



Independence, Confidence and Support

A resource for
creating better lives



UN Convention on the Rights of Persons with Disabilities, Article 4:

States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability.

To this end, States Parties undertake:

- ▶ (a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention**
- ▶ (b) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities**
- ▶ (c) To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes**
- ▶ (d) To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention**
- ▶ (e) To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise**



- ▶ *(f) To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines*
- ▶ *(g) To undertake or promote research and development of, and to promote the availability and use of, new technologies including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost*
- ▶ *(h) To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities*
- ▶ *(i) To promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights*

Introduction

When a person is diagnosed with dementia, or even before that point, they can see their world start to shrink. They may become gradually excluded from familiar places and activities. Friends may disappear and it may become increasingly difficult to find meaningful social interaction. It may be a challenge to get to places by car or to navigate public transport; once well-known buildings may seem like a foreign land. Even the home, that has been a place of security, may begin to seem strange and unfamiliar. The senses that help us see, hear, taste, touch and smell the world around us may seem to fail as the brain misinterprets the data it receives.

The effect of these changes on a person's sense of wellbeing, independence and confidence can be immense. This is why it is so important that communities and public bodies, in partnership, do their utmost to ensure that life does not close in on the person with dementia and their family.

The work outlined in this book gives a clear illustration of some of the ways that a person living with dementia can be supported to live a life that is fulfilling and productive; a life where they can continue to thrive and a life that, when the time comes, ends well. This kind of work should be supported routinely by public authorities and other funding bodies across Scotland.

Public bodies, in fact, have a duty (Equality Act 2010) to address disadvantages experienced by people due to their disability. They should be taking very active steps to meet the particular needs of people with dementia, and of unpaid carers. Promoting the independence and confidence of unpaid carers should also be a top priority, firstly, because unpaid carers have a right to such support and, secondly, because without them the State would buckle under the weight of their caring responsibilities.

The wide-ranging work in this book, and the rest of the box set, clearly illustrates what a 'whole life approach' to dementia should look like.

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The arts and dementia



An Talla Solais: Dolphin Arts Project, Ullapool



Highlands

An Talla Solais is Ullapool's visual arts centre and we have two galleries that host a range of contemporary artwork throughout the year.

Our main gallery is home to an annual programme of exhibitions featuring a wide variety of exciting and thought-provoking contemporary artworks, including painting, sculpture, ceramics, installation, drawing and performance.



Our smaller gallery, The Room, shows a selection of paintings and sculpture that is changed on a regular basis to complement our main exhibition programme and to offer our visitors the opportunity to view and purchase work from some of Scotland's leading contemporary artists.

We also run events and activities linked to our exhibition programme and the studios on our Market Street site. We offer workshop spaces and a ceramics facility to artists and groups.

What we do

The Dolphin Arts Project offers regular creative activities to people living with dementia and unpaid carers. At its heart is a weekly art session, which uses a rich combination of activities to explore a series of themes that unfold from month to month.

Poetry and, increasingly, song are an integral part of these sessions, with words being celebrated and enjoyed alongside the process of making art. Our process of 'word gathering' is also an important element of the activities, with individuals' comments and conversation being recorded in snippets and read back periodically to the group almost as its own poetry, giving a sense that people's words are listened to and savoured.

An important element of these activities is that they involve a handful of volunteers who work alongside the group, creating a sense of equality and community rather than 'participants' versus 'helpers'.

Increasingly we understand that the value of these sessions lies in the richness of creative stimulation, whether or not participants felt at the start that art is 'their thing'. The social stimulation and pleasure of shared activity, focus, humour and emotion is also a substantial benefit for those involved.

We also work regularly in local care homes to ensure that residents who can't get to the group sessions aren't excluded, and we run a monthly art conversation, usually in Ullapool's gallery.

The Dolphin Arts Project is leading Ullapool's momentum to become a dementia friendly community. This side of our work involves liaising with other creative organisations, businesses and local networks to ensure that access to Dementia Friends sessions and dementia awareness sessions are readily available across the village.

What we are achieving for people with dementia and unpaid carers

- ▶ for those living with dementia: access to a reliable creative form of support that stimulates them, is pleasurable, mindful and involves building the social connections that resist isolation
- ▶ for unpaid carers: a combination of 'respite without separation', the reassurance of knowing their companion is benefiting from an activity, but also one which they can enjoy themselves
- ▶ for those living with dementia: dignity, choice and a chance to be heard, as well as opportunities to explore and unearth creative pleasure
- ▶ the wider community is increasingly aware of how to support those living with dementia, and puts this into practice in such a way as those living with dementia feel valued in their daily lives



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Capital Theatres



Edinburgh & the Lothians

Capital Theatres is the largest independent theatre organisation in Scotland. We operate three busy theatre venues in Edinburgh: the Festival Theatre, the King's Theatre and The Studio. A registered Scottish charity, our vision is to inspire a life-long love of theatre, to increase and deepen cultural engagement.





What we do

In 2015, we founded a dementia friendly community, to enable people living with dementia, their friends and family to continue engaging with live performances. The community has flourished and there are now four core strands to this work:

- ▶ programming: providing opportunities for people living with dementia, their friends and family to access live performances, both bespoke work and performances adapted to meet the needs of people living with dementia
- ▶ creative engagement: an ongoing programme of work that supports people living with dementia to be active as artists, collaborators, performers and participants in creative work
- ▶ our buildings: an ongoing programme of improvements to our buildings, to support people living with dementia to navigate the physical environment
- ▶ training: a training and development programme for staff and volunteers at Capital Theatres and indeed for colleagues in the wider creative and cultural sector
- ▶ underpinning our dementia friendly community are: a focus group, putting people living with dementia at the heart of the community and its development, a volunteer programme, drawing on skills and experience within the wider community to support and develop our work and a newsletter for Edinburgh & the Lothians.

In our work from 2018-20, we are striving in particular to promote positive engagement in our activities among diverse groups of people, including people who may not have a track record of engaging with culture and/or may face additional barriers to engaging with culture.

What we are achieving for people with dementia and unpaid carers

- ▶ opportunities to engage with the performing arts as audience members and active participants in creative work, as before or for the first time
- ▶ a positive experience of our organisation, in terms of our staff, volunteers and buildings
- ▶ positive developments in the broader creative and cultural sector through sharing our learning and supporting artists and other arts organisations to develop their own dementia friendly work

Training

We deliver a training programme for artists and arts organisations. Other training and informal consultation may be available on request, so please contact us! We are in the process of developing a dementia friendly toolkit for performing arts organisations and anticipate this being available online and as a hard copy in 2020.

Please see page 17 in the Information, Awareness, Training and Education book for more information. See also www.lifechangestrust.org.uk/project/capital-theatres

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Centrestage: Gie it Laldy!



Ayrshire

We are a registered Scottish charity that firmly believes in having fun by playing to our strengths. We all need some fun at times to escape the daily routines and challenges. From our Centrestage creative learning activities to our Centrestage productions, there is so much fun to be had across our projects. We now welcome over 2,500 participants across our projects and activities each week.

What we do

At a Gie It Laldy session, music and conversation intertwine to provide the perfect formula to improve the health and wellbeing of our friends living with dementia and unpaid carers. The music not only rekindles old memories but ensures new happy memories are made for our participants. Our sessions ensure new friendships blossom and a support network is created for both people living with dementia, unpaid carers and wider families. We currently have one core session at our premises and visit three care homes weekly.



Every week on a Tuesday we host our core session at Centrestage, which welcomes 50-60 participants. What makes our Gie it Laldy sessions unique and welcoming is that we pay attention to the finer details – everything from the flowers on the tables, the colour of the tablecloths and the choice of sweets and cakes is given careful consideration.

The session welcomes our friends with a selection of refreshments, followed by several 15-minute sets of songs interspersed with conversation and occasionally games. Our sessions are quite often sensory and involve children and young people to add an intergenerational aspect to the project.

The themed sessions are hugely popular with our participants and are often inspired by a conversation one of our leaders has had with a participant. By planning the sessions around our friends' interests and their life events, we give them a voice, a sense of value and a purposeful role in the running of the project.

Every Tuesday, there is a tangible excitement as our friends enter the auditorium in anticipation of the theme for that week and the fun that awaits them. Participants enjoy exploring the props on the table and examining any photos or pictures we have laid out. These serve as reminiscence tools, as well as conversation starters.

One of our strengths is our ability to provide participants with the opportunity to take the lead in the session.

The sessions in the three care homes we visit weekly differ slightly, in that they are not themed. However we continue to listen to the interests and personal preferences of the residents and respond appropriately. Many of the residents in the care homes simply light up when they see us arriving. We know we are offering alternative approaches to practice in care homes by inspiring the staff there to use song and music as part of their routine.

Conversation is a key part of all our sessions. This project will never simply be a sing-song, although music is at its heart. We take time to sit, hold hands and chat to our friends living with dementia and to unpaid carers. We get to know our participants well and become friends.



The sessions are fluid and react to the mood and energy in the room. Our talented keyboard players are able to take requests and play them almost instantly. This ensures our sessions have a personal touch and are never forced upon our participants.

What we are achieving for people with dementia and unpaid carers

- ▶ we have created a community of support for people living with dementia and for unpaid carers where they feel they belong
- ▶ we challenge the stigma and barriers surrounding dementia, tearing down preconceived perceptions
- ▶ our friends living with dementia have a voice in our project. We listen to them, respect them and allow them to do things that matter to them

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Western Isles (Eilean Siar)

An Lanntair is a hub for creativity and the arts in the Outer Hebrides. We are a multi arts venue – at one and the same time a contemporary art gallery, a theatre, a cinema, a dance studio, a concert hall, a platform for poetry and literature, a studio – with every space stretched to showcase the arts in multiple forms. Our work stretches across a national and international platform, yet our distinctiveness lies in being ‘of the place’, rooted in who we are, and the creativity of Gaelic and the Outer Hebrides takes centre stage. Our mission is:

to connect and inspire people in producing extraordinary, creative programmes, uniquely rooted in the place and reflecting the arts and ideas of our time.





What we do

Cianalas is a Gaelic word which does not have an exact translation into English but is related to belonging and, in particular, a warm feeling of home. It is a word that is rooted in the culture of the Outer Hebrides.

Cianalas is An Lanntair's dementia friendly community project, formerly Arora, funded from April 2018 to March 2020 by the Life Changes Trust and The National Lottery Community Fund.

As part of Cianalas, we share the inspirational An Lanntair arts programme in the form of exhibitions, festivals, classes and talks and in particular we offer tailored new events and collaborations for people living with dementia and for unpaid carers. We also strive to offer activity that maintains connections between people within their communities, providing access to arts, cultural or heritage events that are relevant to them. Our current themes explore the material culture of the place through film-making, dance, photography and sonic textiles and through Gaelic/English podcasts.

We create resources for the community to share, such as community artworks, podcasts, films, memory boxes and crafting kits. We offer a regular, seasonal newsletter online and in spoken word format. We have specialist freelance Creative Care Practitioners throughout the islands and artists in various media with specific skills relating to our work.

Rooted in research, we aim to continue to collaborate with our academic, health, third sector and local authority partners to find ways to resolve issues raised by people living with dementia and by unpaid carers and to uphold their rights and ensure that their voices are heard as valuable contributors to the community.

The importance of remaining active and moving regularly is supported by our dance project. Our Woven Communities work with the University of St Andrews, demonstrated the immense value of cultural, lived experience. Our Sonic Textiles work with Lucy Robertson, PhD student at Duncan of Jordanston, has been investigating how to strengthen communication between friends and for self-expression.

What we are achieving for people with dementia and unpaid carers

- ▶ we uphold the right of people living with dementia and for unpaid carers to remain involved and connected to the community around them
- ▶ we demonstrate the valuable contributions people living with dementia and unpaid carers can make to local services, to tangible and intangible cultural and heritage collections and to the community
- ▶ we offer opportunities for people living with dementia and to unpaid carers to engage with arts, academic, cultural and heritage opportunities, in order to strengthen communication, self-expression, community cohesion and personhood
- ▶ we share and inform research
- ▶ we find creative ways around problems and issues raised by people living with dementia and unpaid carers so that they are leading the project work
- ▶ we offer lifelong learning opportunities through our community workshops with local and visiting artists

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Glasgow Film Theatre: Movie Memories



Glasgow

What began as a single screen cinema over 40 years ago has become Scotland's most diverse and best publicly attended independent cinema in the country, with Glasgow Film Festival one of the top three film festivals in the UK.

Glasgow Film Theatre is a national centre for film and moving image media where audiences and filmmakers experience and debate cultural practice and ideas through diverse, unique and quality programmes that transform the way people see the world, through film.



What we do

In a time of social austerity, endeavoring to achieve our ‘cinema for all’ ethos has never been more crucial. Within the framework of Equalities, Diversity and Inclusion, we at Glasgow Film Theatre are acutely aware of our duty to provide and provoke connection, community and culture through engagement with film, for people of all ages.

Movie Memories is a monthly programme funded by the Life Changes Trust presenting film screenings alongside a programme of multi-arts entertainment in a dementia friendly environment. With dementia aware staff and a team of trained volunteers (Movie Memories Ambassadors) running the event, this programme is designed especially for people affected by dementia. This encompasses people living with dementia, unpaid carers, friends and family.

People living with dementia play a central role in the programme delivery – Agnes Houston MBE is our Movie Memories Coordinator. Movie Memories is developed and informed by a steering group, including Deal with Dementia, GCVS Community Connectors, Dementia Carers Voices, Health and Social Care Alliance Scotland, DEEP, Glasgow’s Golden Generation, Alzheimer Scotland, North Dementia Forum and **tide**.

Running alongside the programme is a vital academic research programme led by Brian Smith, Glasgow Caledonian University.

What can I expect at a Movie Memories event?

- ▶ a welcoming and safe environment
- ▶ a social space, where conversation is encouraged
- ▶ dementia aware staff and volunteers
- ▶ free refreshments and an interval
- ▶ all tickets are £3



Access Information:

- ▶ all events are seated
- ▶ the venue has clear signage
- ▶ there is an accessible toilet
- ▶ the flooring in the cinema is short pile carpet
- ▶ the venue is well lit – the cinema stairs are lit at all times
- ▶ the venue is well ventilated

What we are achieving for people with dementia and unpaid carers

- ▶ people with dementia and unpaid carers have a significant say in how their dementia friendly community is run
- ▶ people with dementia and unpaid carers know they have a community of support around them
- ▶ people with dementia and unpaid carers are included
- ▶ people with dementia and unpaid carers feel safe, listened to, valued and respected
- ▶ people with dementia and unpaid carers are empowered to do the things that matter to them

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Heart for Art: Church of Scotland



Scotland

The Church of Scotland is one of the largest organisations in the country. We have over 340,000 members, with more regularly involved in local congregations and our work. Within the organisation, we have around 800 ministers serving in parishes and chaplaincies, supported by more than 1,500 professional and administrative staff. Most of our parishes are in Scotland, but there are also churches in England, Europe and overseas.

The Church of Scotland works with communities worldwide. We are one of the largest organisations in Scotland that has a pivotal role in Scottish society and indeed religion throughout the world.





