

Befriending and Dementia

October 2016 to September 2017



**NATIONAL
LOTTERY FUNDED**



“I feel cared for. I feel I have a friend. I feel understood most of the time and I enjoy the time together. It’s great to have a befriender. It’s good to talk about shared interests – it takes me away from my caring role. It adds another dimension to my life which is just ‘me’ not Mother or Granny or Carer, not looking after anyone.”

“It is a rest from my caring role and a space for ‘me’ and ‘time out’.”

“She is so patient with me as I get very muddled these days but she doesn’t judge me, she just lets me be me.”

“It restores my husband’s sense of dignity by not treating him as a man with dementia. He feels included, not a bystander.”

“You contributed so much to B’s enjoyment over the last two years of his life. He thoroughly enjoyed everything from the Laughing Session to the Indian dancing. Your tireless organisation was very much appreciated.”

Introduction

Since October 2015, the Life Changes Trust has funded seven befriending projects across Scotland. These projects will be funded until October 2020. With the exception of one befriending project for carers, all of the projects provide befriending for people living with dementia who are at various stages of their dementia journey. These initiatives are all very different. Five operate across a particular geographical area. One provides a befriending service in care homes. Another provides befriending in a purpose built centre in a rural area or in a person's own home as part of a therapeutic model.

Over the last two years these projects have supported 302 people with dementia, 279 carers and worked with 179 volunteers. They have begun to share their experience and expertise with other statutory and voluntary organisations, positively influencing how these organisations shape their services by involving people affected by dementia. A couple of the projects have started to deliver services in new areas where a need has been identified and others have become centres of training and are providing opportunities for others to learn from them.

Since the funding began, the projects have been part of the Life Changes Trust growing network of funded projects which meets regularly to share progress and learning. These opportunities have helped to foster new relationships, encourage collaboration and create an environment of support and innovation.

This second report has been written using evidence gathered by projects from October 2016 to September 2017. This evidence has been collected from people with dementia, project staff, volunteers and carers. Feedback is gathered from structured questionnaires with befriendees in review meetings, observations and notes from volunteer befrienders, observation from carers or care home staff, evaluation forms, photographs, videos and diaries.

Through funding these projects the Trust has gained more understanding of the benefit of befriending for people affected by dementia and unpaid carers. Projects have reported back on challenges and learning over the past year and the innovative solutions they have often used to address these challenges. This report is intended to share this learning and demonstrate why befriending is so important to improving the quality of life for people living with dementia and their unpaid carers. It shows the positive difference that befriending 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. It is hoped that this will result in people living with dementia experiencing a greater sense of confidence, independence and well-being, as well as being able to exert more choice and control in their lives.

We will produce further reports on befriending between now and 2021.

We hope that you will enjoy reading 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 befriending?

The recently published draft national strategy to tackle loneliness and social isolation¹ sets out a vision for a Scotland 'where community connections are increased and no one is excluded from participating in society for any reason.' The strategy recognises the key role that strong social relationships and connections have in determining our quality of life.

Following a diagnosis of dementia, people often experience a loss of friendships and connections. This can happen for a number of reasons. Friends may be unsure of how to act, or the relationship with a partner can change to more of a caring role. A person with dementia may have to give up working, losing more connections. They may have to give up driving and may experience other health issues which can restrict how much they can get out and about. All of this can lead to isolation and loneliness, which can have a significantly negative impact on a person's sense of well-being and their physical and mental health.

And it is not just the person with dementia who is affected. Research carried out by Carers UK suggests that '8 out of 10 carers have felt lonely or socially isolated as a result of looking after a loved one.'²

Befriending is particularly valuable to people living with dementia, not only in terms of reducing loneliness, but also in providing information and signposting to other services and activities that could be of benefit.

Befriending for carers can deliver equally important benefits for health and well-being. Evidence from all of the Trust-funded befriending projects demonstrates how important these social supports are for carers in reducing isolation and increasing their well-being and ability to cope.

1 A Connected Scotland: Tackling Social Isolation and Loneliness and Building Stronger Communities <http://www.gov.scot/Publications/2018/01/2761/0>

2 Carers UK. No one Should Have to Care Alone: Break Isolation. <https://www.carersuk.org/breaking-isolation>

Research into befriending services shows that, on average, people who used a befriending service reported feeling more connected, more interested and more mentally resilient than they did before the service. People also reported a significant change in lifestyle as a result of the volunteers who had befriended them.³

In their report on the benefits of befriending, Befriending Networks state that ‘befriending provides companionship, stimulation and, in some cases, enabling people to maintain a level of physical activity and sustain connections with their local community by supporting them on outings.’⁴

John Swinton agrees. In his report, ‘Living Well with Dementia in Aberdeen City: Creating Communities that Care’⁵, he refers to friendship as the essence of community and that dementia friendly communities require dementia friendly people. He goes on to suggest that ‘a well-supported and effectively structured befriending scheme could function in a way that befrienders could also potentially have the role of supportive, collaborative advocates’.

In a sense then, befriending can act as a bridge between the self and the wider community. Befriending can support someone lacking in confidence to attend a group or go out for a walk, to go back to their scrabble club or go out for lunch. Or they can simply provide some company, conversation and laughter.

Researchers at the University of Stirling, in ‘A Good Life in Later Years’⁶, report that ‘good relationships were considered important for well-being and for ensuring reciprocal support, whether peer support or befriending’. Being able to interact with others provided people with a sense of purpose and was important to avoid loneliness. Physical frailty, lack of mobility, sensory impairments and dementia were considered challenges for keeping connected, and in such circumstances efforts could be made to keep people socially and mentally engaged through interaction and befriending.

There is an opportunity through the new Health and Social Care Standards and Self-Directed Support legislation to inspire innovative practice which can reduce isolation (including befriending) and ensure that individuals diagnosed with dementia remain connected to the things that are important to them.

