

Peer Support and Dementia

October 2016 to September 2017



“ I was completely unaware that what I was doing was a carer role and of the effect it was having on me and my health. I didn't think about reaching out for support for myself. ”

“ Family and friends are very supportive but they don't really understand. After attending the Group I no longer feel alone. ”

“ Once I knew that someone was here to listen, I felt better. ”

Introduction

In October 2015, the Life Changes Trust made a commitment to fund six peer support initiatives across Scotland for a five-year period. Two of these initiatives provide peer support to people with dementia, one of which has a focus on food and keeping well. One provides peer support to carers of people with learning disabilities who have dementia, whilst the other two initiatives support carers in their caring role.¹

Over the last two years these peer support initiatives have supported 190 people with dementia, 339 carers and have trained 251 volunteers. Through their support and encouragement, people with dementia and their unpaid carers have shared their experiences and expertise, not just amongst themselves, but with health and social care workers, students, doctors, local businesses and universities. Participants have co-produced resources which are being used to change the way that services are being delivered and ensuring that people with dementia and carers are consulted and involved in care provision.

The peer support initiatives have benefited from their own peer support through the Life Changes Trust's growing network of funded projects which meets quarterly to share learning, provide encouragement and to facilitate collaboration. Peer support also takes place quite naturally in the Dementia Friendly Communities funded by the Life Changes Trust² and in the Scotland-wide networks for people with dementia (DEEP)³ and for carers (Tide).⁴ You can learn more about these networks on our website.

1 One project, Health in Mind, closed in March 2017. Initial recruitment difficulties and fewer than expected referrals prevented the project from running more peer support groups and, after discussion with the Trust, Health in Mind made the difficult decision to close the project.

2 <https://www.lifechangestrust.org.uk/sites/default/files/publications/Dementia%20Friendly%20Communities%20Third%20Report.pdf>

3 <https://www.lifechangestrust.org.uk/projects/dementia-engagement-and-empowerment-network-deep-innovations-dementia>

4 <https://www.lifechangestrust.org.uk/projects/Tide-carers-network-scotland>

This second report has been written using project evidence collected by funded organisations between October 2016 and September 2017. A wealth of evidence has been gathered from people with dementia, project staff, volunteers and carers, through observations, evaluation forms, photographs, videos and diaries, some of which are included in the appendix. Each project has, with members, developed its own way of collecting the views of its members and uses this to inform activities, information and support.

Through funding these projects the Trust has gained more understanding of the benefits of peer support for people affected by dementia and their unpaid carers. This report is intended to share this learning and demonstrate why peer support is so important to improving the quality of life for people living with dementia and their unpaid carers. It shows the positive difference that peer support can make to health and well-being, to confidence and self-esteem and to reducing social isolation and loneliness.

The Trust is keen to share this learning so that there is greater information available to those whose lives are affected by dementia which will enable them to seek and find the help and support they need. Our hope is that the evidence from the Trust-funded peer support projects will contribute to the growing body of evidence that demonstrates the positive impact of peer support on the quality of life of people with dementia and their unpaid carers.

We will produce further reports on peer support between now and 2021.

We hope that you enjoy this report.

**Andrena Coburn, Funding and Research Manager
People Affected by Dementia Programme, March 2018**

Overview of Progress from October 2016 – September 2017



Why do we invest in peer support?

The Mental Health Foundation defines peer support as ‘the help and support that people with lived experience of a mental illness or a learning disability are able to give to one another. It may be social, emotional or practical support but importantly this support is mutually offered and reciprocal, allowing peers to benefit from the support whether they are giving or receiving it.’

Peer support is one of the services which people with dementia and carers say they most value because of the positive impact it has on the person with dementia and/or their carer. Peer support helps keep people more socially connected, giving them confidence and motivation to participate in their communities. It also helps them to feel valued by being listened to and being able to help others with similar experiences. Peer support builds on the skills and knowledge that already exist in the community.

In funding peer support across Scotland, the Trust aims to provide greater awareness and understanding about the benefits of peer support for people affected by dementia and carers by contributing to a growing evidence base. This includes identifying ways of establishing long-term peer support initiatives that are innovative, sustainable and cost-effective and which can operate alongside existing services as part of a continuum of approaches to support and empower people affected by dementia.