What we do

Heart for Art provides therapeutic art groups all over Scotland for people affected by dementia. These groups meet weekly or fortnightly in community spaces, bringing people together to produce artwork. The sessions are facilitated by trained Heart for Art staff and supported by volunteers. During the sessions, participants choose what they would like to draw or paint and the team support them to make this happen.

This is a person-centred approach to enable and empower people living with dementia to be creative. From selecting images or subject matter to inspiring their creation and choosing what materials to try, Heart for Art aims to encourage, uplift and energise participants.

Unpaid carers are also benefiting from the therapeutic and relaxing qualities of this type of activity. In many cases, we have found that including participants in creating something improves their focus and mood. Through unpaid carers taking part in some sessions, this has relaxed participants, reducing agitation and anxiety and contributing to a positive ethos.

The artwork that is produced is often exhibited, whether in a local or national exhibition. The artwork acts as a reminiscence tool for participants, however it also informs and opens up dialogue with members of the public. Speaking about dementia is so important. By talking about it, we not only educate and demystify dementia, but we share strategies for living well. Heart for Art has a profound impact on people, from participants themselves gaining confidence and support, to the whole group sharing and enjoying each other's company. There is then the wider impact of taking this experience out into public spaces and engaging conversation.

What we are achieving for people with dementia and unpaid carers

- ▶ use of creativity to bring enjoyment and inclusion to people living with dementia
- ▶ improved quality of life through either retaining artistic skills or gaining new artistic skills
- ▶ use of art as a medium to actively engage people and be a catalyst for conversation
- ▶ through art, imagery, colour and textures people tell us how they feel. People are listened to, valued and accepted as they are
- ▶ when unpaid carers see the needs of their loved one being met, they feel supported
- ▶ the sessions bring some relief and support to unpaid carers, be it a couple of hours of respite, chatting with trained volunteers and staff or actively creating art for themselves

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Playlist for Life



UK-wide

Playlist for Life is a music and dementia charity that helps people living with dementia find the soundtrack to their life. Music is neurologically special because it activates many parts of the brain simultaneously. There is growing international evidence that ‘personally meaningful music’, the music that takes you back to a time, place or person whenever you hear it is even more powerful. It is deeply rooted to an individual’s memories and emotions, making it a uniquely powerful tool for people whose memories, emotional connections and very sense of self are being eroded.

People will want to consider getting involved with all the music-based interventions available for people with dementia. Making a playlist is an easy one to start with because you can get going in your own home straight away and then your playlist can go everywhere with you.

With the right tools and knowledge any person can create a playlist for themselves or another person.



What we do

We provide support, tools and training to help people find the right music and when to play it. We reach people at home through our growing grassroots network of community Help Points. Raising awareness about Playlist for Life through talks and conferences is an effective way of spreading the word. Our website and mobile app provide helpful tools to teach people how to track down the soundtrack to their life. Healthcare professionals are taught how to integrate Playlist for Life into care through our face-to-face training.

It is our aim to ensure every person living with dementia has access to a personal playlist by 2020. Using a personal playlist brings benefits not only to the person with dementia, but can also reduce carer stress and provide respite.

Benefits of using a personal playlist can include improved mood, recovery of words and a reduction in administration of psychoactive drugs. Importantly it also supports closer connection between the person with dementia and unpaid carers. Playlist for Life can bring moments of happiness and a sense of familiarity to the person with dementia, improving their overall quality of life.

Scheduling the music at specific points in the day can help manage symptoms, reducing instances of stress and distress. It can be used at any time of the day whenever the person needs it, making it accessible to all. For care practitioners it enables a truly person-centred approach and can make caring for the person easier.

We want to make it as easy as possible for people to use Playlist for Life. The benefits of using Playlist for Life can only be realised if the individuals and organisations a person with dementia comes into contact with, know how to use it. Growing our network of community Help Points and increasing the number of practitioners in the field through tools and training addresses this. Playlist for Life is also a fun activity which can be incorporated into other individual or group activities.



What we are achieving for people with dementia and unpaid carers

- ▶ people with dementia have access to their unique personal playlist and, by using it, are empowered to manage their symptoms, experience improved wellbeing and schedule activities throughout the day
- ▶ people with dementia and their family carers use the creation of a playlist and listening together to support communication, improve their relationship and reduce social isolation and loneliness
- ▶ volunteers working to support people with dementia have greater knowledge of dementia and a new means to connect with people affected by the condition
- ▶ services for people with dementia are improved, as tools and training for the use of personal music are shaped more directly by people affected by dementia and personal music becomes a common means to support wider activity
- ▶ personal music is a consistent thread supporting connections within and between dementia friendly communities, as more people with dementia have playlists and more organisations know how to use them

Evaluation

Playlist for Life is based on an evidence-based protocol¹ developed at Stanford University about how to use personal playlists to deliver tangible health and wellbeing benefits.

There has been a number of small-scale studies using Playlist for Life in the NHS, including in A&E. We maintain up to date details of these on our website www.playlistforlife.org.uk

We have a research partnership with the Dementia Prevention Research Group at the University of Edinburgh, who are currently scoping a major efficacy study. We are also working with Glasgow Caledonian University on a PhD examining the impact of Playlist for Life on the culture of care.

1 <https://stanford.io/38Q0j7o>

Training

Playlist for Life provides face-to-face and online training to health and social care professionals, community organisations, students and carer groups. Our training courses provide the knowledge and skills to become music detective and how to integrate Playlist for Life into care plans. For community organisations, it can strengthen existing services through the use of music.

Please see page 30 of the Information, Awareness, Training and Education Book for more information. See also www.lifechangestrust.org.uk/project/playlist-life

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Regional Screen Scotland: Screen Memories



Scotland



Regional Screen Scotland helps communities to enjoy great screen experiences. We do this by:

- ▶ providing advice and information on setting up local screen facilities
- ▶ operating the Screen Machine mobile cinema
- ▶ managing a grant aid fund for local film festivals across Scotland
- ▶ advocating for the social and economic benefit of cinema for local communities

We provide information, advice, contacts, and support to both individuals and organisations seeking either to start or to develop opportunities for cinema-going in their communities. We're committed to helping to bring people together to share and enjoy exciting, high quality screening experiences, where they live.

At Regional Screen Scotland, we work particularly with those communities across Scotland that have no access – or only very limited access – to the full range of screening possibilities.

What we do

Screen Memories uses film still images, memorabilia and selected film extracts to provide structured experiences to stimulate recall, boost self-esteem and confidence. We establish connections within a community of interest for people who are living with dementia and other memory problems, as well as those who are lonely and isolated.

Group and one-to-one film reminiscence sessions are held in a variety of appropriate settings, such as peoples' own homes, hospitals, care homes, day centres and community facilities. These are facilitated by activities coordinators, trained volunteers and senior students. Staff, volunteers, family members and unpaid carers receive training in cinema themed reminiscence and all involved have access to online resources and advice. A Volunteer Handbook is available after completion of training: <https://bit.ly/2nb5y00>.

We use specially-commissioned compilation DVDs, which mix archive material, period adverts, and trailers and extracts of classic films, to recreate 'A Night at the Pictures'. We also use still images and posters of films from the 1940s, 1950s and 1960s prior to the showing to engage in conversations, trigger memories and set the scene. We also create Oscar-type events where the people living with dementia select their favourite film, actor and actress and stage a special event modelled on the famous event. We also have singing and acting activities based on songs and iconic scenes from famous films.

The unique element of our project is the use of film as a reminiscence trigger. The recreation of the whole cinema experience in a familiar setting involves staff, volunteers and unpaid carers. The acting element is unique and the boost to self-confidence and mood is obvious.

The breadth and depth of recall is spectacular in many cases, including details of plot, dialogue and film stars.



What we are achieving for people with dementia and unpaid carers

People living with dementia

- ▶ improvement in mood, self-esteem and confidence
- ▶ improved communication skills
- ▶ more confident, relaxed, involved, stimulated
- ▶ reconnecting with family, volunteers through shared interest
- ▶ part of a community of interest – shared experiences
- ▶ rediscovering old skills, such as singing, drawing and acting
- ▶ making new friends within the group, care home or hospital
- ▶ triggering memories of films, cinemas, events, and from these, remembering elements of past life – school, work, family, friends
- ▶ provision of a safe, welcoming environment to relax and share in fun and laughter

Unpaid Carers

- ▶ connecting with family members through shared film experiences
- ▶ respite from full-time care
- ▶ support, help and advice from professional staff on hand
- ▶ ideas and resources for home engagement in film

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Scottish Ballet: Time to Dance

**SCOTTISH
BALLET**

Scotland

As Scotland's national Dance Company, our mission is to inspire on stage and beyond. In 2019 the company celebrated 50 years of a creative vision crafted by Scotland. Based in Glasgow, the company performs regularly all over Scotland – from our biggest cities to our most remote communities, and increasingly throughout the UK and internationally – promoting Scotland's pioneering spirit far and wide.

Our creative vision goes beyond choreography. From digital platforms to novel ideas that engage our audiences, we're always seeking new ways to bring the power of dance to as many people as possible.

We are dedicated to supporting the arts and communities in Scotland.

Scottish Ballet nurtures the talent of tomorrow, supporting dancers, choreographers and a wide range of artists. Our goal: to inspire excellence and creativity in everyone and bring dance to people we haven't reached before.

We want to bring the joy and benefits of dance to everyone regardless of age, ability and background. Our engagement programme promotes confidence, fosters wellbeing and encourages creativity in all by delivering inspirational programmes tailored to the needs of each group.



What we do

- ▶ intergenerational community dance classes and social cafes at Scottish Ballet, for people living with dementia, their families, friends and unpaid carers
- ▶ taster workshops and consultations in community settings, including care homes, daycare centres and dementia cafes around greater Glasgow
- ▶ we have developed dementia friendly workshops to take on tour as the performing company travels around Scotland. This is essentially a Care Homes Tour running in parallel to the company's winter and spring national performance tours

So far 13 care home workshops have been delivered in Inverness, Aberdeen and Glasgow during Scottish Ballet's winter tour of Cinderella and again for our spring tour, 'Spring!' reaching 217 people, including 167 people living with dementia.

What we are achieving for people with dementia and unpaid carers

- ▶ people living with dementia have a significant say in how their dementia friendly community is run
- ▶ people living with dementia have a community of support around them
- ▶ people living with dementia are included
- ▶ people living with dementia feel that they are safe, listened to, valued and respected
- ▶ people living with dementia are empowered to do the things that matter to them



A project evaluation, undertaken by Dr Bethany Whiteside at the Royal Conservatoire of Scotland and published in 2020, drew on a mixed methods approach in the form of a narrative inquiry, to best explore and reflect the core intergenerational aspect. Participant observation, semi-structured and ethnographic interviews, and the UCL Museum Wellbeing Measures Toolkit were utilised to better understand the person-centred nature of Time to Dance, over the three years, and the cultural and social experience of participating. The report showed that the specific model of practice developed within the Time to Dance programme positively impacted on the quality of life of dancers with dementia, their family members, friends and carers.

You can read the evaluation report at <https://bit.ly/3r152hW>

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Further reading

- ▶ Art and dementia in the UK South Asian Diaspora (2019, Baring Foundation)
<https://bit.ly/2PCPyPZ>
- ▶ Becoming a dementia friendly arts venue: a practical guide (2015, Alzheimer's Society)
<https://bit.ly/2ZcQMVu>
- ▶ Creating artists in residents: a national arts in care homes participatory and mentoring programme (2017, Age Cymru)
<https://bit.ly/2S9upOY>
- ▶ Creative Health – Arts for Health and Wellbeing (2017, National Alliance for Arts, Health and Wellbeing)
<https://bit.ly/2PB2vtJ>
- ▶ Dementia and Imagination, Qualitative research findings from a visual art and dementia study (2016, Bangor University)
<https://bit.ly/2s2j0Gc>
- ▶ Each breath is valuable: an evaluation of an arts in care homes programme (2018, Baring Foundation)
<https://bit.ly/2PDd5An>
- ▶ Late Opening Arts and Older People in Scotland (2017, Luminate/Baring Foundation)
<https://bit.ly/35FRFIp>
- ▶ Long Live Arts Manifesto: feel the arts (2016, Baring Foundation)
<https://bit.ly/2PBLiQI>
- ▶ Music and Dementia: development of a conceptual framework (2015, University of Stirling/Life Changes Trust)
<https://bit.ly/34DdNSv>



- ▶ Music, Singing and Wellbeing for Adults Living with Dementia (2016, What Works – Wellbeing)
<https://bit.ly/34wD4ha>
- ▶ The State of Play: Arts and Older People Programme (2018, Arts Council of Northern Ireland)
<https://bit.ly/2EBO6XL>
- ▶ What would life be – without a song or dance, what are we?(2018, International Longevity Centre UK)
<https://bit.ly/2EFGLGB>
- ▶ ‘Quite an adventure’: some lessons from digital arts projects with older people (2019, Social Tech Trust/Baring Foundation)
<https://bit.ly/36OMUfO>
- ▶ Ark Ageing Programme: evaluating arts-based programmes for people with dementia, and their impact on wellbeing (2015, Queen’s University Belfast)
<https://bit.ly/2PCXGA9>

Physical activity and dementia

The Ecology Centre: Wide Open Doors



Kinghorn, Fife

The organisation came into being through an advisory group set up by people from the local community and residents of Craigenfalt Farm. The purpose of the organisation, known then as Craigenfalt Ecology Centre, was to develop and manage the Kinghorn Loch site for community use. In 2006 a decision was made to change the name of the organisation and today we are known simply as The Ecology Centre.





What we do

Wide Open Doors is a programme of dementia friendly activities on offer at The Ecology Centre. We think of ourselves as being dementia friendly every day, but on Thursdays we have extra staff on hand and provide a safe and warm welcome to people living with dementia (and their support workers or family) and enable them to take part in meaningful volunteer activities.

Our dementia friendly Tool Shed sessions run on Thursday mornings and afternoons. They encourage people with an experience of working with hand tools to be part of our wider tool refurbishment programme, diverting old tools from landfill and sending them for a new life as part of training programmes in Africa or given to local community groups.

We are opening up opportunities for gardening, growing food for our community kitchen and cooking. All activities have a purpose and positive feedback is given to all participants.

We have also established an informal drop-in for people from 1.30pm until 3pm on Thursday afternoons, to come and find out more about what is on offer. These sessions are short and informal and give people the opportunity to chat to staff, have a cup of tea and take part in a short wellbeing activity (e.g. art, aromatherapy, music or exercise).

Each activity hub has an indoor base, but we try and get outside as much as possible. Tea breaks and a shared lunch are highlights of Thursdays.

By taking part in activities at the Centre, working together and spending time working outdoors, people benefit from improved health, wellbeing, confidence and self-esteem.

