might have prevented carers from accessing activities and services. Some key themes emerged:

**Perception**

The tipping point with regards to accessing services is whether someone perceives and identifies themselves as a carer.

This is an important point. Many carers, particularly older carers, do not see themselves as a carer and therefore when services are advertised they don’t feel they are for them. This can be a real barrier for isolated carers who would greatly benefit from accessing help and support:

“How do we recognise that’s what we are … carers?”

Many carers in the focus groups were either the spouse of the person being cared for or a close family member. As a consequence, they felt it was their role or duty to look after the person in receipt of care:

“I am a wife; in sickness and in health … that is still the case, rather than a carer.”

“Men tend to get more support from the system … women tend to think it’s their job.”

One carer highlighted that they felt there was a generational issue with older people not being prepared to ask for any help or support but just getting on with things. Another stated that some carers were too “proud and independent” to access services.
That first step

Taking that first step to meet new people and access services proved to be very difficult for a number of group members.

“The opening of the door to the carers centre and walking in is hard.”

“A lot of encouragement is needed when you haven’t joined in with anything or gone out for years.”

Carers identified that activities were easier in small groups and that coach holidays together were very beneficial.

Gender

Only seven out of the 39 participants in the focus groups were men and not all had accessed the programme. Those that had had benefitted from activities including yoga, exercise classes, massage and weekends away with other carers. A number of older female carers recognised the different challenges faced by male carers:

“It is probably harder for men to come through the door … men don’t work in groups, they need more of an activity to focus on then they would talk … Also women may not be as open if men were in the group.”

“Basket making, one man attended. Needs to be other hobbies that men can do … fly time, for making fishing hooks.”

“Not as social as women. Like something with a purpose … An activity/men’s shed.”

“Cultural issues for men accessing services. Particularly those from the military. There are a lot of older male carers ex-military.”
A staff member commented that it is challenging making contact with and accessing male carers. One Network Partner brought together a group of men and 60% wanted to do something alongside the person they cared for. This creates a challenge for Network Partners to develop services for both the carer and the person in receipt of care.

Another Network Partner reported that they had more male carers engaging in the Improving Health Outcomes programme than any other project they run.

**Transport**

Issues were also raised surrounding the challenges of public transport in different areas, including the changing of bus routes to no or poor public services in rural areas and the impact this had on carers being able to attend Network Partner events. Linked with this was the fact that taxis were too expensive to use.

Network Partners have responded to these challenges by delivering sessions in more isolated areas in order to improve and increase access for older carers.

> “Particular difficulties being in a rural area … transport … got to drive … don’t go anywhere at night.”

> “Transport is a major challenge.”

> “Had to organise taxis so that carers could take part but this is very expensive.” (Staff member).

> “Many of us could not attend the regular activities without the transport provided.”

**Guilt**

Guilt also came across as a very strong theme in a number of the focus groups and can limit older carers accessing services/activities. It can play a major role in caring situations and is sometimes used as a control mechanism by the person being cared for or other family members. Feeling guilty can place an enormous amount of pressure on the carer and they can find it very difficult to deal with:

> “My husband makes me feel it’s got to be me and nobody else … that cares for him.”
“Got to be me or my son … to look after him. My sons won’t allow anyone else to look after him either.”

“My mum makes me feel guilty … Wants to come with us … me and my husband … all the time.”

“It’s a form of control, guilt.”

“My father says you need to have a phone on you all the time just in case I need you.”

“Just to be me for a few hours not somebody’s wife, mother, carer. But still half the time thinking is he alright?”

Some of those in the focus group expressed a need for independence but showed a reluctance to leave the person they cared for to take a break, as they had asked them not to leave them. This made it very difficult for the carer to have their independence.

**Lack of knowledge**

A participant in one focus group raised particular concerns around the lack of knowledge of other services they can access.

“Information … about what support is available for carers … is there, still need to know where to go. Lots of people still don’t know.”

“Have to be more creative to get information out.”