In a report summarising evidence from more than 1,000 studies on peer support, Nesta and National Voices found that peer support has the potential to improve experience, psycho-social outcomes, behaviour, health outcomes and service use among people with long-term physical and mental health conditions. The studies also showed that peer support can potentially improve experience and emotional aspects for carers.⁵

⁵ https://www.nationalvoices.org.uk/sites/default/files/public/publications/peer_support_-_what_is_it_and_does_it_work.pdf

Attree argues that using an approach where people can use their experiential knowledge to help to design or improve services can increase confidence and self-esteem, give people an increased sense of control over decisions affecting their lives and may lead to more positive health outcomes.⁶

Studies have shown that peer support for people with dementia has a beneficial impact in increasing well-being, self-esteem and reducing depression, which may delay the need for more intensive support interventions or institutionalisation. “Peer support can reduce the risk of reaching a ‘crisis point’, with people either feeling more able to manage their situation or seek initial support and advice from peers or staff at the group before contacting the GP or emergency services.”⁷ So peer support not only benefits the individual or group members, but can benefit wider society through financial savings relating to health and social care.

NHS Health Scotland’s Strategic Outcomes Model for Optimising Older People’s Quality of Life recognises the contribution that peer support can make in keeping people socially connected in later life and the positive impact that this can have on health, well-being and quality of life.⁸

In ‘A Good Life in Later Years’, a Scottish report published in 2017, health and well-being (including having good physical and social health) were considered by many people as being central to a good quality of life in later years. Having good relationships and being able to interact with others was thought to provide a sense of purpose which helps to reduce loneliness and maintain good health.⁹

6 Attree P, French B. Testing Theories of Change Associated with Community Engagement in Health Improvement and Health Inequalities Reduction. London: NICE; 2007.

7 Banerjee et al., 2003; Leung, Orrell, & Orgeta, 2015

8 <http://www.jitscotland.org.uk/wp-content/uploads/2014/10/Outcomes-Framework-Book-STRATEGIC-MODEL.pdf>

9 <https://www.lifechangestrust.org.uk/sites/default/files/publications/Good%20Life%20in%20Later%20Years%20FINAL%20NOV%202017.pdf>

An evaluation of three dementia peer support groups in South London found that key outcomes for people with dementia were mental stimulation and a reduction in loneliness and isolation.¹⁰ The study, undertaken by the Health Innovation Network, found that there were significant benefits from being able to talk to other people with dementia and their carers and from sharing practical advice and emotional support. Having the opportunity to meet others in a similar situation regularly (such as Dementia Friendly Communities, Dementia Engagement and Empowerment Groups or Tide carers groups) can help people feel less lonely and isolated. This experience is valued by people with dementia and by carers.

A universal outcome across all groups in the study was a reduction in the burden of care and stress, demonstrating the positive impact that peer support groups can have for carers. Reasons for this included meeting other carers with similar experiences, carers being able to have some time for themselves and feeling reassured that their relative was being cared for in their absence.

This study also looked at how much social value the peer support groups created in relation to the cost of investment, using a Social Return on Investment (SROI) model. Findings showed that the three groups produced a social value greater than the cost of investment, ranging from £1.17 to £5.18 for every pound (£) of investment, dependent on the design and structure of the group.

Like the Trust's Dementia Friendly Communities, peer support challenges a medical and deficit model of disability and instead focuses on the assets that people living with dementia and unpaid carers bring to support others going through a similar experience.

Peer Support through Dementia Friendly Communities

For more information on the Trust-funded Dementia Friendly Communities and the nine key principles that underpin these communities please see the "Community and Dementia: Dementia Friendly Communities in Scotland" report.

<https://www.lifechangestrust.org.uk/sites/default/files/publications/Dementia%20Friendly%20Communities%20Third%20Report.pdf>

¹⁰ Quantifying the benefits of peer support for people with dementia: A Social Return on Investment (SROI) study, Willis, Semple and de Waal, 2016.

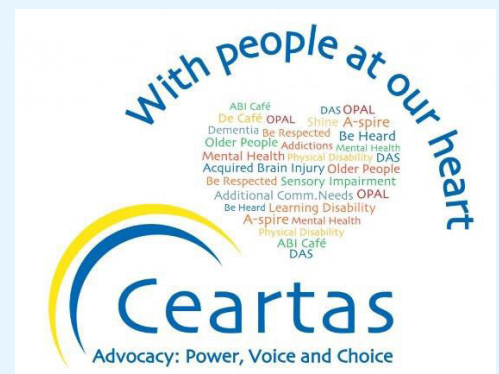


Trust-funded peer support projects 2015-20

Ceartas

Advocacy charity Ceartas delivers 'De Cafés' in Kirkintilloch, Bishopbriggs, Bearsden, Milngavie and Lenzie. This cafe model, which provides peer support to people living with dementia, is aimed at people worried about, or living with, dementia as well as carers and former carers. They offer information and advice, and also provide space for people living with dementia to run and promote the cafes, assist in delivering training and address stigma about dementia by talking to professionals and others in the community about it.