³ [http://www.befriending.co.uk/assets/downloads/publications/wemwbs_study_report_-final_\(with_covers\).pdf](http://www.befriending.co.uk/assets/downloads/publications/wemwbs_study_report_-final_(with_covers).pdf)

⁴ [http://www.befriending.co.uk/assets/downloads/publications/wemwbs_study_report_-final_\(with_covers\).pdf](http://www.befriending.co.uk/assets/downloads/publications/wemwbs_study_report_-final_(with_covers).pdf)

⁵ <http://acvo.org.uk/wp-content/uploads/2018/02/Swinton-dementia-report-14-12-2017-2.pdf>

⁶ <https://www.lifechangestrust.org.uk/sites/default/files/publications/Good%20Life%20in%20Later%20Years%20FINAL%20NOV%202017.pdf>

Scotland's National Dementia Strategy 2017-2020 has made a commitment "to work with partners to explore the potential to promote and support increased participation in dementia befriending." It is not clear yet whether any additional resources are available or how this commitment will be delivered, but befriending has clearly been recognised as one important element in supporting the creation of dementia friendly communities.



Trust-funded befriending projects 2015-20

Alzheimer Scotland Forget Me Not Project

Forget Me Not was set up in 2008 to recruit and train volunteers to befriend people with dementia who are living in care homes or are in long-term hospital care. The befriending relationship encourages the person with dementia to feel more confident in taking part in social and community-based activities, lessening their isolation and keeping them connected for as long as possible. Funding is being used to develop the service, try out new approaches with music and technology and evaluate the impact of the service.

http://www.alzscot.org/services_and_support/search/2802_forget_me_not_service



Alzheimer Scotland Knowing Me Knowing You Project

This is a volunteer buddying scheme for people with dementia in Lanarkshire. Funding provides reminiscence therapy sessions from trained volunteer befrienders, to people at all stages of the dementia journey, within their own homes. Reminiscence sessions cover a broad range of subjects, from sport, local heritage and music to working life or cultural changes, and are tailored specifically to each individual. Memories are often captured in a life story book to help families to connect with their loved ones in a way that can continue even as their condition changes.

http://www.alzscot.org/volunteering/opportunities/3590_knowing_me_knowing_you_befriending_project_lanarkshire



Quarriers

This befriending project currently delivers a service for people with dementia across North Ayrshire. The project provides companionship and encouragement to people with dementia, using befriending as a means of reducing isolation and helping them stay as mentally and physically active as possible. It also supports people with mild to moderate dementia to continue to live in their own homes for as long as possible, and provides extra support for full time family carers.

<https://quarriers.org.uk/services/dementia-befriending/>



The Eric Liddell Centre

This personalised and flexible support employs a range of creative and therapeutic activities to reduce isolation and loneliness for new carers. It offers carers opportunities to talk about and share their feelings on their caring role, and to have a break from their caring responsibilities, promoting confidence and self-esteem.

<https://www.ericliddell.org/services/befriending/>



The Haven @ Home Project

Based on a successful pilot, this innovative initiative delivers complementary therapy sessions for people living with dementia and their carers at The Haven Centre in Forth. The therapy sessions aim to improve emotional health and well-being and reduce stress so that people with dementia and their carers are more able to cope with illness and caring. Families benefit from having someone to talk to and confide in as well as from the short respite breaks provided by volunteer befrienders with therapy skills.

<http://www.thehavencentre.com/about.php>



Town Break Stirling

Town Break provides a befriending service in the Stirling District geared towards people who have early to moderate dementia.

Services are focused on people who may not receive other support or those who have no carers and live alone. Weekly visits provide companionship, mental stimulation and new friendships, supporting people to continue to live in their own homes for as long as possible, increasing confidence and reducing isolation.

<http://www.townbreakstirling.co.uk/befriending/>



Town Break
Dementia Support Services

Voluntary Action Shetland

Voluntary Action Shetland offers a one-to-one befriending service across Shetland to support people living with dementia. They recruit volunteers from the local community who are trained as befrienders. Volunteers are matched with someone with a diagnosis of dementia and undertake a range of purposeful activities with them in the local community on a weekly or fortnightly basis for a limited time. This enables carers to have a break from their caring role to do something for themselves on a regular basis. The aim is to increase well-being through supported participation in activities chosen by the person living with dementia.

<http://www.shetland-communities.org.uk/subsites/shetland-befriending/>



What are the key factors needed for a successful dementia befriending project?

In providing financial support to befriending initiatives over a five year period the Trust hopes to demonstrate the wider benefits of befriending 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 understand me
- I feel less lonely and more positive about life
- I have an increased sense of well-being
- I feel safe, valued and respected
- I have more confidence to do the things that matter to me

The ways in which projects are benefiting people living with dementia and unpaid carers are discussed later in the report. The next section outlines the key factors that need to be in place to deliver an effective befriending service for people affected by dementia and/or carers.

Committed Volunteers who are Well Trained and Supported

Recruitment and Retention of Volunteers

On the whole, despite initial challenges, the Trust-funded befriending initiatives have been very successful in attracting and retaining volunteers from a wide range of age groups and backgrounds. For example, Quarriers has volunteers of mixed gender ranging in age from 19 to 65 years. Some are students but there are also people who are seeking employment, retired or currently employed. This diversity appears to bring benefits.

“Involving people from various age groups and communities allowed for a cross section of the community to increase their knowledge of people with dementia.” (Extract from Quarriers evaluation report)

This awareness raising is important in helping to reduce stigma and share stories of how people are living well with dementia. The Eric Liddell Centre and Town Break Stirling successfully recruited small groups of high school pupils and student volunteers who were supported to befriend people with dementia.

Many volunteers have little or no knowledge of dementia. Some volunteers have previous experience of supporting someone with dementia, working as a nurse or community psychiatric nurse or have previous befriending experience but many are new to befriending and dementia and require a great deal of support, training and reassurance. Voluntary Action Shetland discovered that the lack of knowledge about dementia was making some people reluctant to volunteer, but volunteers felt better once they had completed the initial volunteer training, particularly a week on training which is specifically about dementia.