Some Network Partners have been innovative in highlighting the services available, however clearly in some areas there is more to do.
Timing of activities

The timing of activities is very important for older carers and needs to be carefully considered by Network Partners in order to maximise access. For some, it is easier to go out in the evening rather than the day due for example, to hospital appointments that have to be attended. For others, the day time is better indicating a range of flexible services/activities would be of great benefit:

“Arrange things when convenient … not lunch time or early morning.”

Respite

More than any other issue, the focus groups discussed the key theme of no or little respite being available. This has an enormous impact on older carers in terms of their ability to access any type of service or activity for themselves and as a consequence a massive effect on their own physical and mental health and wellbeing.

“There is no respite care in the area which means planning any time away incredibly difficult. A lot of notice is needed to plan a trip. Family and friends are relied on.”

One carer commented:

“Financially quite challenging … attending activities … a sitter for a cared person is £19 a session.”

“Respite is expensive and not always available, it is limited by social services – six hours a week is the standard, but this is mostly used for completing necessary chores like food shopping etc.”
Older carers’ recommendations for services that could better meet their needs

Many carers in the focus groups struggled to identify what other services/activities could better meet their needs. For many, it appeared that they didn’t have the capacity, given all the stresses and strains of caring, to even think about what activities would improve their own health and wellbeing. They had enough to cope with on a day-to-day basis and were happy with the services/activities that were being delivered.

“The opportunity to have time out is difficult. Sometimes you don’t want things to be structured, just flow. You don’t have to learn something.”

“Soft edges, you don’t want a classroom … You learn more from everyone else.”

Some of the suggestions for other services/activities include:

- Crisis services.
- An End of Life Care Course.
- More crafts.
- Intergenerational cookery classes.
- Joint activities that included the person in receipt of care.
- Picnics, cinema visits and trips.
- Weekends away (activities where they were completely removed from the caring situation).
Conclusion

Overwhelmingly, carers in the focus groups had gained a great deal from accessing Network Partner services/activities through the Improving Health Outcomes programme. The different projects had had a positive impact on carers’ own health and wellbeing and their ability to fulfil their caring role.

Meeting together and talking came over as the most important activity for older carers. The vehicle for doing that, whether through arts and craft classes, walking groups or trips, was secondary. The connection with another person or people who understand what a carer experiences and deals with on a daily basis was incredibly valuable.

“I feel more relaxed about what I say or don’t say … no one judges you.”

“It doesn’t matter if you fill up a bit … you get a cuddle. I miss the closeness [with the person in receipt of care].”

“There are no words to describe what it means [to have the support of staff, volunteers and other carers].”
Case studies

This next section details five case studies from older carers who had accessed Improving Health Outcomes programmes from across England, Scotland and Wales. The individual stories highlight many of the themes raised by focus group members. Names and photos have been changed to protect identities.

Daphne, Bob and John

Daphne and Bob are in their early and mid-80s and live in an outer London borough. Both care for each other and their middle-aged son, John, who has physical and learning disabilities. Daphne has hearing and sight problems and Bob has diabetes. They also both have mobility problems – Daphne cannot manage the stairs or gradients and Bob uses a stick and other mobility aids. Both were very concerned about their mobility issues particularly given their caring role for their son. They were both worried about how John would cope without them, how to plan for his future and had a deep mistrust of any statutory service intervention.

The couple had registered with the local Network Partner in 1994 but had not accessed many of the services or activities on offer. With their changing circumstances, particularly their poor health and anxiety about John’s future, the couple got back in touch with the Network Partner and completed an activity questionnaire highlighting their interests and mobility issues.

As a consequence, the couple were invited and started to attend an afternoon Tai Chi class and a subsequent chair based exercise class. For the first time in years Daphne reported that she could touch her toes and through regular attendance both profited from increased mobility. From that initial engagement the couple also attended the weekly walk to health group and theatre and craft classes.

Daphne feels much healthier since she began the regular exercise classes and she enjoys the social aspect of the activities and engaging with other people. Bob feels that the project has brought them closer together as a couple as they were not engaged with any activities outside of their caring role and he has also reported improved mobility.