<http://www.ceartas.org.uk/what-we-do/de-cafe/>



ENABLE Scotland

The Cuppa Club established in Moray by ENABLE Scotland provides one-to-one peer support to older carers of people with learning disabilities who also show signs of, or have a diagnosis of, dementia. The stress of caring can affect physical and mental health so the project supports carers to remain connected to a strong network of support in their community. It decreases their social isolation by providing respite care, friendship, recreational activities and information about other help that is available.

<http://www.enable.org.uk>



North West Carers Centre

This peer support project supports carers to gain confidence in their own skills and abilities, by sharing their experiences with someone who understands the difficulties and challenges they face. The service provides social meetings for small groups of people who have dementia, with their carers. The aim is to relieve carers of some of their direct responsibilities so they can enjoy the company of someone who understands the impact of their caring responsibilities and the emotional journey involved in looking after someone who has dementia.

<https://nwcarers.org.uk/>



Outside the Box

This charity and social enterprise has developed 'Food Buddies', a peer support service for people with dementia and/or their carers, with a focus on food and keeping well. The initiative enables someone with experience of dementia to provide practical advice and on-going individual support to others, addressing concerns such as safety in the kitchen, losing skills around preparing and cooking food, safety around shopping and storing food as well as concerns around not eating.

<http://otbds.org/projects/borders-food-buddies/>



VOCAL (Voice of Carers Across Lothian)

Based in Edinburgh, VOCAL supports carers of people living with dementia to improve their health and well-being, increase their confidence in their caring role and their ability to engage with and influence services. Support is provided through a combination of small group and one-to-one peer support by volunteer peer mentors who have personal experience of caring for someone with dementia. Both services are embedded in VOCAL's well established Carers Support Team, providing access to a range of information and advice.

<https://www.vocal.org.uk/>



What are the benefits of peer support for people affected by dementia and unpaid carers?

In providing financial support to peer initiatives over a five-year period the Trust hopes to demonstrate the wider benefits of peer support for people affected by dementia through funding projects that contribute to the following outcomes for people living with dementia and carers:

- I know that I have someone who will listen to me and who understands my situation
- I have support to face the challenges in my life
- I have an increased sense of well-being
- I feel safe, valued and respected
- I am supported to make choices and do the things that matter to me

The ways in which projects are benefiting people living with dementia and unpaid carers are discussed below.

Practical support, information and advice

“It’s not an easy illness to deal with. You don’t get any training in how to cope.”

Peer support initiatives have found that carers appreciate being pointed in the right direction for information because many are unsure where to access information and support. This was particularly relevant for members of the Cuppa Club, which supports carers of people with a learning disability and dementia. These carers are often hidden and potentially isolated, but those who attend the Cuppa Club have commented that they now feel better informed about, and supported in, their caring roles.

There have been other issues in accessing information. Many carers find sources of information confusing, overwhelming and difficult to access, especially online sources. Cuppa Club members decided to compile resource folders on welfare benefits and allowances from trusted sources. As a result, members are now able to access this information in a format that they prefer, as often as they wish, either individually or as part of a group discussion.

Simply having access to information, particularly financial information, can make a big difference. Following a presentation by the Citizens Advice Bureau on welfare benefits, a member of the Cuppa Club peer support group received further advice and support from the in-house benefits advisory team at ENABLE. This resulted in the person that the carer supports receiving an increase to their benefits and access to a mobility grant.

At North West Carers Centre (NWCC), if staff are unable to provide a particular service or specialism, for example benefits checks, they are able to signpost to the relevant agency. Carers can be supported to get access to Attendance Allowance, Council Tax reduction, blue badges, taxi cards and other grants.

Not having to worry about finances can relieve some of the stress for carers.

Ceartas have made numerous referrals to additional services, befriending services, Citizens Advice Bureau, carer support services and in-house services. Referrals have been made to emergency care planning, at home health services, Community Care Assessments and mental health services.

Carers at Vocal have also benefitted from high quality information on sources of support.

“A carer who participated in peer mentoring reported that she was now clearer on what statutory services do and who to approach if she needs support. She noted that the information was useful but also that talking to someone who had ‘been there too’ had been helpful, giving her confidence.”

Personal Story - North West Carers Centre

Mrs Smith* helps to support her husband who, following a stroke, experiences memory loss and difficulty coping with certain activities of daily living without his wife's support. Staff made an initial visit to Mr and Mrs Smith's home to carry out an assessment to determine the type of support they may need or wish for. The following outcomes were achieved:

- Staff from NWCC accompanied the couple to CHAI's (Community Help & Advice Initiative) office for a benefits check. As a result, Mr Smith now receives Attendance Allowance and Council Tax reduction.
- Mr Smith was referred to Edinburgh Council's Be-Able Service, a 14-week cognitive stimulation therapy programme.
- The couple were referred to NWCC's Alternative to Day Care Project which gives Mrs Smith a three-hour weekly break. Whilst her husband is supported by a NWCC worker and they spend time in his garden, or just sit and chat, Mrs Smith has free time to visit the Kelvingrove Art Gallery in Glasgow and go shopping in Edinburgh.
- Staff provided one-to-one support sessions with Mrs Smith to listen and suggest coping strategies.
- Mrs Smith has attended several Side By Side courses and events, such as a cookery group, a tour of the Festival Theatre, an aromatherapy session and information sessions. She attends support groups and an IT course has given her more confidence to use her iPad. This means she can keep in touch with her family abroad and share photographs.
- Mr and Mrs Smith have attended tea dances, barge trips, and theatre trips together.