The success in attracting volunteers has not, however, been without its challenges. Recruitment and retention are an ongoing issue, particularly where specialist skills are required. The Haven's unique approach to befriending through provision of complementary therapy sessions has meant that, **“volunteer therapist recruitment takes longer than anticipated due to the level of skills, qualifications and experience required and to ensure a high quality at home project and service for this client group.”**

The Alzheimer Scotland 'Knowing Me Knowing You' project has a particular challenge due to geography. This project covers a large area in Lanarkshire and referrals do not always match available volunteers. To address this **“the Volunteer Co-ordinator has made contacts in each locality and gained a knowledge of local groups and events and used these to advertise for volunteers. Local Facebook groups and newspapers have also been helpful. Links with the Dementia Adviser have also helped as they have a good understanding of what is going on in localities.”**

These challenges have prompted the befriending projects to expand their recruiting activities, for example advertising volunteer opportunities through volunteering events, university intranets and other organisations' newsletters. In addition to this, many of the befriending projects participated in a variety of promotional activities in order to further advertise their volunteering opportunities, raise the profile of their project and to learn more about current volunteering trends. For example, Alzheimer Scotland 'Knowing Me Knowing You' set up a Twitter account and the Eric Liddell Centre started vlogging.

Recognising that a number of projects were facing similar challenges, the Trust provided staff with the opportunity to attend an event hosted by the Scottish Government and Volunteer Scotland. The event focused on improving volunteer management, particularly the recruitment and retention of volunteers. Feedback was very positive. Reflecting on the event, Louise McGinty from Quarriers commented **“I found the day to be valuable in networking and learning from other organisations in relation to different approaches in good practice... Understanding that the model of volunteering has changed and volunteers tend to move on more quickly and try out other organisations as opposed to long-term engagement with one organisation, the approach now is to celebrate the time and input each volunteer provides rather than get caught up on length of time they stay...to ensure the volunteers’ motivations were being met, their skills fully utilised and contributing to the organisation’s mission.”**

The Alzheimer Scotland ‘Forget Me Not’ project, which provides volunteers for befriending in care homes across Glasgow, has learned that retaining volunteers depends on responding individually, understanding the demands on volunteers and keeping arrangements flexible. **“Our service has accommodated the changing needs of our volunteers, as some take time out of their volunteering role due to family responsibilities or study needs.”**

This project had experienced a very positive unintended consequence of volunteering when a former Forget Me Not volunteer befriender, a fifth-year medical student at Glasgow University, was inspired to set up the university’s first Dementia Society. Nat Quail’s aim was to inspire students to participate in meaningful activities and gain a better understanding of others in their community. The society now has over 40 active members. Nat initially began volunteering to accompany his studies however he quickly forged friendships with those he visited. Since September 2016, the Dementia Society has raised money for Alzheimer Scotland through bake sales, social media and fundraising events. Nat explained that becoming a volunteer is **“a chance for us, as passionately idealistic students, to physically contribute towards shaping the type of caring society we’d like to see.”**

Training, Developing and Supporting Volunteers

It is essential that volunteers feel supported, encouraged and valued and that they feel a sense of attachment to the wider organisation. This is achieved through access to a wide range of training and development opportunities and social events to celebrate and share learning. Training does not just include statutory requirements, such as Adult Protection but includes training in different approaches which have been shown to benefit people living with dementia, such as reminiscence, life story work and Playlist for Life. Volunteers at Alzheimer Scotland's 'Knowing Me, Knowing You' project are being equipped with tool kits to support volunteers to get to know the befriender and to help make their time together more interesting, fun, engaging and suited to the individual's needs.

Volunteer Training Story – Alzheimer Scotland 'Knowing Me, Knowing You'

The Volunteer Co-ordinator at Alzheimer Scotland's 'Knowing Me Knowing You' project has worked with the Learning Officer from North Lanarkshire libraries to run a reminiscence learning session for volunteers at the Heritage Centre in Motherwell. Volunteers looked at the benefits of reminiscence and how to use everyday objects to do this, for example, photo books, household items, music and movies. To further develop volunteers' confidence a day was planned to look at life story work and music lists. Each volunteer is encouraged to think about the person they befriend and what would work best for them before discussing this with the person.

Quarriers made an internal promotional video which supports volunteers by helping them to better understand what it is like to live with dementia. Their volunteer co-ordinator has also completed a Train the Trainer course in order to be able to provide more flexibility around training for the volunteers. They also offer online befriending training, 'Vital Skills in Befriending', through Befriending Network Scotland which can complement face-to-face training.

Voluntary Action Shetland have involved one of their volunteers in the training. The volunteer has personal and volunteering experience of supporting someone with dementia and shared these experiences during training. **"This allowed new volunteers to ask questions, brought the training to life and helps to reduce any anxiety around supporting someone with dementia."**

Project managers continue to enhance their own skills by undertaking additional training. For example the Dementia Carer Befriending Co-ordinator at the Eric Liddell Centre is now NHS trained in Cognitive Stimulation Therapy and is undertaking counselling skills training.

Alzheimer Scotland's 'Knowing Me Knowing You' project has worked very hard to ensure that volunteers feel supported and valued, despite the geographical spread of volunteers. **"To overcome this, individual supervision sessions have been conducted...and... regular contact is also maintained, mainly through email but also phone. Volunteers are aware that there is always support available. Christmas cards and birthday cards are sent and an event is being planned for volunteer week in January."**

Volunteers have been involved in development days designed to motivate, encourage confidence and look at what volunteers want to achieve. They have also benefited from volunteer gatherings where they can share ideas and experiences and receive peer support. At Alzheimer Scotland's 'Knowing Me, Knowing You' project, volunteers can attend monthly meetings/learning events, where volunteers can share a 'success story', that is, something that has worked or benefitted the befriended. This encourages peer support and practice learning.

Quarriers has established Continuing Development Days to support their volunteers continued learning and development. This provides **“an opportunity for Volunteer Befrienders to reflect on their role, take ownership of training by bringing ideas for a speaker or trainer for each event.”**

Volunteers at Alzheimer Scotland were invited to the 2017 Alzheimer Scotland annual staff and volunteer conference as well as social events, such as the “Pie and a Party event,” which was held for Dementia Awareness Week. Quarriers held a celebration lunch for volunteers during National Volunteer Week. These events demonstrate to volunteers that they are valued and appreciated.



Let's Celebrate!

Town Break, a long established befriending service, were awarded the Volunteer Friendly Award by Dundee Volunteer Centre. The award is a quality standard designed by Volunteer Dundee to support, recognise and reward groups who are good at involving volunteers. Town Break felt that this was an important way for them to show how much they support their volunteers.