Please watch this film, which gives further insight into the Project and its impact on people affected by dementia: <http://bit.ly/2vOE70d>

What we are achieving for people with dementia and unpaid carers

- ▶ increase wellbeing of people living with dementia by taking part in outdoor activities
- ▶ more support for close family members of people living with dementia, and an increase in their resilience as unpaid carers
- ▶ improved knowledge and shared experience in providing meaningful dementia friendly activities

If you want to know more, please contact:

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The Ecology Centre

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Edinburgh Leisure: Movement for Memories

Edinburgh Leisure

Edinburgh

We're the biggest physical activity provider in Edinburgh. There's more to us than meets the eye, with more than 30 first-class venues, 13 superb gyms, nine exceptional swimming pools, over 700 fitness classes, all-weather sports facilities and Europe's largest indoor climbing arena.

With venues throughout the city, friendly experienced staff and value for money membership, we make it easier to enjoy a more active lifestyle and keep Edinburgh healthy.

What we do

Edinburgh Leisure's Movement for Memories programme supports people with dementia to be active within Edinburgh Leisure venues and wider community settings. With a range of physical activity options to choose from, including swimming, the gym, golf, tennis and fitness classes, we believe there is something for everyone. Through Movement for Memories we offer both an individual referral programme and a community outreach programme.



The individual referral programme supports people referred either by a health professional, Dementia Link Worker, a member of their family or via self-referral. Once referred to Movement for Memories, a member of our Active Communities team will meet with the participant to identify their interests, motivations and goals, alongside the level of support they need to be active. We also provide a Dementia Friendly Buddy Service, delivered by volunteers, supporting participants to access their chosen activity more confidently. For example, they might meet the participant at reception to show them where to go, they may support them to set up gym equipment or support them round the golf course.

Through our outreach service we provide free tailored physical activity sessions for community groups supporting people living with dementia across Edinburgh. These sessions take place in community venues and are based on the individual needs, interests and abilities of each group. Individuals from the group can then be referred for individual support to access activities in Edinburgh Leisure venues, as described above.

In addition to this we also support unpaid carers to be active, protecting their own health and wellbeing. Anyone caring for someone with dementia in an unpaid capacity can make a self-referral to Movement for Memories and they will receive an Edinburgh Leisure Get Active card, providing them with discounted access to Edinburgh Leisure activities.

We evaluate the impact of Movement for Memories through a range of:

- ▶ participant focus groups
- ▶ observations of participants
- ▶ informal conversations with participants
- ▶ pre and post fitness assessments
- ▶ participant questionnaires



We work with Age Scotland to deliver dementia awareness training for all staff and volunteers:

- ▶ all Edinburgh Leisure staff attend a 60-minute dementia awareness session
- ▶ staff directly involved in the delivery of Movement for Memories activities attend a 3-hour dementia awareness session
- ▶ Movement for Memories' volunteers attend two training sessions:
 - » session one – core volunteer training, delivered to all Active Communities volunteers
 - » session two – Movement for Memories and Dementia Awareness training

What we are achieving for people with dementia and unpaid carers

- ▶ people with dementia and unpaid carers become and remain physically active, doing activities that matter to them
- ▶ people with dementia and unpaid carers shape how Movement for Memories is delivered, ensuring they feel included, safe, listened to, valued and respected
- ▶ Edinburgh Leisure improves accessibility for people with dementia by providing more dementia friendly activities and spaces and by delivering dementia awareness training for all staff and volunteers

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Twitter: @Ed_Leisure

Facebook: www.facebook.com/EdinburghLeisure

Instagram: @ed_leisure



Evanton Wood: Get Outdoors

North Highland

Your wood to enjoy and protect!

Bought by the community in 2012 with support from The Heritage Lottery, Kiltarn Community Council Windfarm grants, local businesses and individuals among others. It has:

- ▶ improved path network and pond with seating
- ▶ installed a woodland cabin and composting toilet – available for events and bookings
- ▶ built a woodland play area – for all abilities
- ▶ developed activity areas at The Dell and The River Bend
- ▶ developed Mag's Wood open area (shelter project to start soon)
- ▶ created a Secret Trail through the thick wood (behind play area)
- ▶ improved a walking route to the spectacular Blackrock Gorge
- ▶ instigated family-friendly events through the year
- ▶ facilitated regular visits by schools and local nurseries
- ▶ created the 'Get Outdoors' Dementia Project (Friday mornings)
- ▶ created Volunteer Fridays (every week) and on the last Saturday of the month - they run from 10am to 1pm and all are welcome

What we do

We run a programme of activities utilising the woodland environment for those with an early diagnosis of dementia. The programme lasts for ten weeks and we meet every Friday from 10.30am until 2pm.

The programme currently operates for two blocks of ten weeks, which best utilises the good weather. We previously had sessions over the winter months, but numbers dropped with the cold being a major factor in this.

The first session is a planning session where we look at what activities the group would like to undertake over the weeks. We then plan food for these sessions as lunch is a major part of the activity. Lunch is a group activity where everyone helps prepare and cook the food, and we have large tables for everyone to eat around. This social aspect of the programme is very important and one which everyone enjoys.

We try to run a programme of activities that are inclusive, enjoyable and different from what the group may be used to, these include:

- ▶ fly fishing
- ▶ cycle riding (on an all abilities cycle track with a multitude of bikes available)
- ▶ woodland dance and movement
- ▶ woodland art (mosaic maps design)
- ▶ woodland storytelling (a local storyteller is helping the group create a story about their lives and links to woodlands)
- ▶ green woodworking (stool making, for example)
- ▶ willow weaving

We have a network of partners who assist in the delivery of these activities and specialise in working with people living with dementia, which allows for a varied and interesting choice of activities. There is nothing similar to the work we do in this area and we are happy to provide this service, as the benefits to those attending are many.



What we are achieving for people with dementia and unpaid carers

- ▶ **Inclusion:** many of our group feel isolated and relish the opportunity to have a fixed day whereby they can catch up with those in a similar situation within a woodland environment. The woodland has no walls and the sense of openness and freedom helps lighten the mood.
- ▶ **Achievement:** we are keen to ensure that activities are achievable by all within the group, which helps foster a greater sense of confidence. We tailor all the activities to the group and ensure that any changes, however small, are undertaken to help the entire group engage with the activity.
- ▶ **Fun:** each session is built around fun. Smiling is often something that unpaid carers and people living with dementia find hard to do due to the situation they are in, we ensure each individual within the group has fun within the session. Laughing is encouraged especially when some of the activities ask for the participants to be very silly, such as making a moving elephant during the dance session.
- ▶ **Intergenerational working:** during each ten-week programme we involve the younger generation to some degree. This has proved very successful with members in the group enjoying the opportunity to engage with young people from nursery age upwards.

Training

At present we do not offer any formal training, although we are linking the programme with another of our projects – Activity Agreements (AA). AA's are aimed at skilling up young people who are not in education, work or training, who come to the woods to develop new skills aimed at raising confidence, self-esteem and interpersonal skills. If appropriate, we involve young people in the Friday project. We provided an insight into the programme, discuss how the young person can be involved, then include the young person gradually into the session.

Film

We commissioned a film-maker to record particular sessions and interview participants. The outcome from this was two films, a short film highlighting the programme which can be used at conferences, and a longer film that will include interviews with the participants.

You can watch the videos here: bit.ly/305GgBW

If you want to know more, please contact:

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Facebook: facebook.com/pages/biz/Evanton-Wood-Community-Company-105048782860982/





Froglife: Green Pathways for Life



Glasgow

Froglife is a national wildlife conservation charity concerned with the conservation of the UK's amphibian and reptile species and their associated habitats. Our holistic approach to nature conservation enables us to take individuals on a wildlife journey, whilst also delivering amazing results for our amphibian and reptile species.

What we do

Froglife is working in partnership with care homes and support organisations in Glasgow to enhance the lives of people living with dementia in the city by delivering practical and educational outdoor activities to improve their local greenspaces for wildlife.

Activities are wildlife oriented and aim to improve local greenspaces for wildlife, to enable participants to share their own knowledge and experience of wildlife and the outdoors.

Sessions focus on improving or learning about local wildlife, especially amphibians and reptiles, and have an element of practical activity. For example, building bird boxes for the gardens at care homes or creating a wildlife pond area within the grounds to improve the habitat for amphibians over a series of sessions during the project.

We also ensure there is a central focus on communication with participants and their enjoyment of the sessions, tailoring activities to groups' abilities and interests.

What we are achieving for people with dementia

- ▶ increase participants' emotional, social and physical wellbeing, as well as their confidence

This is achieved through focusing on improving participants' enjoyment of the outdoors, knowledge of local wildlife (with particular focus on amphibians and reptiles) and their gain of transferable conservation skills.

- ▶ to remove or reduce barriers to people living with dementia from accessing the natural environment

We do this by providing guidance and information during activities, reducing the impact of risk aversion for both participants and group leaders and promoting positive risk-taking during sessions.

We use our own Froglife Curriculum to track the participants' progress during our projects, the improvement of their own knowledge of amphibians and reptiles (and other wildlife), their appreciation of those species and a measure of the 'action' taken to improve habitats for wildlife.

If you want to know more, please contact:

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Golf in Society: Dementia Friendly Golf Communities



Golf In Society

East Renfrewshire

Golf in Society is a social enterprise with a vision to improve the lives of our ageing population by introducing them to the health and wellbeing benefits of golf. Our mission is to put golf clubs at the heart of local communities where people can come together to enjoy a full and active life.



What we do

We improve people's physical, mental and social wellbeing by introducing them to their local golf club. We also provide unpaid carers with much needed respite.

Every week we run a three-hour golf and social session at Mearns Castle Golf Academy. These sessions include two hours of golfing activities and one hour of socialising. This regular support is proving invaluable to people living with dementia and unpaid carers.

The way we combine physical exercise with cognitive stimulation and social interaction using a person-centred approach is why our sessions are proving popular.

In a single intervention we address four major challenges facing our ageing population, in particular those living with dementia:

- ▶ improved physical health (balance/coordination/dexterity/muscle strength)
- ▶ improved mental health (self-esteem/purpose/achievement)
- ▶ social interaction (reduction in loneliness/making new friends)
- ▶ respite care for families/primary carers

We're also proving how golf clubs can become an integral part of dementia friendly communities.

What we are achieving for people with dementia and unpaid carers

- ▶ people living with dementia enjoy a fun and rewarding day out with other people who enjoy golf and socialising
- ▶ people living with dementia are able to use again the skills they had or learn new skills
- ▶ people living with dementia feel valued and develop new friendships



- ▶ people living with dementia secure their human right to enjoy sport rather than have it removed from their life
- ▶ unpaid carers have time to do the things that they enjoy in life or catch up with tasks they cannot do when caring

Training

We provide dementia awareness training to local businesses, community members and deliver workshops at local schools.

If you want to know more, please contact:

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Instinctively Wild: Eco-therapy for people with dementia



Borders

Instinctively Wild runs inspiring programmes that help people of all ages and from all walks of life to learn about themselves and others through being outdoors.

What we do

We have been working with NHS Borders Mental Health Older Adults team for several years and run an outdoors eco-therapy-based programme for people with early onset dementia, as well as unpaid carers.

Along with NHS staff and unpaid carers, we have devised a programme that is fluid, responsive, creates a lot of room for participants and offers a social, relaxing environment. We use a wonderful community woodland (Wooplaw Woodland in the hills above Stow) and set up a space around an outside campfire, or with a wood burner inside a log cabin, surrounded by the calming, sensorial setting of trees and nature.





At the beginning and ending of sessions there is always lots of tea and biscuits, with the Instinctively Wild/NHS team engaged in conversation, allowing room for anecdotes and reminiscences. Within the team we also have a beautiful singer/harpist, who often plays for us and sings songs based on participants' interests, and a professional storyteller, who weaves tales based on local environments. In many ways, this social space is the heart of the sessions.

We always gauge the mood/feelings of the group by involving them in a review activity both at the start and end of the session, which we have developed over time. For example, this could be placing stones decorated by participants, onto faces matching different feelings, to monitor mood changes. We then always go on a walk to connect with the senses and collect natural objects that match the week's activity, giving time to discover the environment and listen to birdsong. It is then time to engage in the session's main activity back at base, e.g. clay work, natural art, tool work, fabric dyeing, badge making and many other nature-based crafts. These are responsive and designed to match people week-to-week. We spend a lot of time listening to and observing people, which builds on our activities. The walk is an opportunity for a healthy activity, but also for social chat and 'therapeutic conversation'. To assist with this, we also have high ratios of staff to people living with dementia and unpaid carers (including NHS staff).

During all of the sessions, we support people living with dementia and unpaid carers to create their own 'log book'. Every week they write about their activities and how they have felt (with support where needed), and paste in copies of activity photos we offer. They have proven to be really valuable to people as they are a 'visual diary' and record in different ways what activities have been engaged in. Once each participant has completed the round of sessions, they get their own book to take home with them as a memento, giving a permanent pictorial record of experiences shared.

What we are achieving for people with dementia

- ▶ encourage physical exercise and improve physical health
- ▶ increase self-esteem and confidence
- ▶ facilitate opportunity for social interaction and the development of supportive peer relationships
- ▶ increase wellbeing through the stimulation of the senses whilst in the woodland environment
- ▶ use our local assets to provide an opportunity for those living with dementia to participate in a meaningful outdoor activity

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Paths for All

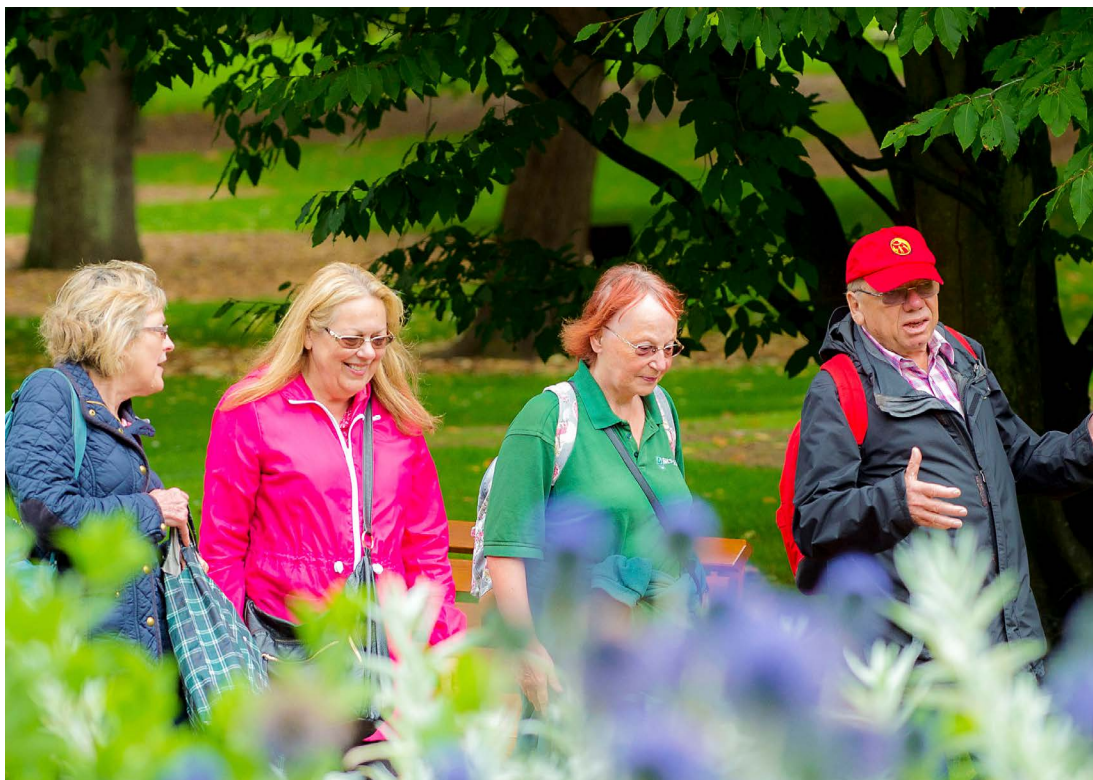


Scotland

Paths for All is a Scottish charity. We champion everyday walking and work to improve environments to support access to the outdoors as the way to a happier, healthier Scotland.