“We are so lucky; I don't know what we would have done without the help from North West Carers.”

**names have been changed*

With the support of project staff, people living with dementia and carers are starting to develop resources that address the gaps in information and support that is currently available. They are using their experience to inform the development of new information resources which are co-produced with people with dementia and carers, and which are full of useful tips and experiences.

As mentioned earlier, feedback provided by Cuppa Club members about the lack of information available about learning disabilities and dementia led to the development of an Age Scotland resource which will be part of the Early Stage Dementia suite of resources on their website here: <https://www.ageuk.org.uk/scotland/information-guides-and-fact-sheets/being-dementia-aware/>.

At Food Buddies, participants who were part of developing the Winter Tips booklet enjoyed being involved and the sense of helping other people. People who are using the booklet say that the resource has increased their well-being, **“showing that ordinary life is possible and that adapting to situations is ok, showing how not to get stressed and choosing to focus on what is good rather than only on what someone is no longer able to do. People say they feel more confident in going out to shops and in being able to manage at home.”**



Winter Food Tips Booklet - Outside the Box

In this booklet, people affected by dementia share their experiences in day-to-day situations that are linked to food. The tips include practical information for people on shopping for food, foods that work well for people with dementia and their carers and easier preparation and cooking.

Copies have been shared with carers centres, dementia services, voluntary services, hairdressers and every library in the Borders, including mobile libraries.

People affected by dementia appreciate the positive tone of the Winter Tips booklet and it is helping to facilitate peer support and open up conversations. This has been successful in prompting other people to talk about the difficulties they face and the types of support that would be helpful. Since the Winter Tips booklet was launched many people have talked to Food Buddies about how worried they are about someone who has not been eating properly. This includes relatives, friends and neighbours. It also includes older people who do not have a diagnosis of dementia but are living alone and coping less well than before.

Age Scotland has updated their Eat Well booklet to include reference to the Food Buddies Winter Tips booklet.

A local community cafe is also going to use the tips. **“Great recipes and helpful ideas to make what we do work better for people who have dementia and others who may be struggling to eat enough.”**

<https://www.lifechangestrust.org.uk/sites/default/files/publications/Winter-Tips.pdf>

In the case of the Winter Tips booklet, this resource is also now being used in advocacy for people with dementia.

“Several people have told us about using the Tips and/or Carers’ booklet to explain to other services about the type of support they want for their relative and why the current arrangements around food are not right for this person. This makes carers feel safer themselves as well as the person they care about being safer.”

Food Buddies has also found that the conversations that they are having with community groups, such as lunch clubs, are helping to give people living with dementia a voice.

“Each time we meet with volunteers and workers there we ask about the views of people living with dementia and their ideas: this has led to other people listening to them and trying to understand their situation better.”

Following conversations with people affected by dementia, the Food Buddies project has also identified diabetes as a high priority and they are working with the Borders Diabetes Group to develop a booklet about diabetes and dementia. They have also launched a new tips booklet for older people and people with dementia who are vegetarian or vegan in collaboration with Vegetarian for Life.

These resources are important because they are written from the point of view of someone living with dementia or from a carer’s perspective and present a genuine understanding of a person’s experience as well as providing learning strategies for managing situations.

The Trust has also recently funded a peer to peer resource which has been developed by the National Dementia Carers Action Group (NDCAN) to support carers. The information leaflets cover a wide range of topics and are written by carers for carers, sharing tips, experiences and links to further sources of information and support. The resource is available on the Trust and Alzheimer Scotland websites: <https://www.lifechangestrust.org.uk/people-affected-by-dementia/ndcan-resilience-booklets>

Peer support initiatives are also working with other Trust-funded organisations to ensure that they continue to reflect the views and wishes of people affected by dementia. Food Buddies continues to work with the DEEP (Dementia Engagement and Empowerment Project) network in Scotland to ensure that all of their information is relevant and appropriate.

They are also working with Berwickshire Housing Association and Seton Befriending Project, whilst the Festival Theatre in Edinburgh, a Trust-funded Dementia Friendly Community, supported Food Buddies to develop a dementia friendly checklist for assessing hospitality settings.