The Alzheimer Scotland 'Knowing Me Knowing You' project has also received this award.

The Eric Liddell Centre Lunch Breaks Team won an Inspiring Volunteers Award from Volunteer Edinburgh.

Befriending has often been a very positive experience for volunteers. Quarriers is working with the 'Positive Steps with Partners' service which supports long-term unemployed people to find volunteer placements that help them to gain new skills and experiences which will enable them to progress towards employment. One of their volunteers, who gained new found confidence through her volunteering role, successfully applied for a place at college and a temporary post with Quarriers supporting their summer programme.



Volunteer Personal Story – Quarriers North Ayrshire Dementia Befriending Service

“My confidence was really low when I applied to become a volunteer as I have been out of work for a few years so I thought it would be good experience for me to volunteer, I am really enjoying it and really enjoying getting to know my befriender. We chat, laugh, talk about old times, watch and join in with quiz shows on the television and we look through memory boxes and play cards. I have enjoyed all of the training that has been offered to me and although I have only been here a few months I have much more confidence and in fact I have just been accepted into College to do a Social Care course.”

Emotional Support

Due to the nature of dementia, participants can sometimes no longer engage in befriending due to ill health, deterioration of their dementia, a move into residential care or because they pass away.

Quarriers have found that one of the challenges in supporting volunteers is when the relationship ends. Quarriers recognised a need for additional training around endings in order to reduce the emotional impact of losing a befriender. **“Depending on the reason for ending the volunteers may go through many emotions from feeling a failure to being sad and grieving. We have learned that relationship endings needs to be sensitively addressed as early as possible from induction and included in training. As much as possible endings will be planned and the volunteer kept well informed and supported. Unfortunately this is not always possible as sometimes we are not informed until the day of a planned visit and the person with dementia does not know they are going into long-term care and saying goodbye is not possible.”**

Some volunteers were leaving due to the emotional impact of losing a befriender. Alzheimer Scotland's 'Forget Me Not' project and Quarriers introduced flexible volunteer placements and 'time out' options to allow volunteers to continue volunteering and to reduce the emotional impact of ending a befriending relationship. **“Some volunteers took time out from volunteering while others switched to group befriending. Other volunteers responded to requests from families who wanted a visitor for their loved one while they were away on holiday. One volunteer recently requested not to be offering one-to-one support in the future after the death of the resident she had previously supported. Now when she visits the home she chats to all residents, rather than focusing on a single individual.”**

At Quarriers, support is available from the Volunteer Co-ordinator and peer support from group supervisions and development days have been invaluable in offering a safe forum for discussion. Volunteers are also able to access Quarriers Employee Assistance Programme which offers free expert advice, counselling and support.

They have also introduced a period of 'time out' for volunteers, **“to give them a break, reflect on the positive aspects of their befriending and the opportunity to come back to volunteering if they choose.”**

Good to Know

The University of Stirling recently carried out some research into volunteering in dementia care and developed a guidance for practitioners called ASUME Volunteering in Dementia. The ASUME website (www.asume.co.uk) provides useful information under the headings of Attract, Sustain, Understand, Motivate and Environment. Each heading presents key findings from the research, points to consider and best practice examples.

In summary, the befriending initiatives would attribute their success in recruiting and retaining volunteers to:

- having volunteers who are a range of ages (multi-generational)
- providing volunteers with good training and ongoing support, especially emotional support
- allowing volunteers to have time to reflect, share and learn
- affording flexibility and patience to volunteers
- giving volunteers opportunities to celebrate the difference they are making

Town Break's Top Ten Tips for Working With Volunteers

- Spend time designing your promotional materials and place them in appropriate places
- Offer volunteers relevant training for the role and in various formats, for example, visual, written, group work, etc
- Always ask for two referees and undertake PVG checks, if appropriate
- After training, ask volunteers to sign up to a Volunteer Agreement which sets out what you expect of the volunteer and what they can expect from your organisation
- Be prepared to undertake ongoing training and support. Some volunteers may need a bit more support than others
- Offer a choice of volunteering roles
- Take every opportunity to say thank you to your volunteers through, for example, awards ceremony, certificates, volunteer lunch, press release, social media, etc
- Be prepared to say "No" if necessary if a volunteer is not suitable for the role/organisation
- Offer new volunteers a 'buddy' to help ease them into their role
- Investigate 'Investing in Volunteer' schemes

Partnership Working and Collaboration

Partnership working has been key to the effective delivery of befriending projects. Projects have benefited from access to wider networks of third sector organisations through which to recruit volunteers. They have worked closely with other organisations and networks to identify families that could benefit from befriending.

Partnership working has helped to establish referral pathways, provided access to venues and to information about other services. Partnerships have enriched the befriending programmes, enabling projects not only to provide a more holistic service, signposting people with dementia and their carers to further support, but also to influence the way that other service providers work with people living with dementia and their carers. Examples include the Eric Liddell Centre project referring carers with additional needs onto appropriate organisations for additional befriending support, and The Haven and Alzheimer Scotland referring people for advice on benefits and respite care.

The Haven has established new referral pathways with Alzheimer Scotland, health professionals, South Lanarkshire Carers Networks and Community Psychiatric Nurses. Other projects have worked with Mental Health and Social Work teams, Community Psychiatric Nurses and sheltered housing complexes.

Attendance at local dementia cafes has also been helpful in raising awareness of befriending projects and has encouraged joint working with dementia advisers. For the 'Knowing Me, Knowing' You project, attendance at the Thematic Befriending Network Group has provided an opportunity to raise the profile of the project and share information. The project has also advised other organisations on how to recruit, develop and train volunteers, including, where relevant, delivering dementia awareness training and other training.

The organisations funded by the Trust have found it helpful to be involved in local networks, such as Older People's Service Providers or befriending networks – this helps to keep up to date with strategic developments, promote collaborative work and reduce the possibility of duplication of services. For Quarriers, participating in North Ayrshire Support Service meetings with Alzheimer Scotland, Ayrshire Community Trust (TACT) and the Ayrshire Independent Living Network (AILN) has helped to address the issue of low or inappropriate referrals to the service.