What we do

Paths for All supports a network of health walks across Scotland. For the past three years, we have been working with people living with dementia to make our activities more accessible and inclusive. A dementia friendly health walk is much like any other walk. It's social and open to the whole community, led by a walk leader, uses safe, accessible paths and is an opportunity to enjoy the outdoors and fresh air all year round.



What makes a health walk dementia friendly is including people living with dementia in the development of walks, providing Dementia Friendly Walk Leader training to volunteer walk leaders, building partnerships with organisations and agencies and ensuring that people living with dementia know about walking activities in their community.

We have created a Dementia Friendly Accreditation, which recognises the positive changes put in place by Walking for Health projects to make their health walks accessible to people living with dementia. Projects working towards the accreditation can access a range of tailored support from Paths for All, including Dementia Friendly Walk Leader training, small grants, resources and networking opportunities.

We also want to ensure that everyone living with dementia can enjoy the benefits of walking, being outdoors and connecting with nature.

That's why we have been looking at how our paths and walking environments can be more welcoming to people living with dementia. We have been working to raise awareness of the challenges and issues faced by people with dementia in accessing outdoor spaces and develop training, resources and support for organisations and groups involved in planning, designing and maintaining paths and outdoor environments. In June 2018, we launched Scotland's first dementia friendly park in Kings Park, Stirling. People with dementia, local community groups and organisations were asked about topics, including wayfinding, park facilities, atmosphere, safety and pre-visit information to help identify areas for improvement. A series of changes were then implemented in the park, improving signage, wayfinding, seating and facilities.



What we are achieving for people with dementia and unpaid carers

- ▶ being with other people: walking groups give people with dementia opportunities to socialise and share experiences with other people, in a safe and comfortable environment
- ▶ being outdoors: walking groups give people the opportunity to access the outdoors and a safe and secure environment
- ▶ ethos and atmosphere of achievement: attending walking groups enables people with dementia to demonstrate what they can still do, rather than the problems they face due to dementia
- ▶ feeling secure: walks improve people's confidence as they are able to participate, but also know that help is available if required
- ▶ quality leadership and organisation: the confidence in volunteer walk leaders is essential to the success of groups and supporting walkers
- ▶ feeling included in the community: we have also found that people value having inclusive walks that are open to everyone, rather than walks just for people with a dementia diagnosis

The University of Stirling carried out a qualitative evaluation with dementia friendly health walks and the report can be accessed here: <https://bit.ly/2mkri9A>

Training

Paths for All has developed a half day training course for volunteer walk leaders, focusing on how we make walks accessible for people living with dementia. We also deliver regular networking opportunities for our health walk coordinators.

In addition, we deliver one-off workshops on dementia friendly design targeted at outdoor access professionals and volunteers. See our latest Dementia and the Outdoors Guidance Note: <https://bit.ly/2n00pcF>

Please see page 25 in the Information, Awareness, Training and Education Book for more information. See also www.lifechangestrust.org.uk/project/paths-all

If you want to know more, please contact:

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Sporting Memories

Scotland

Sporting Memories Foundation was founded in Scotland to become the first of its kind dedicated to the development and use of sports reminiscence, inclusive physical activities and intergenerational activities to support isolated older people across the country.

What we do

Our weekly Sporting Memories Clubs are inclusive, dementia friendly groups aimed at older people with an interest in or passion for sport. They take place in a range of settings from local sports clubs and village halls to sheltered housing complexes, community centres and libraries. Our social activities include reminiscence, games and quizzes like 'Spot the Ball', as well as inclusive physical activities like Boccia and New Age Curling that are suitable for all. We encourage everyone to contribute, whether it be sharing stories of watching or playing sports, coming up with quiz questions or helping to organise games. Our participants become Club members and their specific interests and preferences are reflected in the particular activities at their Club.

Once established, our Clubs also get involved with intergenerational activities, which can take place at area 'hubs' where we can bring different Sporting Memories Clubs together to enjoy different kinds of inclusive sporting activities and games.



What we are achieving for people with dementia and unpaid carers

People living with dementia:

- ▶ have a significant say in how their dementia friendly community is run
- ▶ have a community of support around them
- ▶ are included
- ▶ feel that they are safe, listened to, valued and respected
- ▶ are empowered to do the things that matter to them
- ▶ have improved mental and physical wellbeing
- ▶ experience reduced loneliness and isolation
- ▶ connect with wider social and health networks in the community

Training

Free guidance for one-to-one reminiscence is available on our online learning zone at www.sportingmemories.info and we also have a free Replay Sporting Memories App available to download at Playstore for Android or at the iTunes shop for Apple devices.

Please see page 38 in the Information, Awareness, Training and Education Book for more information. Also see www.lifechangestrust.org.uk/project/sporting-memories-network-get-outdoors

If you want to know more, please contact:

Website: www.sportingmemoriesnetwork.com, for contact details and information about Club locations

Facebook: www.facebook.com/SMFScotland/

Twitter: @SMN_Scotland



Further reading

- ▶ A qualitative investigation of a community-based sports group for men with early onset dementia (2016, University of Nottingham)
<https://bit.ly/34yMDvT>
- ▶ Age and Dementia Friendly Gymnastics Programme (2017, Age UK and British Gymnastics Foundation)
<https://bit.ly/2Scd4Fd>
- ▶ Dementia Adventure Impact Report (2017)
<https://bit.ly/36Vubzn>
- ▶ Dementia Friendly Walking Project (Paths for All): Evaluation Report (2018, University of Stirling)
<https://bit.ly/2r9L9e5>
- ▶ Football reminiscence for men with dementia in a care home: evaluation of a pilot study in Scotland (2015, University of the West of Scotland)
<https://bit.ly/2MbjSz8>
- ▶ Greening Dementia (2013, Natural England, Dementia Adventure)
<https://bit.ly/38TUuHZ>
- ▶ Is it nice outside? (2016, Natural England, Dementia Adventure)
<https://bit.ly/2PBJ1VG>
- ▶ What is the impact of using outdoor spaces, such as gardens on the physical and mental wellbeing of those with dementia? (2014, University of Exeter)
<https://bit.ly/36RS5vo>

Befriending

Eric Liddell Centre: Dementia Befriending



Edinburgh

We are a registered Scottish charity providing specialist caring services from a unique historic building in south central Edinburgh. Founded in 1980 by local people, all of our trustees are volunteers who live or work in Edinburgh.

Our building was formerly Morningside North Parish Church and continues to be extensively modified to meet local community needs.

In 1992 the Centre was renamed the Eric Liddell Centre in memory of the Olympic gold medallist who was portrayed in the 1981 Oscar award-winning film 'Chariots of Fire'. Eric Liddell lived in this area of Edinburgh whilst studying at Edinburgh University in the early 1920s.

What we do

Our Befriending project is designed to expand the types of support for people living with dementia and unpaid carers within Edinburgh. Our programme was initiated as a further extension to the Eric Liddell Centre's (ELC) Carer Befriending programme that has been operating in the ELC since 2013. The programmes have continued to work together and learn from one another, sharing ideas, expertise, training and events. For example, the Carer Befriender monthly drop-ins and our Saturday dementia friendly drop-ins, have both proved popular and bring together unpaid carers looking after a person with dementia, with unpaid carers in quite different situations. This offers mutual support and space to discuss day-to-day issues, sharing with others who have natural empathy for the stress of caring. Our one-to-one volunteer befriending has been expanded both to unpaid carers and to people living with dementia.



Also, during this time, the ELC has begun to develop into a small hub of training for others who work in dementia care, support or befriending. We have developed a partnership with Napier University's music department, and now with their film and photography departments. This has evolved into the Centre being that students regularly carry out projects supported by those who attend our programmes. We have provided training for a pastoral care group on a voluntary basis. In July and September, we offered the creativity, interaction and dementia sessions via VOCAL's programme for unpaid carers and also offered a 4-week creative writing for wellbeing course for unpaid carers. This was delivered by our Programme Manager who is a poet and who is undertaking her Counselling Diploma. They have also been trained in facilitating creative writing for wellbeing courses.

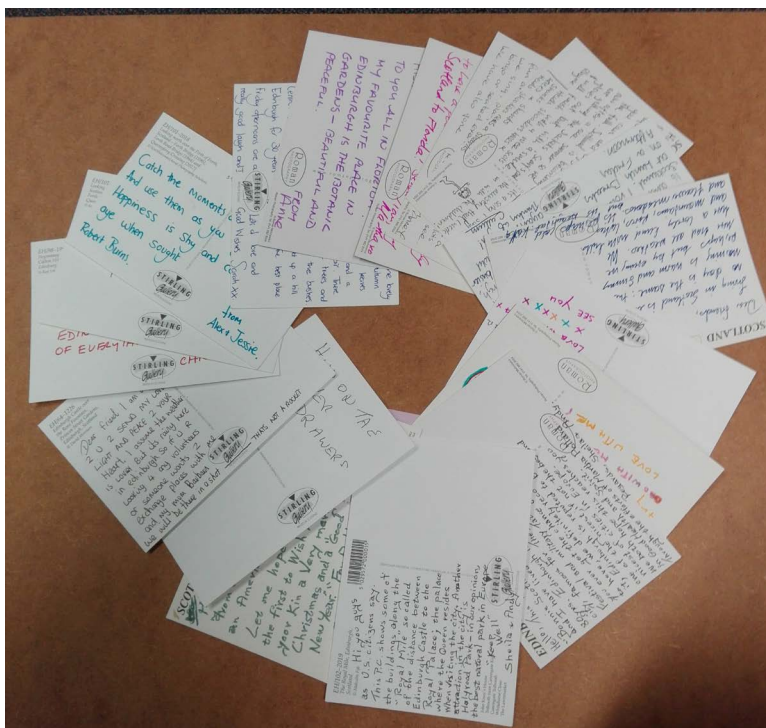
In strengthening our organisation to become a centre of learning and sharing of good practice in dementia care and support, including impacts on emotional/social and peer support, we have undertaken the following developments:

- ▶ recruitment and training of befrienders, including training in dementia awareness and dementia friends
- ▶ widening and growing participation in our lunch clubs for people with dementia and unpaid carers to attend together, including a two-year funding award from Celtic Football Club Foundation
- ▶ development and delivery of training courses for other befriending organisations in Dementia and Interaction, and also offer this training to unpaid carers
- ▶ collaboration with the Alzheimer Scotland Dementia Research Centre and the University of Edinburgh and the Edinburgh Centre for Research on the Experience of Dementia, through our Programme Manager's 3-year PhD studentship in Counselling and Dementia

This has resulted in wider connections for the Eric Liddell Centre to become a growing Centre for training and good practice in supporting people affected by dementia who are living in the community. We have received feedback that this is much appreciated support for carers, in one-to-one matches, the new group befriending initiative and in Lunch Breaks.

What we are achieving for people with dementia and unpaid carers

- ▶ they know that they have someone who will listen to them and understand them
- ▶ they feel less lonely and more positive about life
- ▶ they have an increased sense of wellbeing
- ▶ they feel safe, valued and respected
- ▶ they have more confidence to do the things that matter to them
- ▶ they can give examples of how befriending has made a difference to their life





We are also trying to achieve the following focused outcomes in relation to our dementia friendly programme:

- ▶ people with dementia have increased opportunities to maintain, grow and enrich their connections with community
- ▶ people with dementia and carers have improved access to opportunities to socialise in an everyday activity, such as going out for coffee/tea together in a friendly community environment
- ▶ carers report being better able to cope with their caring responsibilities because of improved access to community socialising at the drop-in coffee mornings, and because of having weekly respite time when the person with dementia whom they care for is with their befriender

If you want to know more, please contact:

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Dementia Befriending and Carer Support Programmes' Manager
and PhD student in Counselling and Dementia

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Facebook: facebook.com/EricLiddellCentre/

Twitter: @theericliddell

Forget Me Not Service



Glasgow

Alzheimer Scotland is the leading dementia organisation in Scotland. We campaign for the rights of people with dementia and their families and provide an extensive range of innovative and personalised support services.

What we do

Alzheimer Scotland's Forget Me Not Service provides enjoyable and creative support for people with dementia through a highly successful volunteer programme. The volunteers offer their support in a variety of settings: in residential care homes, hospitals and within our Alzheimer Scotland services in and around Glasgow. We recruit and gain references/PVGs for volunteers as well as offering them induction and ongoing support.

We encourage volunteers to carry out their support in ways that meet both the needs of people with dementia and the volunteers themselves. Volunteers come from a wide age range and have many diverse skills, as do people with dementia. As a result, we continually observe how inventive our volunteers are, and we are delighted with the unique and meaningful interactions between our volunteers and people living with dementia.

The success of our well-established recruitment strategies, which include young people, students and people interested in a new career, means we have volunteers from many different communities. An example of how we can tailor our support is where residents of care homes who are losing their second language of English are often matched with a volunteer who speaks their first language.



Other examples include a volunteer who utilised her studies to offer art therapy to the users of our support service in Bridgeton Resource Centre. The value of this work was evidenced by the service users' comments, such as ***“I have learned new skills”*** and ***“I have enjoyed coming”***.

Where young volunteers chose a hospital setting to offer their support, they said:

So far my experience in the Royal has been amazing! Every month there is a dementia cafe which I have had the opportunity to help at. It is amazing to see the effect this has on the patients – some chat and tea/cakes can completely change one's mood. I have met so many amazing people with dementia and it's so interesting in listening to all of their life stories.

Alzheimer Scotland did really well today. They had organised an event at the Tickled Trout and I helped assist a few residents from Abbotsford to listen to an orchestra. It was very good. Part of their 'show' is to ask if anyone ever wanted to be an orchestra conductor. One of Abbotsford residents was up like a shot and had a ball and did a really good job.

What we are achieving for people with dementia

- ▶ people with dementia know that they have someone who will listen to them and understand them
- ▶ people with dementia feel less lonely and more positive about life
- ▶ people with dementia have an increased sense of wellbeing
- ▶ people with dementia feel safe, valued and respected
- ▶ people with dementia have more confidence to do the things that matter to them
- ▶ people with dementia can give examples of how befriending has made a difference to their life
- ▶ strengthening volunteering capacity



Feedback from our volunteers often illustrates that we are achieving this:

I went to the care home last night to see M and I'm glad I did. She was in the day room when I arrived (in her wheelchair) and the nurse said that she was a wee bit upset and that perhaps a visit would cheer her up. She does seem to recognise me, I always greet her as you suggested 'hello M, it's Sophie, lovely to see you again', and that way she's not starting off anxious that she's forgotten who I am.