Through regular attendance at the Network Partner not only did Daphne’s and Bob’s health improve but their confidence grew. Increased awareness and understanding of the services that were available can help them plan and support their son with his continuing independence.
Sarah and Steve

Sarah lives in the Midlands, is in her late 70s and looks after her husband, Steve, who has Parkinson’s disease. Sarah worked into her 70s as an active and ‘young’ older person. She provides the majority of personal care to her husband who had a fall two years ago and has never fully recovered from a broken hip. Steve was a marathon runner, keen golfer and played squash and tennis in his younger years.

Steve struggled with illness and depression which, being very alien to his former good health, hit them both very hard. Eventually Steve was diagnosed with Parkinson’s.

In recent years, due to Steve’s ill health, Sarah has had to forego many of the activities she has always enjoyed such as visits to the theatre with friends and to London to stay with her sister. The impact of caring meant that they both became more isolated and Sarah’s health began to deteriorate, as she became less active.

Following contact with their local Network Partner Sarah had a carer’s assessment. From this it became clear, for her own good health and in order to help her continue to care, that she needed the opportunity to see her sister, as well as a chance to resume some of the activities she enjoyed before becoming a full-time carer. Sarah also needed some help with accepting that her husband could be left with trained staff and would be cared for well with all his needs met.

Sarah got a great deal of pleasure from planning the trip to see her sister. The trip went well and her husband was fine during her brief respite. She was able to tell him all about the trip on her return which they both enjoyed. Sarah realised the benefit the break had given her and also accepted some one-to-one training on moving and handling to help her lift her husband safely. The Network Partner was also able to order some equipment which helped with this aspect of care and reduced the risk of falls.

Sarah had previously resisted any support believing that it was “her duty” to care for her husband regardless of how much strain she was under but she had reached exhaustion point. Sarah has now willingly accepted more services and now goes out regularly (once a month) to the theatre and this brings her a great deal of enjoyment and relaxation. She has since had another overnight stay as well. She has said that she will continue to use her Network Partner to support her in looking after her husband and now realises that she can’t do it alone and needs help so she can continue to care for him and look after her own wellbeing.●
Samantha, Sylvia and Peter

Samantha is 47 and lives in Wales. She has been supporting her mother, Sylvia, who is in her mid 70s to care for her father, Peter, since his accident over 20 years ago in which he was paralysed from the neck down. Peter is in his early 80s. As an only child Samantha, although living elsewhere, provided respite care, and helped with medication and any other tasks needed.

Samantha had recently noticed a deterioration in her mother’s health. Sylvia was getting more and more forgetful and she was making random phone calls and would sometimes ring and not really know why. Peter had also noticed a change and raised his concerns with his daughter. He was worried not only for Sylvia’s safety, but also for his own, as he relied on his wife for simple things like using the telephone.

Samantha discussed the situation with her husband and her children but it wasn’t practical for them to offer any help that would enable her parents to stay in their own home. Samantha was getting more worried as each day passed and did not know who to speak to. The pressure became so great that she broke down at work. It was then that she confided in a colleague who suggested she phone the council for some advice.

After contacting the council Samantha made an appointment with a social worker who gave her a leaflet about Carers Training at the local Network Partner. A series of training courses provided her with the information and support to begin to make some changes. Samantha spoke to social services about increasing the home care package to include her mother’s care as well as her father’s, registered as a carer and looked for aids and adaptations for supporting people with memory loss.

Samantha made the most of the training sessions by speaking to as many other people as she could and gathering information on available services in order to support her family in their own home. However, when her father thought that a residential home would be the best solution Samantha felt that this option meant that she was letting her parents down and felt guilt that she was unable to care for her parents.

Gradually, the training sessions enabled Samantha to deal with her own feelings. Samantha’s parents did eventually go into a residential home and both are doing well. The training sessions helped provide her with the information, skills and contacts necessary for caring. She developed a great friendship with one of the other carers and has a much better support network in place but is still addressing her feelings of guilt around both parents going into residential care.
Audrey and Brian

Audrey is 78 and lives with her husband Brian who is in his 80s in a very rural location in South East England. Audrey is the main carer for Brian who has dementia. Audrey also has her own health issues and is on medication. Additionally, she cares for her two brothers Frank and Malcolm who are advancing in years, very frail and almost house bound.