Quarriers staff attend carers meetings at Brooksby Medical Centre and attend the Brooksby Memory Café which is run by Community Psychiatric Nurses. Staff at the medical centre make referrals to the befriending service at Quarriers. Staff from Quarriers have also been involved in helping to establish the memory café at Park Church in Ardrossan.

The Haven multidisciplinary team of nurses, therapists and volunteers works together with local communities, empowering people to cope with the complex emotional and practical impact of illness and caring responsibilities. The team aims to relieve stress, anxiety and social isolation in supporting clients to live positively. Feedback from health, social care and community partners is demonstrating The Haven's position within the community as a valued step up/step down organisation and service. The Haven hope that sharing learning from this rural project can be used to steer service and policy development and attract funding for further services for people living with dementia and their carers. They are also using learning from the befriending project to shape future developments and delivery of Haven services to people affected by dementia within all Haven centres, including Blantyre and Wishaw.

Staff from The Haven have provided information about dementia support groups in their area and signposted to health and community groups for additional support, for example, setting up an anticipatory care plan and advice on Power of Attorney.

Partnership Story – Community Mental Health Team Nurse

“As a Community Mental Health Team for Older People, we provide one year’s support for people with dementia, in line with the dementia strategy. As an organisation we do not have infinite resources to continue to support our dementia patients and carers at the end of this. Haven dementia project provides an invaluable resource for step down to provide ongoing emotional support and therapeutic intervention. The Haven @ Home project and access to the purpose built facility, complementary therapies and patient/carer support are essential to engaging with patients and carers, improving community links and enhancing quality of life. The excellent networking and multi-agency approach enhance the existing services that we can provide for one year and hugely support and benefit our dementia patients and carers.”

The Eric Liddell Centre has become a small hub of training for others who work in dementia care, support or befriending. They have developed a partnership with Napier University. **“The music department of Napier University has now been partnering with us for a few months, to offer training to their music therapy students in delivering interactive singing sessions to our Lunch Breaks group.”** The Centre is also offering opportunities for practical experience to photography and film department students.

The Centre has developed a strong partnership with VOCAL, a carers’ organisation which receives funding from the Life Changes Trust to deliver peer support to carers. **“VOCAL offers courses for carers at the ELC; and in July and September this year, the ELC Dementia Befriending & Carer Support Programmes Manager will offer sessions on Dementia, Creativity and Interaction to unpaid carers via VOCAL’s programme. Others have been put in touch with VOCAL to help carers with financial/welfare assessments and paperwork.”**

The Dementia Carer Befriending Co-ordinator at The Eric Liddell Centre has joined wider networks such as the Scottish Care/SSSC 'Promoting Excellence in Dementia' group and has taken up training opportunities in befriending, counselling skills, mindfulness and cognitive stimulation therapy. This has served to strengthen service provision and helps the befriending programme to diversify and flourish.

The range of support available to carers and people with dementia has been widened through new programmes developed with Mindfullybeing, Alzheimer Scotland and Age Scotland. These programmes have allowed carers and people with dementia to have trips to places of interest, to see concerts and to take part in a range of talks relevant to care roles, as well as to attend classes such as yoga, tai chi, and qigong.

Next year the Centre will provide training workshops on Creativity, Interaction and Dementia for pastoral carers in partnership with Faith in Older People.

Town Break is a partner in a new training course offered to volunteers and carers who are supporting people affected by dementia. The Carer and Volunteer Training Programme is being delivered in partnership with the Dementia Services Development Centre at Stirling University. Town Break has also expanded its befriending service into a rural area, Killearn, through negotiating the use of the Killearn Village Hall Garden Room one afternoon a month for free for six months. They now run regular group befriending in this area.

Staff from Town Break also attended the first Scottish Volunteering Festival which was organised by Stirlingshire Voluntary Enterprise and Volunteer Scotland, Stirling Soup and Stirling University Psychology Department.

“Networking with these organisations strengthens our work as we have access to a wider variety of materials and expertise that we can tap into when necessary.” They have also become involved in the wider dementia friendly initiative, Dementia Friendly Stirling.

Whilst there have been many added benefits from partnership working there is also a responsibility to manage the expectations of service providers, statutory organisations, families and the person living with dementia. For the 'Knowing Me, Knowing You' project it has been challenging to manage the expectations of organisations and individuals making referrals, including social work, NHS and families. Their Co-ordinator has addressed this by making sure that the role of the befriender is clarified at the first meeting, particularly specifying that a befriender is not a support worker.

Quarriers continues to receive inappropriate referrals, such as people who are unlikely to benefit from the service due to their advanced condition or those in need of personal care. This is challenging for the Volunteer Co-ordinator as she has to deal with expectations from the person referred and their families. There can sometimes be disappointment when informing families that a service cannot be provided. In these cases, the Volunteer Co-ordinator provides information and advice so that families can access other services which are more appropriate.

“We acknowledge that we will have to continually remind referrers and highlight at network meetings what our service can and can’t provide.”

Involving different generations

Town Break has developed an eight-week intergenerational befriending project in partnership with Wallace High School. Four sixth year students befriended four Town Break clients. Students spent time with their befriended and talked to them about their lives. This information was then combined with pictures submitted from the befriended’s family to create a life story book.

One gentleman with dementia who worked with a Wallace High School student on his life story book said, **“normally I just sit and look out of my window when I am at home and now I’ve got my memory book to look at instead. I’ve lost many memories and now I have them all back in a book. I’m overwhelmed.”**

A lot of useful learning has emerged from running this intergenerational project. Different schools have different restrictions which can prevent pupils from befriending, for example not allowing students to go into people’s homes to befriend. The organisation has had to take into account school holidays and in-service days as well as managing the expectations of the students.

“We have learned that progress does take time and it has taken longer than expected to build up good relationships with our local schools but that the time spent has been worth it.” (Extract from Town Break evaluation report)

The numbers of young people getting involved with the service is growing and schools are keen to get involved with Town Break.