If you want to know more, please contact:

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Glasgow
G5 9EP

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Website: www.alzscot.org

The Haven: @ Home Volunteering Befriending Initiative



South Lanarkshire

The Haven Centre was opened in May 2002 to provide care, complementary therapies and information to people affected by life limiting illness such as cancer, multiple sclerosis, motor neurone disease, Parkinson's disease and Huntington's disease and also to their carers and family members.

We strive to give the highest standard of care to everyone affected by life-limiting illnesses and we work closely with other organisations to achieve this.

We try to make our visitors feel welcome. We have a comfortable lounge and kitchen area where they can relax and chat, or simply have a cup of tea or coffee. There is also a 'quiet room' where visitors can have a discussion in private with nurses or volunteers.

Volunteers are a very important part of our service and are always pleased to welcome new and returning visitors.

What we do

The Haven@Home Volunteer Befriending Initiative offers tailored, flexible support to families affected by dementia living in South Lanarkshire, including rural Clydesdale, both in the comfort of their own homes and within The Haven centres in Forth and Blantyre. The initiative delivers flexible, timeous, tailored, specialist Haven services that support improved emotional wellbeing, improved social interaction and support people to connect to wider services within their community.

The Haven's multidisciplinary team of experienced Nurses, Befriender Therapists and Peer Volunteers ensures each support session is purposeful and supports increased social interaction, builds trusting relationships, improves self-esteem, resilience and confidence, whilst providing companionship to reduce isolation and loneliness.



Haven nurses coordinate the programmes of support, working with each family to identify what is most important to them and agree appropriate programmes of support.

Haven Volunteer Befriender Therapists provide complementary therapies, which reduce stress and anxiety and improve wellbeing. They are beneficial both to the unpaid carer and the person living with dementia, providing families with much needed short respite breaks. Haven Peer Volunteers provide a befriending/emotional support role within Haven centres – a caring, ‘listening ear’. Trusting, welcoming relationships develop within appropriate boundaries within the centre, reducing loneliness and isolation for the clients attending.

Signposting to a wide range of additional Haven, community and statutory services is integral to the service, and families are encouraged by all members of the multidisciplinary team to connect to and participate in additional activities and local support networks.

What we are achieving for people with dementia and unpaid carers

- ▶ increased sense of wellbeing, reduced stress and anxiety, improved ability to relax through learning self-management approaches
- ▶ having someone to listen to and understand, via therapy befriending and the trusting relationships of staff, therapists and peer volunteers
- ▶ feeling less lonely and isolated through increased social interaction via nurse and therapy befriender sessions and peer volunteer interactions
- ▶ progressing from Haven@Home service to Haven Centre service as trusting relationships become established, enabling access to a wider range of Haven services and a timetable of dementia inclusive group work activities
- ▶ strong community signposting pathways and links to wider community groups/other support networks so that families develop wider support networks

- ▶ people affected by dementia feeling more confident to do things that matter most to them through bespoke and flexible programming of specialist Haven support which fits into family routine and supports stressful transition stages of the condition
- ▶ short respite breaks – therapies, time out, views in centre, quiet space

If you want to know more, please contact:

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Forth, ML11 8AJ
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The Haven
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University Hospital Wishaw
50 Netherton Street
Wishaw, ML2 0DP
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Email: info@thehavencentre.com
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Facebook: www.facebook.com/TheHavenCharity



Knowing Me Knowing You



Lanarkshire

Alzheimer Scotland is the leading dementia organisation in Scotland. We campaign for the rights of people with dementia and their families, and provide an extensive range of innovative and personalised support services.

What we do

'Knowing Me Knowing You' provides at-home befriending for people living with dementia.

The service is based around reminiscence and uses several tools, such as life-story work, music and memory trees. Where some other reminiscence projects focus mainly around sport and football in particular, this project encompasses a much greater range of subjects from local heritage to working life or cultural changes. These memories are then recorded in a life-story book completed by the volunteer befriender in partnership with the person with dementia and their family. These resources aid families in reminiscing and connecting with their loved ones in a way that may previously not have been possible, and in a way that can continue even as their condition deteriorates. All reminiscence is person-centred, catering for individual needs, unique to each person.

Compared to the group model of reminiscence, we can reach out to many more people within the community. This project provides a service that gives carers the added opportunity for respite and for people with dementia it builds confidence, offers more social connections and helps to reduce loneliness, isolation or the onset of depression.

The service offers reminiscence-based support earlier to people who may be on the waiting list for local groups, as well as offering an alternative option to people who may prefer one-to-one support. For example, if a person on the waiting list for a local group had a volunteer buddy in the interim, it would help that person to enter the group with confidence and enjoy the experience when a place became available.

The scheme also offers increased flexibility for people who need to access support at a variety of times.

The project covers the whole of Lanarkshire and the befriender visits the befriender on a weekly basis.

What we are achieving for people with dementia

- ▶ people with dementia know that they have someone who will listen to them and understand them
- ▶ people with dementia feel less lonely and more positive about life
- ▶ people with dementia have an increased sense of wellbeing
- ▶ people with dementia feel safe, valued and respected
- ▶ people with dementia have more confidence to do the things that matter to them
- ▶ people with dementia can give examples of how befriending has made a difference to their life
- ▶ strengthening volunteering capacity



If you want to know more, please contact:

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Quarriers: North Ayrshire Dementia Befriending Service



North Ayrshire

Quarriers is one of Scotland's leading social care charities. We provide practical care and support for vulnerable children, adults and families who face extremely challenging circumstances. We challenge poverty and inequality of opportunity to bring about positive changes in people's lives.

What we do

Quarriers Dementia Befriending Service was established to provide an integrated befriending service, in and outwith the home, for people with dementia living in North Ayrshire to promote their empowerment, confidence and wellbeing.

The Dementia Befriending Service is for people diagnosed as having mild to moderate stages of dementia. Priority is given to those who have no support from other services, family or friends. Having learned about the impact of film, we had a promotional film produced, which provides insight into the work of the befriending service².



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



When safety recruitment checks have been completed for volunteers, all training is provided. The Volunteer Coordinator will accompany the volunteer to each weekly visit for a period of time. This ensures all parties feel comfortable with the match, volunteers feel confident in accompanying the person to activities in the community and completing the Volunteer Log, as well as allowing the Volunteer Coordinator an opportunity to observe the match.

The volunteers involved in the service range from ages 19 to 65. They include students, people seeking employment, retired and currently employed, with many having little or no knowledge of dementia. Involving people from various age groups and communities allows a cross section of the community to increase their knowledge of people with dementia.

The Volunteer Coordinator monitors the progress of befriending relationships and offers support and guidance when needed. We know the importance of well managed endings. To support this, we include a period of “**time out**” for volunteers. This gives them a break and offers them time to reflect on the positive aspects of their befriending and the opportunity to come back to volunteering if they choose.

To try and capture the many memories created during visits, volunteers record what they did on the day of their visit in a visitor’s book:

Margaret enjoyed going for a walk on the beach today and had a fish supper. She laughed so much when a seagull tried to swoop down and steal her fish!

This is really helpful for families and also helps volunteers deal with loss when befriending relationships end. We have also introduced photo albums to enable photos to be captured and kept by the service user and the family.

What we are achieving for people with dementia and unpaid carers

- ▶ people with dementia are listened to and understood
- ▶ people with dementia feel more confident in taking part in new activities and feel less isolated
- ▶ people with dementia look forward to their next visit, building on their confidence and wellbeing
- ▶ unpaid carers have a break from the pressure of caring and that this supports their wellbeing by giving them time to do something they enjoy and not worry about the person they care for

If you want to know more, please contact:

Quarriers North Ayrshire Dementia Befriending Service
25 Manse Street
Saltcoats
KA21 5AA

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Tel: 07812 228 447 if unavailable call 01505 616109

Email: volunteer.centre@quarriers.org.uk

Website: www.quarriers.org.uk



Reading Friends: the Reading Agency

READING
FRIENDS

UK-wide

At The Reading Agency, we work every day towards a world where everyone is reading their way to a better life.

As an organisation, we believe that it doesn't matter what you read, as long as you read. Whatever your fancy or needs, we believe there's a book for you and our programmes are designed to help unlock the value and benefit of reading.

What we do

Research carried out for The Reading Agency shows that reading together can help older people to build social networks and connect with others. Evidence also shows that reading has a positive impact on empathy, cognitive function and wellbeing, and can reduce the risk of dementia.³

The Reading Agency has developed Reading Friends, an exciting UK-wide programme, funded by the National Lottery Community Fund. The programme, delivered by volunteers and co-produced with older people, connects people by starting conversations through reading. Reading Friends meet regularly to chat and share stories in groups or one-to-one sessions. It aims to empower, engage and connect older people who are vulnerable and isolated, people with dementia and carers.

The programme has been running since June 2017 and has seen The Reading Agency work in partnership with a range of organisations and communities to test different approaches to delivery. In Scotland, Scottish Book Trust works in partnership with Stirling library services and Artlink Edinburgh and the Lothians to deliver two Reading Friends pilot projects.

³ BOP Consulting for The Reading Agency (2015) [Literature Review: the impact of reading for pleasure and empowerment](#)]

Town Break charity in Stirling supports people who have dementia to stay connected to their communities. They have worked with Bannockburn High School to recruit pupils to take part in Reading Friends with residents from a local care home. The group meets at their local library every Friday afternoon, and a number of pupils asked to continue with the programme during the school holidays. Other libraries in the Stirling area are now planning intergenerational reading opportunities between older people from other care homes and pupils from other high schools.

In Liberton Hospital, Finlay House, and the Western General Hospital, older people with dementia who are on community wards and may be experiencing isolation are being supported to participate in Reading Friends through Artlink Edinburgh and the Lothians. A fly-fishing kit was brought in for a gentleman on a stroke ward who had a love of fly-fishing, and identifying flies was linked to examples from books to expand the discussion and reading aspect.

If you want to know more, please contact:

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Outreach Manager

Scottish Book Trust

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Twitter: @korensbt @ScottishBkTrust

Facebook: facebook/scottishbktrust



Town Break: Befriending Service



Town Break
Dementia Support Services

Stirlingshire

We support people throughout the Stirling District who have dementia to stay connected to their communities by offering various supportive services.

What we do

We provide support to people who have early to mid-stage dementia to live well and connect with their community. The Befriending Service aims to prevent social isolation and helps people gain the confidence to take up new skills, take up hobbies or simply to socialise and connect with someone over a cup of coffee.

The Befriending Coordinator carefully matches the befriender with someone who has early to mid-stage dementia so they can live well. We offer comprehensive training to volunteers, alongside regular volunteer meetings and ongoing support. We are in the process of expanding our befriending service, with a focus on intergenerational befriending, as well as group intergenerational befriending.

We have been working with Stirlingshire Voluntary Enterprise to encourage younger befrienders (18-25) to take up befriending and as a result of this, have two new young volunteers. In October 2018 we started a really exciting intergenerational art project with a local primary school. This took place over six weeks with a well-known Scottish artist, Lucy Campbell, who also illustrates children's books.

This was an opportunity to see how we can further develop future projects, with a view to making our Friday lunch club an intergenerational lunch club. This means that not only will children get to experience the benefits of learning and interacting with older people, but also to enjoy the important social activity that is having lunch with people, as it is a time to talk and enjoy each other's company. This is a fairly unique project and means that our older service users who do not have any family get to enjoy a group meal with a very lively and fun group of children! It is also a good learning experience for the children who will be encouraged to behave well at the table, as well as having a nutritious meal. We are in the process of developing a child friendly training session so children have an understanding of dementia and dispel any of the myths that may surround it.

We offer induction training, first aid and manual handling training to all volunteers. We have also partnered up with the Dementia Services Development Centre at Stirling University to offer all volunteers and unpaid carers training in dementia. We will give all the children taking part in the project a talk on dementia in a way that explains but does not scare.

What we are achieving for people with dementia and unpaid carers

- ▶ people with dementia feel more confident
- ▶ people with dementia have increased self-esteem
- ▶ people with dementia have increased self-respect and dignity
- ▶ people with dementia experience an increase in their quality of life
- ▶ unpaid carers benefit from a period of respite, which will help them be in a stronger position to support their loved one for longer in their own home



We plan to record children's attitude through a fun exercise before the children come to the pilot project, then again after, with any necessary alterations. We will also use this for the roll-out of the intergenerational project on a Friday. We shall also use quality of life questionnaires for people with dementia, which might be at the beginning and end of each session.

If you want to know more, please contact:

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Stirling Business Centre
3 Whitehouse Road
Stirling, K7 7SP

Tel: 01786 476797

Website: www.townbreakstirling.org



Voluntary Action Shetland

Shetland Befriending Scheme

Voluntary Action Shetland seeks to respond to and support voluntary services in Shetland by meeting present and emerging needs, developing and promoting new ways of responding and encouraging people in Shetland to offer voluntary service to their community.

Our aims:

- ▶ to assist the development of voluntary organisations
- ▶ to encourage the voluntary participation of local people in community organisations and volunteering in general
- ▶ to provide practical and advisory services to VAS members (and non-members)
- ▶ to support collaborative activities between voluntary organisations and local statutory bodies

What we do

We support older members of the community affected by dementia, living at home, and who are significantly socially isolated and/or may be experiencing a period of significant loss or change in their lives to access the services of a volunteer.

What we are achieving for people with dementia

- ▶ people feel listened to and understood
- ▶ help reduce the feelings of loneliness and increase positive feelings about life
- ▶ increase the sense of wellbeing
- ▶ increase feelings of safety, being valued and respected
- ▶ increase confidence to do the things that matter



If you want to know more, please contact:

Shetland Befriending Scheme

Market House

14 Market Street

Lerwick

Shetland

ZE1 0JP

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Fax: 01595 696787

Website: www.shetland-communities.org.uk/subsites/shetland-befriending

Facebook: [facebook.com/Shetland-Befriending-Scheme](https://www.facebook.com/Shetland-Befriending-Scheme)

Further reading

- ▶ Befriending and Dementia (2018) (Life Changes Trust)
<https://bit.ly/3drq1T4>
- ▶ Befriending Networks
<https://bit.ly/2Mdzbaq>
- ▶ Stitch in Time Befriending Report (2015)
<https://bit.ly/2Q0sWYO>

Dementia Dog



Scotland

Assistance Dogs

Dementia Assistance Dogs are trained to live at home with families, where a person has an early stage diagnosis and lives with a full-time carer. Pilot programmes in Scotland and Australia are demonstrating this model brings joy, companionship and practical help to both immediate family and their network.

Community Dogs

This pioneering animal-assisted intervention programme involves goal-oriented visits from a Dementia Community Dog and Handler who, working alongside a healthcare professional, can help people with dementia feel more independent, confident and connected in their community.





Dog Day Events

Based at dementia resource centres, Dog Days are fun group events bringing together people with dementia and their carers, with trained pet dogs and Dog Day volunteers. These monthly events encourage communication, positive reminiscence and joy, as well as help building social connections.