Emotional support

“Many people are looking for more traditional forms of support for themselves or the person they care for, and are not certain about peer support because they don’t think that they, or other people in their circumstances, would have any experience or ideas that could help other people.”

Evidence from the peer support projects highlights a number of challenges for carers, in particular, difficulties talking to friends about their challenges as a carer and addressing feelings and emotions, especially around guilt. Peer support group members have recognised that they needed emotional support which is wider than the family and that it helps learning from and hearing other people’s experiences. Peer support groups offer carers the opportunity to share experiences and realise that their responses to their situation are completely normal.

Evidence of the power and benefit of sharing experiences came through very strongly in comments from carers at the recent Trust-funded Carers Conference which was organised and led by carers and focused on topics which they felt would be useful to other carers. The Trust’s website has links to the resources developed for the conference and a video of carers talking about their experience of being involved in organising and delivering the conference.¹¹

The Cuppa Club co-ordinator has underlined the important distinction between peer support and ‘expert’ advice from professionals and stresses that this value of peer support should not be underestimated.

“The peer support group gives members an opportunity to discuss a concern or problem with someone who shares their caring role as opposed to speaking to ‘experts’ and others who do not share their daily challenges.”

¹¹ <https://www.lifechangestrust.org.uk/people-affected-by-dementia/events>

The co-ordinator feels that peer support fulfills an important role in the face of gaps in services and believes that members of the Cuppa Club valued the group, not only because there was a lack of information on how to cope following diagnosis but also because carers felt listened to and not judged. Through peer support, carers are being given support to face challenges that the dementia caring journey brings.

Health in Mind also discovered that participants, at times, needed additional support to face challenges in life and to feel able to take action. Group members noted that the support was not always there – or wasn't there at a time and in a way that was most needed.

Following discussion with their peer mentors, carers at Vocal reported improvements in communication with other family members, reduced isolation and feeling reassured in their caring role. This reassurance comes from sharing experiences, both positive and negative.

“I get lots of tips from all the folks, [it's] a life line. Everyone is so caring, everyone cares for everyone else. Its excellent, you get time to give your own story.” (A carer at North West Carers Centre)

Carers also reported that peer support helped to provide a sense of normalcy and new friendships. Carers felt that they were helping others and that often current friends did not understand the challenges of being a carer.

“It is hard to share with my friends sometimes as they know him and it feels a bit disloyal.” (A carer at Vocal)

At North West Carers Centre a lot of time is invested in building a relationship with the carer. **“The home visits and face to face meetings take up time and sometimes there are more than two to three visits as the person lacks confidence and understanding of the illness but we feel this is the best approach as carers receive so many pieces of paper – relationship building is vital.”** They have also learned not to overload carers with information too quickly in the relationship and that it is important to give carers time to reflect on what they need and want so that they can receive the right service at the right time. They also stress that services cannot be time limited.

North West Carers and Food Buddies have found that friendships between carers have been forged and the relationship of support continues beyond the regular peer support provided by the project. Carers often phone each other or meet for coffee.

“The group of people living with dementia and their spouses who met in the cafe have continued to support each other. The feedback from them is that this is one of the few places they have where they can talk about their situation with other people who understand. For them, this includes wanting to enjoy life together and get on with everyday living.” (Outside The Box Food Buddies project)

The emotional support from peers can often help carers at difficult points in the dementia journey. When they lose the person they care for and need ongoing support to get through this challenging period, carers often benefit from peer support from other carers with whom they have formed supportive relationships. For this reason, carers will often continue to attend meetings and activities when the person with dementia goes into long-term care, long stay hospital or passes away. A number of carers at Ceartas, who benefited from the support and information from others at the cafe, wanted to continue to provide this support to others.

“These more experienced carers are often seen speaking to newer members letting them know about their experience of caring and what they found useful.”

Some of the volunteers at North West Carers Centre are former carers who have “walked” the dementia journey. Staff consider them to be highly skilled at listening and empathising and have found them to be a great asset during group activities and events.

The knowledge that they are helping others can give carers a sense of purpose, confidence and empowerment.

In addition to a lot of evidence from projects regarding the positive impact of peer emotional support for carers, there was some evidence of the impact for people living with dementia. Feedback from Walking Football participants at Ceartas revealed that people with dementia enjoyed being part of a team and being valued by peers for their football skills. They also enjoyed the chance to reminisce and talk about old players, managers and teams they had played for.

“People also told us they could forget about their dementia for a while and focus on the football.”

Members of the Ceartas Knowing Me group participated in a group film which explored the benefits of peer support. During this film, members spoke about how good it is to be able to connect and speak to other people living with dementia. The link to the video is in appendix 1.