“We are delighted that our intergenerational project has been well received. The young people involved told us how much they had enjoyed meeting the service users and learning about their lives and things they had done... Some of the young people hope to go onto caring careers and found this experience very thought provoking and informative.” (Extract from Town Break evaluation report)

The Eric Liddell Centre is currently developing a relationship with the Duke of Edinburgh Scheme and two young volunteers from a local high school and Edinburgh University have joined Lunch Breaks as volunteers.

The Alzheimer Scotland ‘Knowing Me Knowing You’ project has established partnerships with St Maurice’s, Kilsyth Academy and Chryston High whose pupils attended the Kilsyth Dementia Support Group to entertain through singing and playing instruments. They hope to continue these partnerships with all schools.

Impact on People with Dementia and Unpaid Carers

Key to all of the work funded by the Trust is that project design, delivery and evaluation involves people living with dementia and unpaid carers and ensures that their voice is included at all times. For the befriending projects this is achieved through actively involving people with dementia in setting their own goals and discussing different activities they would like to undertake. Befriending can be tailored to what the person wants to do. A great deal of time is spent ensuring that the person with dementia is matched to the right person for them. For example, people may be matched because they come from the same area or have shared interests and/or hobbies, such as cooking, playing scrabble, football or knitting.

Regular reviews are held with befriendees to reassess their goals and the activities they would like to participate in with their befriender. The progressive nature of dementia makes it essential that adjustments are made regularly to enable people with dementia to continue to benefit from the befriending relationship and from connections with family, friends and the wider community.

Town Break Befriending Service, Stirling

“Our Befriending Service aims to help people who have dementia and their carers increase their well-being and be more positive about life.

Our Befriending volunteers all help focus on what can be done rather than what can't, help eliminate social isolation and are there to listen to any issues ... support by signposting to other organisations or offer suggestions and also encourage both the person with dementia and their carer to come along to our monthly Friendship Group where they can meet other people in the same situation as themselves.

When someone is being befriended they get the opportunity to socialise, to go outside to benefit from getting some fresh air and exercise, and their mood increases so their sense of well-being increases also.”

It takes time to build up a relationship with the person with dementia before introducing him/her to a volunteer. The Development Worker at Voluntary Action Shetland works at the pace of the person with dementia and, **“this has meant engaging with some people for short periods of time, three times or ten times before she introduces a volunteer.”**

Befriending has to be sensitive as well to differences in culture and language. For example in Shetland, the way that the service is presented to a person with dementia means that they can relate to it in their own terms. Rather than presenting it as a formal service, it is more about having a regular visitor with whom the person can have a chat and do things that they enjoy.

As with all of the projects funded through the Life Changes Trust Dementia Programme, the main aim of the befriending projects was to improve the quality of life and well-being of those whose lives are affected by dementia. More specifically, outcomes for people living with dementia and their unpaid carers related to increasing feelings of well-being, reducing feelings of loneliness, feeling listened to and valued and having more confidence to do the things that matter to them.

Information presented in the annual evaluation reports submitted by projects provides invaluable insight into the positive difference that volunteer befrienders are making to the quality of life of people living with dementia and their unpaid carers.

Benefits for Carers

“Having someone that cares. It’s not a nice feeling to think that nobody cares about you. In this place I live you’re left very much to your own devices.” (A carer who attends the Eric Liddell Centre Lunch Breaks project)

Feedback from projects has shown that befriending has had many benefits for carers. Dementia carers have told nurses at The Haven that they want support with caring responsibilities and to be better able to support the person with dementia. In addition, carers want to feel relaxed, be better able to manage stress, have increased confidence and to feel better about themselves. Volunteer therapists work to co-produce a programme of care which helps carers and the person with dementia to move towards their self-identified goals. This can include reducing stress and carer fatigue as well as increasing social interaction and reducing loneliness. These befriending therapy sessions give dementia carers short respite breaks in their caring roles and valuable time out from their caring responsibilities. This helps them to recharge their batteries, reduce tensions and helps sustain their caring relationships. The programme also includes signposting to other support agencies and nurse support (face-to-face and telephone).

Knowing that their loved one is looked after and enjoying time with their befriender helps carers in their well-being, by giving them time to do something they enjoy without having to worry about the person they are caring for.

“It helps me to concentrate on working if I know mum is not getting fed up or sitting on her own all the time.” (A carer of a person with dementia, Quarriers Befriending Project)

A carer at Town Break commented **“It’s reassuring to know that her befriender will come and collect Mum and drop her off again. Her befriender knows how to interact with Mum’s communication issues due to the type of dementia she has. It also gives me, the carer, a much needed break each week.”**

A carer from Quarriers commented that **“It’s lovely to see my husband getting out and about and doing things he enjoys, it allows me to go out with my friends and not worry that he is stuck in the house himself or, worse, that he is out alone and possibly lost.”**

Through their client survey, The Haven has discovered that, as a result of receiving Haven @ home services, 100 per cent of clients have stated that they have more confidence to manage the dementia and are better able to cope with the effects of illness. They reported improved outcomes around feeling more involved with family, friends and the things that matter to them. **“Inner peace. Confidence to get on with it, I’m not in this myself – I have support. More positive outlook.”**

In one case this support has resulted in better connections with others. With the support of a Haven nurse one lady was able to **“connect to the local Dementia support group, which she and her husband now attend regularly and which have ‘lifted her spirits’ and helped her to ‘interact with others’.”**

Staff also distribute self-management techniques DVDs to carers and signpost to additional support services. This last point is very important as it can result in additional support that can make a big difference. **“As part of a co-produced care plan the Haven nurse supported a Dementia Carer to make a referral to the Social Work department which resulted in 19 days extra respite care and an increased number of days at the day centre. This has impacted hugely on the carer and the dementia client.”**

In order to address some of the issues around matching befrienders, where the number of befriendees is greater than the number of befrienders, projects have experimented with different approaches to befriending. Through their Lunch Breaks programme, where both the carer and the person living with dementia are supported, the Eric Liddell Centre provides social befriending rather than the more listening-based approach of one to one befriending. **“Support comes from peers as well as via the widely varied activities. The group is also very flexible, in that other family members and secondary carers attend from time to time, in addition to the primary carers.”**

The Eric Liddell Centre also provides group befriending specifically for carers and meetings have developed in an organic way, out of the interests and inclinations of the carers. As well as information-based sessions about services and conversation over coffee and tea, participants have shared creative work they have done throughout their lives and one carer brought his guitar along for a sing-a-long.