What we do with Dementia Assistance Dogs

Our work – a collaboration between Alzheimer Scotland and Dogs for Good – explores how specially trained dementia assistance dogs can support people with a diagnosis of dementia and unpaid carers to enable them to live well with dementia.

Funding from the Life Changes Trust has enabled us to train and place a further eight dementia assistance dogs, hugely expanding our experience and learning from the initial pilot of 3 dogs undertaken in 2012-2015. This marked the first type of project of its kind in the world to train dementia assistance dogs.

Dogs are trained in pairs by our Dementia Dog Instructor, who also simultaneously trains male offenders at HMP Castle Huntly as part of a prison rehabilitation programme we deliver in partnership with the Scottish Prison Service and Paws for Progress. To date, this programme has provided 15 men in custody with valuable life skills, 23 SQA qualifications and enhanced future employability, whilst providing us with an operational base and additional capacity in training the dogs.

Examples of skills the dogs learn include:

- ▶ responding to an alarm to fetch a medication pouch to remind someone to take their pills
- ▶ pulling back the duvet to help wake someone up in the morning
- ▶ helping pull off socks, jumpers, trouser legs to help undress someone
- ▶ rolling out a yoga mat to motivate someone to do their daily physio
- ▶ opening and closing doors/cupboards
- ▶ comforting head rests in someone's lap to reduce anxiety in new surroundings
- ▶ walking on a special dual lead to enable two people to walk the dog safely together

Lots of effort goes into assessing and matching the right dogs to applicant families on our waiting list, to ensure a happy lasting bond. Once a match is identified, each dog's training is tailored to the specific needs of each applicant family. Once placed, our team continue to support each family with ongoing aftercare support, to help adapt the dog's training to any changing needs along the dementia journey.

This pioneering approach is currently being piloted in Scotland and Australia, with combined learning being captured through independent evaluation to build an evidence base of learning on how trained dogs can help people live well with dementia.

What we are achieving for people with dementia and unpaid carers

Dogs are trained to provide support in three key areas: helping maintain a structured routine in the home, being a social connector out and about in the community and being an emotional anchor for all the family.



Associated outcomes we hope to achieve are:

- ▶ for families to feel increased confidence and independence with a stronger sense of purpose and motivation on a daily basis
- ▶ the dogs can support an active lifestyle as part of a structured day, as well as helping carers feel more resilient to cope better with the condition as it progresses

We have seen first-hand how the dogs are already achieving these outcomes both immediately following placement and then as their bond develops with their new family.

Evaluation

Our work is being evaluated by HammondCare. You can read our latest reports at <https://bit.ly/2MfrUap>.

If you want to know more, please contact:

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Project Manager – Dementia Dog Project

c/o Alzheimer Scotland

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Twitter: @dementiadog

Facebook: <https://www.facebook.com/dementiadogproject/>

Employment and dementia

University of the West of Scotland: Alzheimer Scotland Centre for Policy and Practice



Dementia in the Workplace

Vision: To be a centre of excellence advancing dementia policy and practice through education, applied research and social enterprise.

Mission: To work collaboratively with people with dementia and carers, the scientific and practice communities to advance evidence informed dementia policy and practice.

Our work focuses on three key activities:

- ▶ applied research for policy and practice
- ▶ education to promote evidence informed practice
- ▶ policy influencing and implementation

At the Alzheimer Scotland Centre for Policy and Practice, we believe that people with dementia deserve high quality care. We know that this is possible when:

- ▶ practitioners have enhanced dementia knowledge and practical skills
- ▶ enlightened policies are put into practice
- ▶ society respects the rights of people with dementia, their family and friends



What we have done

The recent rise in the state pension age and the removal of compulsory retirement at 65 will result in more people with long term conditions being economically active, however, because dementia is usually thought of as something that happens to older people, little attention has been paid to the opportunities for employment.

Dementia in the Workplace is a research project⁴, which was carried out between 2013 and 2015. The overall aim of this project was to explore the employment related experiences of people with dementia or MCI (mild cognitive impairment), and attitudes of employers and/or co-workers towards supporting people with dementia, in order to identify the potential for continued employment post diagnosis.

The Dementia in the Workplace study has identified that continued employment post diagnosis of dementia is possible, although could be complex to support. The supports required to continue working will depend on the type of job a person does, the insight they have into their symptoms and the culture of the organisation they work in as to whether they have the resources to support them. The Equality Act 2010 states that employers have a responsibility to make reasonable adjustments to a person with a disability's workplace, or job description in order to support them to continue employment. However, this study has highlighted a lack of understanding about dementia and therefore a challenge to employers and people with dementia is agreeing what a reasonable adjustment to their workplace might be. This study has highlighted that allowing flexible working (including home working) and a reduction in allocated duties may be two important adjustments, as well as giving all information in written format and creating a quiet space for them to work with minimal distractions. It is also important to highlight the lack of support that was available for people with dementia who left employment, and therefore any future work should consider how to support people with dementia leaving employment, as well as continuing employment.

4 <https://bit.ly/2PmgX8c>

In response to these research findings, we have recently developed a range of resources to support people with dementia, employers and colleagues within the workplace. These provide information about dementia, how it affects someone who is still employed, and provides helpful tips for supporting employees with dementia (see Training section).

What we are achieving for people with dementia and unpaid carers

- ▶ improved employment support for people with dementia
- ▶ improved support for those who leave employment post diagnosis

Evaluation

Executive summary of research available here: <https://bit.ly/3c0wkNo>

Research paper: <https://bit.ly/2veQ0g1>

If you want to know more, please contact:

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Age Scotland also offers a wide range of resources to support employees and employers to be age friendly: See Age Scotland's training section in the Information, Awareness, Training and Education book.

Further reading

- ▶ Dementia and the workplace: a guide for employers in Scotland (2017, Age Scotland)
<https://bit.ly/2Y2US1Z>
- ▶ Employer Responses to Dementia in the Workplace: a Report to the Carnegie Trust for the Universities of Scotland (2018)
<https://bit.ly/2rRrlfX>
- ▶ Evaluation of the Carers in Employment Project (2018, Social Care Institute for Excellence)
<https://bit.ly/36VUNQv>
- ▶ Supporting Employees who are caring for someone with Dementia (2014, Carers UK)
<https://bit.ly/2Z7pOhG>

Home enablement and dementia

Care & Repair: Dementia Enablement Project



Angus, Aberdeen, Lochaber, Lochalsh & Skye

Care & Repair offers independent advice and assistance to help elderly and disabled homeowners repair, improve or adapt their homes so that they can live in comfort and safety in their own community.

What we do

Our approach is person-centred. We assist people living with dementia pre and post diagnosis and people who do not have a diagnosis but where dementia may be present. The service is also available to unpaid carers. Each area employs 'Dementia Enablement Officers' (DEO) who are trained to the standards of the Promoting Excellence Framework⁵.

On the first visit a discussion takes place. This initiates the relationship with the person with dementia and/or unpaid carer and gives time to discuss the service. Any current concerns within the home are also covered. Continuity of staff is crucial to avoid different members of staff going in and out of the home. The first visit is important to develop the relationship with the DEO and the individual and/or unpaid carer. The DEO will maintain their relationship with the person and/or the unpaid carer.

⁵ <https://www2.gov.scot/resource/doc/350174/0117211.pdf>



A home safety assessment is then carried out, taking into account lighting and heating levels, specific concerns relating to or resulting from the person's diagnosis, as well as general security, fire and safety factors. The assessment may identify potential hazards, general maintenance and preventative works around the house that may not directly be related to the person's condition, but which will result in an overall benefit to their wellbeing and ability to live well in their own home. The assessment may also highlight some potential adaptations or equipment, which would address the physical or cognitive issues deriving from a diagnosis of dementia or potential diagnosis. An action plan tailored to the person's needs is agreed and the enablement works are carried out by the DEO. Each case will be considered individually, as the outcomes for each person and their property are likely to be different.

Examples of enablement measures and interventions carried out are:

- ▶ fitting coloured grab rails
- ▶ improved lighting and highlighting of light switches
- ▶ positioning or removal of mirrors
- ▶ installation of wipe clean boards
- ▶ basic decoration (to improve light in room)
- ▶ changing shiny floor surfaces/simplifying changes in colours of carpets or thresholds
- ▶ improving the perception of areas to be used by adding colour or signage notices as reminders
- ▶ a personalised night time safety check list
- ▶ the installation of assistive technology at an early stage (Telecare)
- ▶ supply of bespoke equipment

We work extensively with partners to promote our service, which has resulted in enhanced relationships. We also refer clients, with their permission, to other services which may be of benefit. As well as delivering workshops at the Care & Repair annual conference for the past three years, we have also presented at various national conferences.

We are rigorously analysing data from each area to identify any geographical differences, as well as noting commonalities.

What we are achieving for people with dementia and unpaid carers

- ▶ Care & Repair services are designed and provided in a timely and mutually agreed manner and suit the person's needs, helping them to retain independence, safety, security and activity in their home and the community in which they are settled and confident
- ▶ people with dementia are fully involved in decision-making and so are their families and carers
- ▶ Care and Repair respect people's rights and feelings and set timescales and work priorities in collaboration with the person and with carer(s)
- ▶ people are not rushed to make decisions and there is a recognition that they might need time to adjust to the changes happening in their lives
- ▶ unpaid carers and people with dementia are better supported and have improved independence and confidence



The project has given Care and Repair greater understanding, which they have shared with others so that more people across Scotland, like me, are helped to stay in their own home.

– a person with dementia.

The service provided was first class, people who care for the customer, highest regard for all who came and visited us, nothing was a problem, they took great care that we understood all that was going on. Thank you so much for no hassle visits.

– carer

Evaluation

The final evaluation report of the full project was launched at the Care and Repair Conference on 6 March 2020, a copy can be found here: <https://bit.ly/2YRSzRG>.

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Website: www.lsha.co.uk



Further reading

- ▶ Age, Home & Community 2012-2021, a Strategy for Housing for Scotland's Older People (2011, Scottish Government)
<https://bit.ly/2WOpNih>
- ▶ Being Home, Housing & Dementia in Scotland (2017, Life Changes Trust)
<https://bit.ly/34EYmJA>
- ▶ Blocking Nuisance Calls (2016/17, East Renfrewshire Council)
<https://bit.ly/2PETwb0>
- ▶ COME ON IN: staying connected (2016, Abbeyfield/Care Inspectorate/Scottish Care)
<https://bit.ly/2ZfYI8s>
- ▶ Dementia Pathways: Housing's Role (2016, Chartered Institute of Housing)
<https://bit.ly/2Mbc6W0>
- ▶ Effectiveness of actions to reduce harm from nuisance calls in Scotland (2018, Scottish Government)
<https://bit.ly/2Me28mB>
- ▶ Housing Associations' responses to tenants with dementia from black and minority ethnic groups (2015, Age UK)
<https://bit.ly/2EM3qS1>
- ▶ Housing through the lens of Ageing: Integration, Communication and Community, an analysis of the Age Scotland Housing Project (2019)
<https://bit.ly/34HAO6T>
- ▶ My Life, My Care Home (2017, Care Inspectorate)
<https://bit.ly/2PFyDMB>
- ▶ Shared Lives Plus report (2018)
<https://bit.ly/2S70fMu>
- ▶ Your Tenants are Gay, get over it! Social housing and LGBT+ people – a guide for social landlords (2017, Stirling University)
<https://bit.ly/2EESkxO>

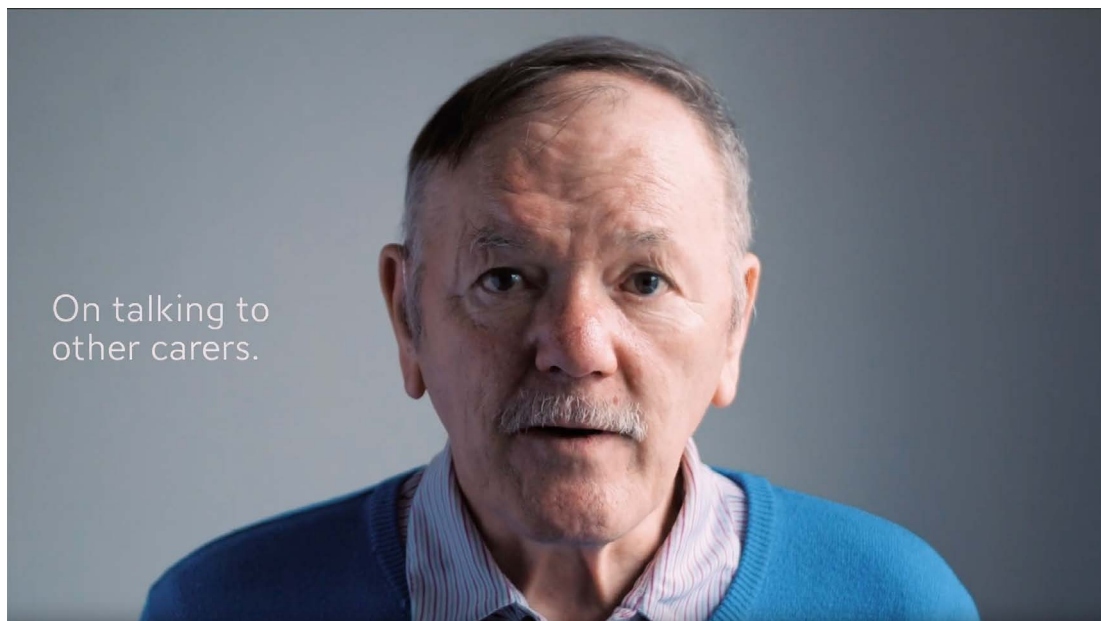
Technology

WILLIAM GRANT
FOUNDATION

Dementia and Technology – a Literature Review and Qualitative Study

The Life Changes Trust and the William Grant Foundation produced a research report and video exploring how people with dementia and their carers engage with assistive technology.

The report and video can be found here: <https://bit.ly/2XSVDKY>





In October 2020, the Life Changes Trust hosted an online learning event called ‘Dementia: A Whole Life Approach – Technology and Dementia’.

This webinar looked at existing and emerging technology, and how this can assist people living with dementia and family carers to live more independently and with more choice. Technology can be small and simple or it can be more ‘whole life’ – for example, using Alexa to help carry out every-day tasks.

At this event, we heard about:

- ▶ the views of carers and people with dementia on assistive technology
- ▶ the new ADAM tool, a free service which helps you to find technology products tailored to your needs and preferences
- ▶ the way in which people living with dementia are using technology and the impact it is having on their lives, as told directly by people with dementia and unpaid carers themselves
- ▶ the Human Rights Charter for Technology and Digital in Social Care

Our Chief Executive Anna Buchanan launched a report which was funded by the William Grant Foundation and produced by the Trust, ‘Dementia and Technology - A Literature Review and Qualitative Study report’.

The report looked at what technology was available to people living with dementia, whether they could easily access or use this technology, what technology they were actually already using and how we can improve design and accessibility. The report also asks, is technology one of the key ways forward for supporting people living with dementia and unpaid carers?