The story below, about a lady with dementia who attends a Ceartas De Café, also demonstrates that peer support for people with dementia enables them to benefit from the company of others who are undertaking a similar journey.

Sharing Experiences

Personal Story - Ceartas

“Mr and Mrs F have been regularly coming to De Café for six months. They are both quiet but Mrs F will chat when approached. In March another lady living with dementia, Mrs L came to De Café for the first time. She sat next to Mrs F and as the meeting went on they struck up a conversation. I observed both women chatting to each other for some time. Mrs F seemed to be quite animated and was smiling a lot. I heard Mrs F saying that it was the first time she had been able to speak to someone about dementia who understood what it was like to have dementia.” (Interaction observed by the Dementia Services Worker)

Improved health and well-being

Information submitted by the peer support initiatives shows that people living with dementia and their unpaid carers are benefiting from improved health and well-being as a result of peer support. As part of their service evaluation and personal outcomes reviews, Vocal found that 91% of carers participating in their peer support groups reported an improvement in their health and well-being.

Staff at Vocal have noted an improvement in the mental health of carers participating in group peer support.

“Carers highlighted a number of different reasons for this, including time out from the caring role, feeling more confident and less anxious due to knowledge gained from speakers and the rest of the group and being able to talk about things in a safe place.”

Some of this improved health and well-being appears to result from people with dementia and carers feeling valued, being listened to, being involved and feeling in control, for the first time in a long time.

Carers have also highlighted the importance of carers looking after themselves in order to be able to carry on in their caring role. At the Cuppa Club, peer support has enabled members to meet the additional challenges of dementia by providing a supportive environment which nurtures their physical and mental well-being. Carers have commented on the importance to them of being able to continue to provide care to their loved ones at home.

Food Buddies held taster sessions in Burnfoot Community Hub in Hawick, an area where there is very little community support for older people. The taster sessions focussed on food memories, easy ways to cook at home, samples of easy recipes and exploring foods that work well for people living with dementia. However, staff also found that these sessions often led to conversations about how people manage and tips to make life easier. They resulted in participants suggesting additional support that they and other people in their local community can offer each other. The sessions also facilitated wider conversations around talking to the GP about health problems and accessing health and social care services.



At North West Carers Centre, carers are acknowledged as active citizens, who have often been active in their own communities and have given to others but now find themselves in a position of having to accept help and support.

“Listening to carers’ thoughts and opinions and providing a safe forum for them to give positive and negative feedback without fear enables them to feel valued, respected and empowered.”

This new-found confidence has led to other positive benefits. People with dementia and carers are starting to do things that they enjoyed doing before the diagnosis of dementia, often trying new activities. In some cases, this has resulted in projects developing additional activities requested by group members. North West Carers Centre has set up a walking group which meets once a month for a walk as well as strength and balancing exercises recommended by Paths for All. Based on feedback from carers, they have also established a crafts group and a singing group. People are enjoying physical activity, such as dancing, walking and kurling.

Ceartas has delivered a Walking Football pilot in partnership with the Scottish Football Association and Paths for All. This pilot project helped people with dementia to learn a new sport, develop their physical activity, meet new friends and be introduced to services delivered by Ceartas and other local partners. As a result, they have developed some good practice tips for running a Dementia Walking Football project (see below).

Dementia Walking Football

**extract from Ceartas evaluation report*

Walking Football has been around for many years but we recognised that the current model was inappropriate for people with dementia and in order to make sure our Walking Football for People with Dementia Project (In Partnership with SFA and Paths for All) was fit for purpose several adaptations were needed to be made before it was launched. For example, when risk assessing the activity, we added in elements to ensure the comfort and safety of participants. These included:

- Using brightly coloured hazard tape on the goals to ensure participants could see the goals more clearly.
- Introducing strength and balancing warm up exercises to assist those with mobility issues.
- The coaches who facilitate the Walking Football have undergone Dementia Informed Training to increase their awareness of the challenges a person with dementia might be facing.
- Breaks every 15 minutes.
- The participants have their own water bottles and are encouraged to drink water during the break as we know dehydration is not good, particularly for people with dementia.

Although peer support is providing opportunities for carers to participate in group activities with other carers while benefitting from peer support, project staff have also witnessed how important it is to carers' mental well-being to enjoy opportunities to do something *with* the person they care for rather than *for* them.

“We don’t do things together. Well we do but it is me doing things for my mum. It will be good to just be her daughter and be going out together. It will take the pressure off the responsibility of it all.”

“I didn’t think I would ever have an opportunity to jive with my husband again.”