One carer wrote to thank the Eric Liddell Centre saying **“I cannot tell you just how valuable you are in relation to Mum and Dad and how things have been so much better for them both. Attending the Eric Liddell on a Friday and now the Photography course [ELC course in partnership with Napier University] has been invaluable in that it is something they can do together and both get something from. That, in turn, makes my life so much better, knowing they are involved and happy.”**

Benefits for the Person Living with Dementia

“When someone has been diagnosed with dementia they can often feel that they are not valued or have lost their place in society. We aspire to encourage these people to feel a valued part of society with the right to make their own choices and have their voice heard.” (Extract from Town Break evaluation report)

At Quarriers all befriendees actively plan what they want to do with their befriender. This can be anything from having a cup of tea and a chat, going through a memory box, visiting different places of interest, planning to attend the theatre or going on a bus run. Progress is recorded weekly in volunteer logs and shows a gradual change from people who felt anxious and lacked in confidence to people who enjoy undertaking different activities or hobbies, often asking if they can have more hours with their befriender.

Personal Story

Mrs W is a widow who lives on her own. She was a keen cook and likes to talk about her mother and the memories they had cooking together. Her befriender got a copy of the Maw Broon cookbook as it contains lot of recipes that were familiar to Mrs W. The book has prompted lots of discussion and stories. During one conversation the befriender discovered that Mrs W used to be a keen knitter. The befriender also knits and brought knitting materials with her for the next meeting. The befriender went through the basics and Mrs W soon picked it up. They have been knitting every week and are now knitting squares to make a quilt that will go to a children’s charity. Mrs W’s sons commented that she told them that she feels useful again and has a purpose.

Town Break also provides group befriending for people with dementia. This has enabled them to support more befriendeds than they would through the one to one befriending service. People can attend group befriending while they wait to be matched with a one-to-one befriender. This introduces them to other people who have dementia and staff have noticed unanticipated benefits through peer support and new friendships being made.

All befriending volunteers are trained to focus on what the person with dementia wants to and can do and how the befriender can support them to achieve their goals. At Town Break, **“Volunteers are encouraged to really get to know the person they are befriending and ensure that they are consulted on the sorts of things they would like to do with their befriender.”**

This ensures that the focus is not on what the person with dementia is no longer able to do but on what they are still able to do, and how the volunteer befriender can support them. Some people enjoy trips to local coffee shops, to places of interest, such as the Kelpies, or walks in the park. However, some people prefer to be visited at home and are quite happy to sit and talk or read with their befriender.

This individual goal setting is important because everyone defines quality of life differently. It is often assumed that everyone values and gives priority to the same things. Individualised outcomes enable people with dementia to set their own goals based on what is important to them and therefore what will ultimately contribute to an improved quality of life.



Personal Story

Mrs C had lost a lot of confidence due to a fall which resulted in a hospital stay. She used to be a member of a scrabble club. Her befriender noticed during her initial visit that Mrs C had a scrabble trophy and this led to a very animated conversation about how she had learned to play scrabble, joined a club and won competitions. Mrs C was reluctant to go back to scrabble club because she was embarrassed about her diagnosis. Following a few meetings, the befriender has encouraged her to have a go at playing scrabble. Her confidence has grown and the scrabble club have agreed to collect her so that she can still attend.

A lot of projects use reminiscence materials or memory boxes and this activity, although often emotional, brings a lot of enjoyment. People with dementia enjoy talking about their childhood, family, working life and where they lived, using old photos and documents. Given that often carers are not present during befriending visits, to try and capture these memories Quarriers has (with the service user and family's permission) left a visitor's book in their home where volunteers record what they did on the day of their visit and how the person with dementia was feeling. This has proved to be really helpful for families that don't live with the service user. They can see that the visit took place, what activity took place and how their loved one was feeling that day.

The Alzheimer Scotland 'Forget Me Not' project is unique in that it provides befrienders to 30 care homes. Due to the advanced nature of dementia usually present in care homes it is often more difficult to ascertain whether befriending is having a positive impact. But the comments from staff, volunteers and family members demonstrate the value of befriending in this setting. Volunteers are often amazed at the difference in their befriendees.

”She enjoys the musical event we go to each month. I know she does not speak any more however I watch her smile, give me eye contact, and at times she will even join in with the songs – not all of course but sometimes I see her singing along.” (Volunteer befriender at a care home)

One volunteer reported: **“We always spent time in the common room in the home, so it was frequently lively and we often interacted as a group with the other residents and their families. Tam and I liked similar music and would speak about The Who, The Clash and The Smiths. We’d listen to music, debate what song was best and read NME. He’d educate me about football and show me the correct way to complete crosswords.”**

Another lady said **“I love knitting. I have been shown how to cast on using my thumb. How great is that? “.....responding with a huge smile and said “I may not be able to do many things now, but I can still do that and I love it. They let me be myself here.”**

There is increasing demand from care homes for volunteers because staff, managers and families can see the benefits. Befriending in some cases has also reignited links with the wider community. One care home manager commented, **“Some residents are now more socially interactive and actively look for the befriender who has been working with them individually. As well as undertaking friendships within the care home, some residents are now venturing outside to the wider community, enjoying visits to cafes, parks and shopping. Others simply value the comfort of having someone close for a time to hold their hand and provide comfort.”**

Activities relating to exercise and sport feature heavily in the feedback from projects. People with dementia want to continue to be as independent as possible, to do the things that are important and meaningful to them and having a befriender is key to this. **“I look forward to going out and playing snooker again and I especially like winning! I’ve really missed it as it’s something I was always able to do on my own.”** (Person with dementia)

“I can’t get out on my own anymore, I used to walk everywhere but now if I go into Largs I get lost on my way back so it’s great having my befriender with me so I can still get out of the house.” (Person with dementia)

Personal Story

Mr R had always been very active man and enjoyed playing darts but had given up a lot of his activities due to a lack of confidence. This resulted in him staying in the house a lot which led to him having a low mood. His befriender discovered that Mr R had enjoyed playing dominoes and bought a large set of dominoes for the introductory visit. As soon as the befriender took the dominoes out of the bag, Mr R jumped up and took them. The befriender asked Mr R to show him how to play and he was delighted. The befriending meetings have increased from one hour to three, with them playing various games such as dominoes and cards. Mr R mentioned that he really missed playing darts and his wife agreed to buy a darts board. He has been playing darts regularly with his befriender and this has encouraged him to ask his son to take him to his local pub for a game. Something he would never have done before befriending.