You can read the report [here](#).

There is also a summary report [here](#).

A Human Rights Charter for Technology and Digital in Social Care

In 2018 Scottish Care published a report ‘Tech Rights’, on the role of human rights in the use of technology and digital in the care and support of older persons, including people and their families living with dementia. The report addressed some of the challenges developers and older people face with the increased use of technology, including ‘care-bots’ and ‘sensor devices’.

In 2019 a group of designers and developers, policy makers, providers and frontline workers, as well as those who use social care supports, worked to develop a human rights-based Charter. It is based on the presumption that the future of care in Scotland has to be one which is based on the human rights, dignity, privacy and control of individual citizens. The Charter for Technology and Digital in Social Care is a contribution to achieving the rights-based care and support our citizens deserve. The Charter is accompanied by a Guidance document, which describes the focus of each of the 17 statements in the Charter and suggests how they can be used to support the human rights of individuals and communities. They have been designed to foster discussion and to promote further reflection.

The Charter can be found here: <https://bit.ly/350DJfv>



Scottish Care

Voice of the independent care sector

A Human Rights Charter for Technology and Digital in Social Care.

As designers, developers, policy analysts, human rights practitioners, politicians, service providers, workers and managers and those who use social care supports, we affirm that the use of technology in the care and support of people in Scotland:

1. must be to the benefit of the individual and the common good
2. cannot be used to restrict or remove any human right but should seek to enhance and fulfil human rights
3. should enable and foster personal independence if so desired
4. has to take account of the unique character and individuality of the person, including characteristics of gender, race and ethnicity, disability, sexual orientation, religion and belief, and age etc.,
5. should always be non-discriminatory in implementation and usage
6. should be accessible, understandable and transparent
7. should use data in a manner which respects privacy, transparency and accountability to the individual
8. should be fair and equal in its treatment and use
9. should only restrict individual choice and autonomy to a degree which is proportionate and rights-abiding
10. should enable an individual to flourish and achieve their full potential
11. should be used with the consent of the individual and in accordance with the previously articulated wishes and views of the person
12. should always be person-centred and focused in its intention and implementation
13. should as far as possible be co-designed with the individual end user's engagement and involvement
14. should seek to involve those important to an individual in the use of technology, include family members, informal carers and paid carers.
15. should be accountable to the individual whose data is held and enable them to check, edit and control that data
16. should not be used to harm, destroy or diminish another
17. should enable and augment human presence rather than wholly replace it.

Artificial Intelligence (AI) in Dementia: Terrifying Thought or Fantastic Future, by Ron Coleman

"Since my first diagnosis of mild cognitive impairment, I have been increasingly frustrated by the negativity with which many workers – and even at times, some family members – have viewed my future, with their thinking seemingly based on me having a progressive downward level of autonomy, until residential care



becomes my destiny. It is my view that by developing real individualised essential lifestyle plans, combined with the use of AI technology, we can significantly slow the rate at which this decrease of autonomy will happen, to the stage where most of us can avoid the feared “death in a strange place” and therefore die in our own beds at home.

"I have heard all kinds of views about using artificial intelligence (AI) as a personal assistant, and one of the most commonly used against AI, is how the use of technology may leave the person without human contact, and that this would be abusive. Though this view may have some merit, I would argue that both the changing demographics (an increasing ageing population), and the difficulty in recruiting the workforce required to deliver face-to-face contact, could contradict this. The quality of human contact is in a downward spiral, due to time pressures on staff, with home visits being constantly reduced, to an almost perfunctory status, often leaving staff, client and family feeling unsatisfied. It is within this context that my comments must be taken, for if we are to move from terrifying thoughts about technology, to a fantastic future that uses technology in general, and AI in particular, in a way that enhances lives, then we must be open to possibilities.



"As I am writing this my wife is away for a few days for work. If I was without technology, this would mean finding someone to ensure that I was safe while she is away. Because of AI, she can both see and hear me at the touch of a screen, and I can contact her using voice. I can also chat to my friends, and if all of us have 'show technology' then we can also see each other. From here our options are endless – coffee mornings, playing games together, education sessions and drop-ins can all be virtual.

"Human contact facilitated by AI is much more realistic for the future than overstretched services trying to find the capacity to provide more face-to-face visits, and even less likely, longer visit times. Even if I was written up for visits, there would be days when I did not need them – perhaps family would be visiting or I am up to doing it myself. I could use my AI to inform my service provider that I did not need them that day, and then this time could be used for someone else who needs it, or perhaps even bank time for myself when I do need it.

In conclusion, a fantastic future is a real possibility, but this will require a move beyond caring for us to one of caring about us. For AI, this only requires a tweak of an algorithm. For humans, it requires a whole change in thinking."

The Life Changes Trust has funded Ron to develop a Peer-to-Peer Resource about his use of AI so that it can inform others. Additionally, Ron has written a stage play 'Alexa and Me' which he has turned into a radio play. You can find both on our website:

<https://www.lifechangestrust.org.uk/project/alexa-and-me>

Ron also hosts a radio station, details of which can be found below:

Summary of Radio Station:

<https://www.dementiavoices.org.uk/group/deep-ness-western-isles/>

Radio Station Website:

<https://www.deepnessdementiamedia.com>

Living and Learning with Dementia

The Scottish Dementia Working Group was awarded £4,500 funding from the Life Changes Trust to produce a short film, which aims to inspire others living with dementia to learn new skills and make friends.

The film features three men – Henry, Pat and Geordie – who all have different types of dementia, and who share learning from an IT course in which they participated.

The film demonstrates iPad/tablet skills that viewers can try and the chaps discuss the importance of friendships and socialising for people living with dementia.

There is also discussion around different types of dementia and how to challenge stereotypes about dementia.

Henry, Pat and Geordie were all involved in the production planning, filming, sound recording and editing of the film, supported by a small video production team from the Untold Motion Picture Company.

The film can be found by clicking: <https://youtu.be/7UCYGnPjdHw>





Further reading

- ▶ A Human Rights Charter for Technology and Digital in Social Care (2019, Scottish Care)
<https://bit.ly/350DJfv>
- ▶ Dementia and Technology (2019, William Grant Foundation)
<https://bit.ly/2Q1Cjr9>
- ▶ Human rights charter for technology and digital in social care – guidance document (2019, Scottish Care)
<https://bit.ly/36QKs8z>
- ▶ Safer Walking – Technology Care as part of Dementia Care: a Practice Note (2017, Scottish Government)
<https://bit.ly/35EoC83>
- ▶ Technology Charter for People Living with Dementia in Scotland (2015, Scottish Government/Alzheimer Scotland)
<https://bit.ly/36YfZp2>
- ▶ Technologies to support community dwelling persons with dementia: a position paper on issues regarding development, usability, effectiveness and cost effectiveness, deployment, and ethics (2017, University of Salford)
<https://bit.ly/2M8kaXu>

Rights made real in care homes



Introduction

The Life Changes Trust invested funding to ensure that the rights of people living with dementia in care homes are recognised and respected.

Care homes across Scotland have benefited from the funding and have used it to demonstrate how they support the inclusion and participation of residents with dementia in a meaningful way, so that residents have a genuine say in their own day-to-day lives. Sometimes the human rights of residents living in care homes can be forgotten or ignored, especially if they have a cognitive impairment like dementia.

Last year, the Scottish Government published Scotland's new Health and Social Care Standards (see: <http://www.newcarestandards.scot/>). These Standards state that everyone in Scotland deserves to receive the care and support that is right for them, focusing on people rather than just ticking boxes. They aim to encourage health and social care providers to think about what really matters to people who receive services, and their experience of the care they receive.

Each of the funded projects is designed to show how these Standards will work in practice, demonstrating how to treat residents with real respect and dignity.



The Mungo Foundation: Bankhall Court Care Home



Glasgow

We are one of the most diverse and highly respected providers of social care and support for vulnerable people in Glasgow, West Central Scotland and beyond. At any one time we will typically run around 40 different types of project, delivering support to over 1,500 individuals, their families and communities.

Our mission is to enrich the lives of those we serve. Our services provide key support and care to the most vulnerable people in our community.

What we do

We believe that everyone has the right to enjoy adventures and that a diagnosis of dementia should not prevent this. An active social life is key to helping people with dementia feel happy and motivated. Encouraging creativity, gentle exercise, and taking part in activities helps the people we support to realise their potential, improve their self-esteem and reduce loneliness.

‘R’ and Running

R has been with us in Bankhall since August 2017. When she arrived, we worked with her on a ‘One Page Profile’. This explains how R likes to be supported and what is important to her. R told her Dementia Care Worker that she used to be very sporty and enjoyed running. Each day R chooses what she likes to wear, and she often opts for sports clothing and trainers, as these are the outfits that she feels herself in. R is proud of her previous sporting achievements and likes to tell visitors about them. She likes to have a healthy diet and always chooses healthier options at meal and snack times.

R told us that she misses exercise, as she used to find that it improved her mood and sleep. R's 'One Page Profile' told us that she used to run 5Ks and 10Ks regularly. R's Dementia Support Worker discussed with R what fitness goals she would like to achieve, and R decided that she would like to run a 5K.

As part of the risk assessment, we consulted the NHS guidelines for older adults aged 65 and over⁶ who are generally fit and have no health conditions that limit their mobility. The advice recommends 150 minutes of moderate aerobic exercise, or 75 minutes of vigorous aerobic activity, plus strength exercises, each week.

There was nothing physically stopping R from exercising. We believe that having dementia should not be a barrier to R realising her fitness goals. However, she did need one-on-one support in achieving them.

We worked with Glasgow Life and Alzheimer Scotland to gain access to their 'Good Sport' programme⁷. As with anyone starting an exercise regime, we consulted R's GP to ensure her training plan was suitable.



6 <https://www.nhs.uk/live-well/exercise/physical-activity-guidelines-older-adults/>

7 https://www.alzscot.org/assets/0002/0805/Alzheimer_Scotland_Active_Programme.pdf



R was supported to train, register, run and walk a 5K. This was a great achievement for R and she was on a high for weeks later. R has the bug again and the staff support R to continue to train and we look forward to R completing another 5K.

This helped R to **“get the most out of life because the people and organisations who support and care for me have an enabling attitude and believe in my potential”** (Care Standard 1.6).

R was able to **“choose to have an active life and participate in a range of recreational, social, creative, physical and learning activities every day, both indoors and outdoors”** (Care Standard 1.25).

R has the **“Right to respect for private and family life, home and correspondence”** (Article 8 Human Rights Act 1998), ensuring that R can maintain a fulfilling and active life, making her own choices as far as possible.

‘J’ and Football

J is very independent. His ‘One Page Profile’ told us that this is incredibly important to him and he wants to remain so for as long as is possible.

J loves Celtic and has followed the team since he was a child. He had a season ticket for many years. His ‘One Page Profile’ also tells us that he enjoys watching and talking about football. On match days, J will come down from his room with his Celtic top on, saying he’s away to the match.

With funding we received from Life Changes Trust we planned an outing for J to attend a football match, to see his team in action. The staff member had to plan alongside J, risk assess the activity and look at transport to and from the match, as well as access to the stadium and where would be best for J to sit given his level of mobility.

J was able to attend the match and enjoyed watching his team. On his return home to Bankhall he shared his experience with other football fans in the service. This experience supported J to develop friendships with his peers.

It means a lot to our staff that they are part of an organisation where the people we support believe “**human rights are central to the organisation that support and care for me**” (Care Standard 4.1) and “**the organisations that support and care for me help tackle health and social inequalities**” (Care Standard 4.2).

What we are achieving for people with dementia

- ▶ people are treated as an individual
- ▶ people feel valued and respected
- ▶ people have a say and are in control
- ▶ people are supported to keep active
- ▶ people feel safe
- ▶ people have access to social contact and experiences

You can read a report sharing more stories from Bankhall Court on our website: <https://bit.ly/2UEYolt>

If you want to know more, please contact:

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Fairfield Care



Fife and West Dunbartonshire

Fairfield Care Scotland is a well-respected, award winning and family-owned company with an excellent track record and extensive experience in providing person-centred care to the highest standard. We operate three first class care homes, where the care delivered in each is as individual as each resident.

What we do

Our work is best described as discovering and building relationships through conversation and sharing stories. It's looking at the good work happening in our care homes and examining it further to explore how to help people living there continue to lead a dignified life and have their human rights protected and respected in the changed circumstances of getting older and living with dementia.

A good cross-section of managers, nursing, care and ancillary staff are involved in a series of workshops. These have been lively and engaging sessions that are looking at the principles and practices of appreciative inquiry⁸, the Senses Framework⁹, caring conversations¹⁰ and relationship-centred practice¹¹.



8 <http://myhomelife.uws.ac.uk/scotland/resources/ai-key-principles/>

9 <http://myhomelife.uws.ac.uk/scotland/resources/senses-framework/>

10 <http://myhomelife.uws.ac.uk/scotland/resources/caring-conversations/>

11 <http://myhomelife.uws.ac.uk/scotland/good-practice/>

This is supporting us to notice and value existing good practices, by becoming more conscious of what we already do well and what people value. We can then stretch ourselves to go even further to help people maintain their identity, play a meaningful part in shared decision-making and make their own choices.

It's still early days. Staff are trying out different techniques to dig deeper in conversations and in their day-to-day interactions with each other and with residents and relatives. We're gathering stories to ultimately help us support people to achieve exactly what they want and enable them to live life to the full within their abilities.

What we are achieving for people with dementia

- ▶ generate new practice-based knowledge of how to enhance human rights for people living with dementia in care homes
- ▶ explore how a focus on inquiring appreciatively supports and stretches staff to value existing good practices and bring them to light to maintain identity, enhance shared decision-making and enact meaningful choices for each person living with dementia in care homes
- ▶ develop and test out a process to capture and work with examples of everyday excellence that extends participation beyond the immediate participants
- ▶ recognise how the best of existing authentic care work, grounded in human relationships, in which ethical and practical dilemmas are negotiated on a daily basis, enables the fulfilment of the health and social care standards and the human rights of all residents
- ▶ understand what is required to maintain momentum for this work in each care home and across the wider health and social care system in Fife, West Dunbartonshire and beyond

You can read a report sharing more stories from Fairfield Care on our website: <https://bit.ly/3hwnKuH>



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Paisley

Royal Blind is Scotland's largest vision impairment charity. We have been providing nursing care to older people with sight loss for over 50 years. We run Scotland's only care homes for older people with sight loss:

- ▶ Braeside House, Edinburgh
- ▶ Jenny's Well, Paisley





What we do

Our project is based on activities and support in care homes for people with dementia and sight loss.

Through the project, Royal Blind is working with residents at our new specialist care home Jenny's Well in Paisley who are vision impaired and have dementia, to ensure that any activities carried out in the home are chosen by them. Residents and their families have been consulted through surveys and focus groups to establish what activities they would most enjoy, and how they would like these activities to be structured. We want to offer a wide range of options, which are based on the residents' preferences and are most effective in enhancing their lives in the way that is important to them.