Audrey had registered with the local Network Partner several years previously and was receiving the regular service newsletter and general information but had not actually accessed any of the services. As part of the Older Carers Project a member of staff, June, phoned Audrey for a general chat and just to see how things were. June informed Audrey that there was a Carers Forum taking place in a few weeks close to where she lived if she would like to join other carers for some lunch and an opportunity to have a talk. Audrey reported that everything was fine and she would give some thought to the invitation.

June phoned Audrey again a few weeks later. At that point Audrey revealed that her husband had been displaying some difficult behaviour and she was feeling very low and isolated. June persuaded Audrey to meet her for lunch during which Audrey agreed for June to come to her home later that week and carry out a full carer’s assessment. June gave Audrey a copy of the Network Partner’s carer training programme which covered all aspects of keeping well and provided information on dealing with challenging behaviour.

At Audrey’s home June carried out the assessment during which Audrey confided that she had not been exercising or sleeping well and had gained a lot of weight due to feeling so low and comfort eating. She also revealed that she had lost interest in her own appearance. It became apparent to June that Audrey did not have any support at all in her caring role. June advised Audrey to see her GP and ask for a full health check and started putting emergency support in place including a sitting service through the Alzheimer’s Society. June also supported Audrey to apply for some funds for a short break and towards some make up and encouraged her to attend a Caring with Confidence training course.

This course opened Audrey’s eyes to the fact that she was not on her own and that there were other people just like her. She said that just having someone take the time to phone her and see how she was made her feel valued and respected and able to sleep better at night. Audrey is now attending older carers lunches regularly. She has booked her break away and is also now getting a sitting service once a week so she can meet her friend for coffee.

The impact of this support has enabled Audrey to continue caring for her husband and brothers. She has regained her sense of identity and is re-establishing contact with her friends. All of her family have remained in their own homes and are receiving appropriate support in their own right. Audrey has also started looking to the future – accessing financial and legal advice and support and making plans and decisions with her husband to fulfil both of their wishes. Conversations have not always been easy but they feel better for taking control of their situation.
Elizabeth and Ken

Elizabeth lives in Scotland, she is 64 and cares for her husband Ken, aged 67, who has multiple sclerosis. Elizabeth and Ken have recently been affected by changes to the financial support they will receive and as a result Elizabeth has been very stressed about the increasing demands on her as a carer and she is also very worried about their financial future. As a consequence she has been physically tired and emotionally drained.

Elizabeth registered with the local Network Partner five years ago and over the years has dipped in and out of the service as she needed it, receiving information and advice, accessing therapy sessions and attending the Christmas lunch. She has recently become a more regular visitor to the Network Partner, getting emotional support, information and advice about her rights and entitlements as a carer, advocacy and most importantly, a listening ear.

It became clear that Elizabeth needed a break from her caring role so the Network Partner asked her if she would like a prearranged trip with other carers. While keen to go she was nervous about meeting other people, saying: “But I don’t want to have to go away with people and explain why I’m there”. To allay her fears, the Network Partner arranged an introductory meeting for all the carers who were due to go away for the weekend. After the meeting Elizabeth said “I don’t know what I was worried about, they are all lovely and in a similar situation to me.”

Seven carers, accompanied by a Support Worker and volunteer set off for the weekend. The trip was a resounding success. The carers really gelled and Elizabeth enjoyed interacting so much with the other carers that she wrote a play about the different characters, including some of the staff who remained back at the office. Everyone acted this out which caused much laughter.

Through the various opportunities Elizabeth has accessed she now realises that she is entitled to a life of her own. She no longer feels guilty about leaving her husband at home with a carer support worker while she is out doing the things she wants to do. This is a huge step forward for Elizabeth. She has accepted that she can still enjoy her life, the fear of leaving her husband has been taken away and she looks forward to taking part in forthcoming activities.

“I was fortunate to receive counselling sessions and cannot emphasise enough how helpful it was to me. I was struggling to cope with the demands of the care involved, and also the loss of our relationship and the realisation that I was wholly responsible for his care and wellbeing.

Counselling helped me realise that there were solutions. I would have been unable to research counsellors without support and would have let things drift.”

Elizabeth •
## Appendix:

List of Network Partners funded by the programme

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