Carers have reported that befriending brings peace of mind, respite and time to do things that they enjoy. People with dementia have reported that befriending enables them to continue to do activities that they previously enjoyed with a little bit of support. Being able to get out and about and benefit from physical activity improves health and well-being through reduced stress levels, increased social interaction and feeling more positive about life. Volunteer befrienders have reported increased confidence on the part of the person with dementia, enabling them to plan events with their befriender.

“I have always wanted to go and walk around Millport for the day and now we are planning on doing this once the weather is a bit nicer.” (A person with dementia, Quarriers)

Befrienders and carers have also noticed how participating in activities and getting out and about again has led to improved eating habits. One carer at Town Break commented, **“Before John started visiting, my husband had gone off food and was picking at his meals which made me quite concerned for his health. Now they go out for a walk to the local coffee shop and have lunch. K always tells me what a lovely meal he had, although he can’t remember what it consisted of. He seems brighter and enjoys his food again.”**

Personal Story

“Before Mr M was supported by our befriending service, he had stopped making himself food, was losing weight, having several falls and was extremely dehydrated. A friend of the family is the only contact he had and only popped in to see Mr M once a month so was unaware of his deteriorating physical and mental health. Once our befriender had visited Mr M, he was able to alert the Befriending Co-ordinator to Mr M’s health and home issues. Following discussion with Social Work, Mr M now has paid carers going into his home four times a day every day. This has made a huge difference to his health. Mr M’s confidence and physical health have greatly improved. He now enjoys weekly trips out, he is eating and drinking regularly, is mentally stimulated, safe and healthy and tells us that he thoroughly enjoys life.”

Participants at the Eric Liddell project have attended dementia friendly poetry workshops at the Scottish National Portrait Gallery, enjoyed drama, musical bingo and lots of other creative activities. The key success factor in activities has been the involvement of people with dementia and unpaid carers in deciding what they want to do.

The evaluation reports have been full of interesting and innovative ways that befrienders have overcome obstacles and challenges in order to ensure that people with additional health issues can benefit from having a befriender.

In Lanarkshire, an occupational therapy student worked with a befriender to support an 86-year-old widow who lived on her own in a very rural setting. This lady was registered blind and had very limited mobility. The befriender and occupational therapist explored different tools, including fragranced play dough to stimulate memories and help to maintain dexterity. The befriender also provides some fun by using a “mystery bag” filled with different objects and textures, such as baby powder and shaving brushes. The befriender and befriendees take turns to take an object from the bag and use smell and touch to identify it. The lady also enjoys listening to relaxing music on her playlist for life and singing.

Personal Story

Mrs X is a widow and lives in a retirement village. She is wheelchair bound following a stroke which affects her mobility and use of her right hand. She used to be a very talented artist. Due to her limited mobility and confidence issues Mrs X had not attended any of the events within the retirement complex and had few visitors. She had become depressed and was referred to the befriending project by a Community Psychiatric Nurse (CPN) who was concerned about Mrs X's low mood.

At the first meeting, Mrs X was very reserved and there was limited engagement, however the befriender was able to discover that Mrs X likes dogs, drawing, painting, birds and wildlife puzzles. The befriender took along an adult colouring in book with pictures of animals and some coloured pencils. At first Mrs X was not keen because she was unable to use her right hand, so the befriender used her left hand and they both began to colour together. Doing this activity together helped Mrs X to relax and the befriender was able to get to know her better.

Mrs X is a happier, more outgoing lady. She smiles and laughs a lot and enjoys reading funny stories, Scottish poetry and singing Scottish songs. The CPN has noticed a positive improvement in Mrs X's mood. The befriender has helped Mrs X to join a social media site and this has helped to reduce her isolation. The befriender has also accompanied Mrs X to the local dementia café, where she has made some friends.

Our FRIDAYS AT
DAY BREAKS FOR
CARERS

Have made a
world of difference
to us.

So many happy hours
of companionship
and enjoyment
thanks to all your
excellent organisation,

Our Very
Sincere
Thanks,



J

Summary of the benefits of befriending

- Company, conversation and laughter
- Increased confidence to get out and about
- Reduces social isolation and loneliness
- Encouragement to participate in other activities and in the wider community
- People with dementia are involved in making decisions
- Befriending focuses on what the person with dementia *can* do not on what they can no longer do
- Increased feelings of well-being through reduced stress and participation in physical activity
- Feeling listened to and valued
- Respite for carers from their caring role
- Peace of mind for carers
- Time for carers to do things they enjoy
- Capturing memories to share with family

Looking forward

Since submitting their second end of year report, the befriending projects have all secured some degree of match funding to continue to deliver their services for another year. Some have even secured match funding that extends beyond the third year. This funding has come from a range of sources including:

- The Robertson Trust
- Alzheimer Scotland
- Stirling Council
- Quarriers Noel Fundraising Lunch
- Celtic Foundation
- North Lanarkshire Health and Social Care Partnership
- Dementia Engagement and Empowerment Network

In addition to this, the Eric Liddell Centre has secured a two-year grant of £53,718 from Celtic Football Club Foundation to expand their Lunch Breaks programme. Celtic Football Club Foundation has also provided £20,000 to provide Celtic-employed tutors/coaches for Lunch Breaks activity sessions during this time.

There is an enormous amount of partnership work coming to fruition, which will add even greater value by offering people with dementia and their carers a range of activities to participate in, some of this with other Trust-funded projects.

One project is considering working towards a Quality in Befriending Award.

Projects are being recognised as examples of good practice and centres of learning, valued within their local communities. They are influencing practice within other organisations and are contributing to building up a body of evidence to demonstrate that befriending should be a key component in any dementia strategy.

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

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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