The importance of relationships and being able to continue those relationships has been a key theme throughout all of the peer support groups. Feedback to Food Buddies demonstrated that one of the key elements of peer support should be the opportunity for couples to spend time together and to **“get away from the distinction that is often made of one person being a ‘dementia sufferer’ and the other being a ‘carer’.”**



Tide Carers Network across Scotland

Tide means 'Together in Dementia Every Day'. Tide is a national involvement network for carers and former carers of people with dementia hosted by the Life Story Network CIC. This new network is bringing together carers of people with dementia, not only to build their own peer support systems, but also to give them the tools and confidence to voice their needs. They can also influence the policies and practices that will improve their experiences as unpaid carers, as well as the services available to those they care for. Tide delivers a carers development programme, designed to give carers practical skills, plus emotional and psychological support to enable them to share their experiences constructively.

In Scotland, Tide brings carers together to campaign for better support for carers of people with dementia, to influence government, legislation, policy and practice at all levels and provide carers of people with dementia with the tools and confidence to help themselves and others. It also connects carers of people with dementia with each other, creating a peer support and involvement network, while retaining support structures after their relative/friend with dementia has passed away.

Influencing and improving service delivery

Being listened to within their peer support groups, and being made to feel that their voice is valued, has boosted the confidence of people with dementia and their unpaid carers to go on and use their experience on a wider platform to influence other organisations.

Peer support groups had lots of examples of where partnership working has provided an opportunity for people with dementia and carers to influence local decision-makers to take their experiences into account. This can help to ensure that services are more effective.

Members of Ceartas' Making Sure Group continually have the opportunity to be part of future planning, and can put forward their views on any aspect of the work undertaken by Ceartas. The group also ensures that the voices of local people with dementia are included and heard at local planning forums, such as the Dementia Strategy Steering Group, which reports to the local Health and Social Care Partnership Board.

Responding to feedback - Knowing Me - Ceartas

People with dementia often speak about the challenges they face and tell us they feel it is important for others to understand these challenges, to raise awareness of dementia and alleviate some of the stigma associated with dementia.

In response to this we re-designed our original training programme (Power, Voice and Choice) to include people with dementia. We created "Knowing Me", which in addition to the original course outcomes, also supports individuals to tell their own story using presentations, audio recording and iPad filming. This was with an overall aim of making our community more dementia friendly. It also supports people newly diagnosed with dementia to have a better understanding of the condition as they will have access to these stories.

**extract from Ceartas evaluation report*

Through participation in the De Cafés across East Dunbartonshire, members of the Ceartas peer support network have been involved in influencing local decisions in other ways. Carers have shared their views of the content on the East Dunbartonshire Dementia website with the Health and Social Care Partnership and these have been incorporated into the new website www.eddn.org.uk.

Ceartas is working with a range of local organisations to raise awareness, including intergenerational work with three local high schools, delivering dementia awareness and dementia informed training. Students got the opportunity to put their learning into practice during placements, by developing a community cafe in a local care home, cascading their dementia training to local feeder primary schools and assisting people with dementia to capture their own story.

The Cuppa Club members engaged in research with Edinburgh University on updating a practice development guide, 'Supporting Derek', published by the Joseph Rowntree Foundation. According to the group co-ordinator, working with the researchers gave the Cuppa Club members a real sense of the value of their caring role. The group also collaborated with Age Scotland on the production of an information booklet on 'Learning Disability and Dementia': <https://bit.ly/2KQT0Cq>

Members of Ceartas' peer support groups have worked with the University of Stirling as partners on a research project, 'Feeling Safe', which explores vulnerability and safety in the everyday lives of older people. This project explored changes in laws, policies and practices concerned with keeping adults safe from abuse and harm. Six older people living with dementia participated in focus groups and one-to-one interviews with researchers discussing practical, emotional, family and health issues around safety and vulnerability.

Carers at North West Carers Centre have been consulted by a social worker about creating a dementia friendly community and about difficulties they have experienced in accessing services. Staff are also involved in the South Queensferry & District Dementia Friendly Initiative, and more importantly, this has provided opportunities for carers and people living with dementia to be involved in these consultations.

Food Buddies has started conversations with the Borders Food & Drink Network in order to reach more people and businesses. They are working in partnership with the Food Foundation (a social enterprise which gives work opportunities to young people with learning disabilities), who are interested in expanding their customer base to include people with dementia. The Food Foundation are now running a pilot 'Meals at Home' service for older people living in Peebles.

Food buddies has also reviewed the development of a health guide produced by the Borders Joint Health Improvement Team. During the development of this guide, they provided evidence and quotes from people in the Borders who spoke about living with dementia and the importance of food as part of keeping well. In addition to this, Food Buddies influenced the language of this leaflet and managed to get a section on food and eating well included within the guide. The Borders Joint Health Improvement Team also included the Food Buddies project as one of the signposts within the nurture section of the guide.



Partnership Story – Food Buddies, Outside the Box

Food Buddies has worked with Eastgate Theatre to make their cafe more dementia-friendly for all customers. The cafe has become the first place in the Borders to have a Food Buddies window sticker. Staff and volunteers both reported an increase in the number of customers affected by dementia who are visiting the cafe. Staff are working with Food Buddies to contact other businesses in the Borders who want to become dementia friendly.

This work led to the development of an assessment tool and training for the Eastgate staff and volunteers who were educated about the sensory challenges experienced by people with dementia. Agnes Houston's Dementia & Sensory Challenges leaflet and DEEP guidance are now used alongside a checklist to help other cafes and retailers assess how welcoming their premises are for people living with dementia.

A celebration event was organised by the cafe and promoted as a Food Buddies event. The entertainment event featured food from the Winter Tips booklet along with a Jazz Ensemble and was sold out. The event was televised and staff from Food Buddies were interviewed about the project on the STV Lookaround news programme.

People with dementia from Ceartas are helping the local community mental health team, by contributing ideas for a community garden where older people with dementia and mental health issues can come to relax and enjoy the tranquillity. They have also provided views on an Occupational Therapy leaflet focussing on what speech and language services can provide for people with dementia.

For a cultural project which focussed on the renovations to the Kirkintilloch Town Hall, Ceartas facilitated small workshops involving people living with dementia who got together to talk about living and working in Kirkintilloch. These workshops involved reminiscence boxes to stimulate memories and conversations, and the stories captured from participants are featured in an anthology called 'Made in Kirkintilloch'.

Summary of the benefits of peer support

- Access to practical information, advice and support
- Carers feel better informed about and supported in their caring role
- Development of new resources by people with dementia and unpaid carers
- Emotional support –sharing experiences, at difficult points of the journey
- Carers feel listened to and not judged
- Reduces isolation
- Forging friendships
- Carers have a sense of purpose, confidence and empowerment
- Reminiscing
- Being able to connect with other people living with dementia
- Improved physical and mental well-being
- Carers feel valued, respected, listened to and in control
- Participating in activities
- Doing something *with* the person they care for, rather than *for* them
- Maintaining relationships and identity and not just being seen as a ‘person with dementia’ or ‘a carer’
- Influencing and improving service delivery by having their voice heard
- Informing the next generation
- Contributing to research
- Involvement with wider dementia friendly initiatives
- Informing and influencing local businesses

Looking forward

Since submitting their second year evaluation reports, the peer support projects have all secured some degree of match funding to continue to deliver their services for another year. This funding comes from various sources including:

- Queensberry House Trust
- Scottish Government Aspiring Communities Fund
- South Lanarkshire Health and Social Care Partnership
- RS Macdonald Trust
- Mclay Dementia Trust
- Soutar Trust
- Stirling University
- Dementia Engagement and Empowerment Group network (DEEP)

The Trust will work closely with the peer support initiatives over the next three years to build up evidence of the positive impact of peer support for people with dementia and their carers.

As outlined, the peer support projects are involved with a number of other Trust-funded projects, and are an integral part of the Trust's wider approach to peer support through the work of the DEEP and Tide networks as well as the dementia friendly communities.

The next report from the peer support projects will be published in spring 2019.

Appendix 1

The Health Innovation Network in South London has developed a useful and comprehensive interactive Dementia Resource pack with information on how to set up, fund and evaluate peer support and has information for commissioners on why they should invest in peer support:

http://healthinnovationnetwork.com/system/resources/resources/000/000/095/original/HIN_Interactive_Toolkit_September_15_LIVE.pdf

Video evidence of a volunteer peer mentor talking about her experiences of supporting carers:

<https://www.vocal.org.uk/carer-support/care-for-yourself/supporting-each-other/peer-mentoring/>

Group of people with dementia chatting to each other at a Ceartas De Café:

https://youtu.be/_Odi5jY4HNI

Interview video of a woman with early onset dementia telling her story to Ceartas:

<https://youtu.be/d96J5HVTVOI>

Winter Tips booklet:

<https://www.lifechangestrust.org.uk/sites/default/files/publications/Winter-Tips.pdf>

Tips for Older Vegetarians and Vegans:

<https://www.lifechangestrust.org.uk/sites/default/files/publications/Tips%20for%20older%20vegetarians%20and%20vegans%20final.pdf>

Supporting customers who live with dementia: Handy notes for staff in shops and catering establishments:

<https://www.lifechangestrust.org.uk/sites/default/files/publications/Supporting%20Customers%20Who%20Live%20with%20Dementia.pdf>

You can also find a wide range of information resources on our website which have been written and designed by people affected by dementia and funded through our Peer to Peer Resource programme.



Getting in touch

If you have any queries or wish to share your views and ideas, you can contact us in a number of ways:

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