Consultation with residents, staff and families led to ideas for activities that were meaningful to residents and a range of projects were developed. As the activities take place, along with residents, we will assess how successful they are for people with dementia and sight loss, and use this learning to inform the planning of future activities, as well as more broadly promote awareness and understanding of the links between dementia and sight loss and how the home can best support people living with both conditions.

What we are achieving for people with dementia and unpaid carers

- ▶ for people with dementia, we want to create a living and caring environment, which best meets their individual needs
- ▶ for people to be as active and involved in activities they enjoy as they want to be
- ▶ to ensure people with dementia can be part of a community in Jenny's Well but also remain connected to the wider community and with family and friends
- ▶ for unpaid carers, we hope this project will help provide helpful information and approaches to providing care for people with sight loss and dementia

One example of developing activity as a result of feedback from our focus groups with people with dementia has been organising a walking activity. We heard from residents that they wanted more opportunities to get out and about beyond the home. As a result of this, we have organised 'Jenny's Jaunt' where volunteers join with staff, residents and family members to go for a walk.

You can read a report sharing more stories from Jenny's Well on our website: <https://bit.ly/3e9naRu>

Training

Royal Blind has already developed training and expertise specifically in supporting older people with sight loss and dementia. See our website for details www.royalblind.org

Please see page 34 in the Information, Awareness, Training and Education book for more information. Also see www.lifechangestrust.org.uk/project/jennys-well

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Twitter: @RoyalBlind



Laurels Lodge Care Home

Aberdeen

Laurels Lodge provides 24-hour nursing care for people with a wide range of needs, specialised support for those living with dementia and short respite stays to give home carers a well-earned break.

What we do

This project focuses on how the team at Laurels Lodge Care Home approach conversations about anticipatory care planning (ACP) within the context of the six-monthly review.

Laurels Lodge cares mainly for approximately 45 older people, the vast majority of whom have dementia. ACP is a process where we seek to understand what the wishes of the person are, particularly considering palliative and end of life care. Traditionally, the focus of such conversations has reflected the paperwork, which doctors need to complete, including wishes around resuscitation, active treatment and preferred place to receive care in the final days of life.



This project focuses on the application of the Caring Conversations Framework¹² (Dewar 2012) in the context of ACP. This emphasises principles of caring conversations that test out:

- ▶ being courageous
- ▶ celebrating what works well
- ▶ connecting emotionally to share how we feel
- ▶ being curious about what matters without making assumptions, considering other perspectives as all our voices matter
- ▶ collaborating to envision what we hope for and bringing that into reality if possible
- ▶ compromising with this so we work with what is real and possible

The approach taken focuses on appreciating what works well, trying things out and seeking to constantly review and improve our care. We engage and involve key staff, as well as relatives to co-create new resources, processes and ways of working. This happens through observations, participatory workshops, working together in resident reviews, reflective workshops and a validation event. This helps staff rely less on documentation in order to focus more on the conversation with the person in front of them. One of the biggest shifts is in how we approach discussing end of life wishes. We have moved from saying **“this is a difficult conversation that neither of us really want to have...”** to **“this is a really important conversation that we would like to have”**.

The project is resident-led in its focus, as the resident is steering their own care and the decisions around their care at the end of their life. Where residents might not have been able to verbalise this, the team consider their previous wishes with help from family members, as well as noticing how their body language and engagement communicate their wishes too.

12 <https://onlinelibrary.wiley.com/doi/abs/10.1111/hsc.12436>



What we are achieving for people with dementia and unpaid carers

The overall aim is to co-create an enhanced process of advanced care planning to enable the human rights of those living with dementia to be met in the final phases of their life.

This is achieved through:

- ▶ using caring conversations to enact ACP with people with dementia, their families and paid carers
- ▶ creating a reflective learning culture in the care home where people will be supported to deliberately reflect on what worked well in the ACP process and how we can amplify this
- ▶ involving the families and paid carers of people living with dementia in giving feedback about ACP
- ▶ developing and modifying the ACP documentation to meet the needs of this group
- ▶ co-creating resources that can be used across the care home sector in addressing the ACP preferences of people with dementia, their families and paid carers

You can read a report sharing more stories from Laurels Lodge Care Home on our website: <https://bit.ly/3xEeUAO>

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Tigh a' Rudha Garden Project

Isle of Tiree

Tigh a' Rudha is a small, local authority care home for the elderly on the Isle of Tiree. It was built in 1968 and has places for ten residents. At the time of writing there were six people living here.

What we do

Tigh a' Rudha is situated in a beautiful spot with sea views but the building is old and we are not likely to get a new one anytime soon. If you are sitting down or in a wheelchair, you can't see out of the windows and, until this project, the main lounge opened onto the car park and the only place to sit was on the pavement outside. Our local school helped us brighten it up each year with tubs and planters but, without any shelter from the wind, you could only sit outside on a calm day and we don't get many of those on Tiree. There was no funding available from the Health and Social Care Partnership for a garden. We used funding from the Life Changes Trust, together with additional funds from Tiree Community Development Trust Windfall Fund, Argyll and Bute's Health and Wellbeing Fund and local sponsorship and donations, to create a dementia friendly sensory garden for our residents.

After a short, but intense, consultation process to find out what people wanted, we dug up part of the car park to create a paved garden with raised beds, handrails, seating areas and space for wheelchairs. It is sheltered by a hit-and-miss fence with a sculptural wavy edge. We didn't want it to feel like a prison exercise yard! There is a wide path looping around a central raised bed and back to the door and a larger bed against one wall. Both beds are at wheelchair height and there are also two wheelchair accessible planters. We have left room for a third, as one resident has a planter of her own that she wants to bring from her daughter's house now that there is somewhere sheltered and sheep-proof for her to put it.



We have started to fill the raised beds with plants chosen for their scent, colour, different leaf shapes and textures and their ability to survive on Tiree. Coloured glass tiles, beautifully tactile, made by staff under the guidance of a local glass artist, run along the top edge of the central bed. These incorporate words (in English and in Gaelic) collected from residents and from a previous community art project, which relate to the garden, to being outdoors and to people's experience of Tiree's community, weather and landscape. We may also include other artefacts amongst the planting, such as creels and buoys, which people may recognise and remember. To the seaward side of the paved garden is a wildflower meadow, sown with machair flowers native to Tiree. We were given the seeds and help to sow them by Tiree's Great Yellow Bumble Bee Project. This meadow will take a few years to establish but eventually we plan to mow a grass path through it so that people will be able to go in and experience the flowers, movement and scents of the Tiree machair.

What we are achieving for people with dementia and unpaid carers

- ▶ people with dementia exercise their right to a garden
- ▶ people with dementia have the freedom to choose to go outside and not be discriminated against because of a lack of safe, accessible outdoor space
- ▶ people with dementia experience the physical and psychological health benefits of spending time outside, to have increased opportunities for sensory experience, both stimulating and calming and a corresponding decrease in boredom and depression
- ▶ people with dementia, whose world so often shrinks, feel that the garden has significantly expanded their world
- ▶ people with dementia, many of whom, in a rural, island community, led predominantly outdoor lives when they were younger maintain or re-establish those connections with the outdoors

- ▶ people with dementia choose how they spend their time, to go outdoors if they want to, and to experience an environment which better meets their needs and respects their wishes and choices
- ▶ families and carers sharing time in the garden, helped to maintain, develop and enjoy their relationship with the person with dementia
- ▶ people with dementia stay connected to their local community

Although it will be a private garden, to meet National Care Standard requirements, we hope that residents will invite members of the community and groups, such as the pre-fives to share it for particular activities or just to enjoy the garden at specified times in the company of those residents who wish to take part.

You can read a report sharing more stories from Tigh a'Rudha on our website: <https://bit.ly/2UHtCrQ>

If you want to know more, please contact:

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Scams, safety and dementia



Trading Standards Scams Prevention Team

Angus Council (Trading Standards)

East Renfrewshire Council (Prevention Team)

South Ayrshire Council (Trading Standards)

Our Trading Standards Services protect and advise consumers and businesses. We are responsible for ensuring quality, quantity, safety, price and description of goods and services.

What we do

We work together to protect residents in challenging situations from financial harm. Residents living with dementia can be particularly vulnerable to scams. We put “simple practical solutions” in place, such as nuisance call blockers. The feedback shows that people feel safer after receiving our bespoke prevention package.

Information will be displayed at www.eastrenfrewshire.gov.uk/prevention as it develops. Be sure to check out the feedback section.

How can we help?

- ▶ we can sit down with the family and provide advice and solutions
- ▶ "no cold calling" sticker for your door
- ▶ access to trusted/reputable traders
- ▶ free nuisance/scam call blocker for your phone
- ▶ advice on keeping safe online
- ▶ tips on reducing utility bills
- ▶ advice on reducing and redirection junk/scam mail
- ▶ advice on Power of Attorney and safer banking
- ▶ links to Telecare equipment and Fire Safety visits
- ▶ information on local social activities
- ▶ access to consumer advice
- ▶ help to claim back money lost to scammers



What we are achieving for people with dementia and unpaid carers

- ▶ residents living with dementia feel safer and capable of maintaining independence
- ▶ carers feel more confident that financial harm will not occur
- ▶ carers feel less stressed and more confident that the person they care for is safe from harm
- ▶ reduced nuisance calls
- ▶ partner organisations are more scam aware
- ▶ Scam Awareness Toolkit developed for individuals, families and professionals to access
- ▶ reduce the amount lost to scams in the local areas, £9 billion is the estimated loss to scams in the UK each year

Evaluation

This project has now been evaluated by Social Value lab and we have published the evaluation report, which includes a measure of the social return on investment (SROI) of the work. The report is available [here](#).

Training

We have produced toolkits, in partnership with Age Scotland, that provide self-help training/guidance for carers and those living with dementia. These can be found here: <https://www.ageuk.org.uk/scotland/information-advice/health-and-wellbeing/dementia/>

This link www.nationaltradingstandards.uk/work-areas/scams-team/ also provides an opportunity to complete a short e-learning awareness tutorial on scams and the opportunity to become “A friend against scams”.

We can provide 'Scam Awareness' training to any national or local organisations based in the relevant areas.

If you want to know more, please contact:

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Ken McLeod, Trading Standards Manager

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Self-directed Support

MECOPP: 3 R's (Rights, Respect, Responsibilities) Project



Scotland-wide

By working in partnership with carers, the voluntary and statutory sectors, MECOPP actively seeks to challenge and dismantle barriers that deny Black and Minority Ethnic carers access to health, social work and other social care services in Edinburgh, the Lothians and further afield.

What we do

Our Self Directed Support legal project has a dementia specific post funded by the Life Changes Trust. It is one of two posts (the other being disability and long-term conditions) but they share common areas of activity across their respective beneficiary group:

- ▶ Front line advice and casework – the project provides both telephone advice and a casework service to individuals who are experiencing difficulties in accessing Self-directed Support. This can include basic advice on rights and entitlements (initial frontline advice) to the submission and resolution of complaints to local authorities, health boards (where applicable) and the Scottish Public Services Ombudsman. The project will refer onwards, if a legal resolution is being sought, to solicitors.

Training

- ▶ The project has developed a 3-day training course for third sector organisations on ‘understanding the law’ in relation to SDS. The sessions are delivered by a range of experts in social care, human rights and equalities law
- ▶ Masterclasses – these provide more in-depth exploration of the issues that have arisen in relation to the implementation of SDS and are delivered by professional legal experts
- ▶ Student placements – these are delivered in partnership with Glasgow University School of Law Internship Hub. Interns are hosted by third sector organisations supporting the implementation of SDS
- ▶ Web-based resources – these are additional resources designed to promote and increase understanding of rights and entitlements under SDS. Click on this link for resources currently available: <https://www.mecopp.org.uk/resources>

Our project is unique in Scotland and is the only source of legal advice and expertise in relation to SDS.

What we are achieving for people with dementia and unpaid carers

The aim of the project is to build the capacity of third sector organisations and individual carers/service users to draw on legal knowledge to challenge local authority decision-making on the award of individual budgets (i.e. direct payments and individual service funds) through Self-directed Support. We are achieving the following:

- ▶ increased knowledge of existing rights and entitlements under social care, equalities and human rights legislation and their inter-related nature to ensure people with dementia have full and equal access
- ▶ increased organisational capacity to challenge decision-making on behalf of people with dementia
- ▶ increased partnership working between the legal profession and third sector organisations supporting individuals with a social care need, including people with dementia



Training

We have developed an online version of our existing 3-day training course, which is available to the public as part of the 'Open Learning' Badge Scheme. Our publication 'Challenging Social Care Decisions in Scotland: A Legal Guide' is also available on our website: <https://bit.ly/2Wkq0dV>

<https://www.mecopp.org.uk/3-rs-project>

If you want to know more, please contact:

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Twitter: @MECOPP1

Website: www.mecopp.org.uk/self-directed-support

Further reading

- ▶ A Human Rights Based Approach to SDS for Older People (2017, Scottish Care)
<https://bit.ly/2Q4YIUj>
- ▶ Challenging Social Care Decisions in Scotland: A legal guide (2018, Tim Haddow/MECOPP)
<https://bit.ly/2UaRIbr>
- ▶ Dementia, SDS and Promoting Individual Autonomy: A guide to Self-directed Support for people with dementia (2018, Jill Stavert/MECOPP)
<https://bit.ly/2XxmkGg>
- ▶ Individual Awards Pilot Projects: Argyll & Bute and Edinburgh (2015, Life Changes Trust)
<https://bit.ly/2tv1HxL>
- ▶ Personal Experiences of SDS Report (2017, The Health and Social Care Alliance)
<https://bit.ly/34wUYjS>
- ▶ Self-directed Support in Scotland (2018, Community Catalysts/Life Changes Trust)
<https://bit.ly/36SPeCI>
- ▶ Self-directed Support Progress Report (2017, Scottish Government)
<https://bit.ly/36P1eF6>



The Life Changes Trust Individual Awards Scheme



Background

Adequate financial resources can mean the difference between living well with dementia or struggling to cope with living with dementia. Following a diagnosis of dementia, individuals and families can experience increased financial disempowerment and vulnerability, even when they have been relatively well off in the past. Loss of earnings because the person with dementia or carer has had to give up work can lead to circumstances where income diminishes (often unexpectedly), there are unforeseen expenses and credit is curtailed. Sometimes the wider family is in a position to help out, but often this is not the case and it can be embarrassing to ask for help.

For many households, savings and assets are the critical first line of defence against emergencies, unforeseen expenses, and income interruptions. Families that have adequate savings and assets may successfully weather such setbacks, but households that lack this security are financially vulnerable and at risk of falling into poverty.

In addition to the benefits increased financial resources bring, also important are strong relationships, time spent with people and the importance of supporting individuals to talk about what matters to them and what impacts their sense of wellbeing. People can be trusted to spend money wisely when given time and support to think about it.

Following a very successful pilot project that ran in Edinburgh and Argyll and Bute, the Individual Awards Scheme ran in Aberdeen, Angus and Locharaber from April 2018, with a planned closing of 30th September 2018. However, due to the popularity of the awards, the scheme closed in early September 2018 as all the allocated funding had been paid out.

In each area, the scheme was again being run by a group of local organisations in partnership with the Trust, led by Care & Repair Aberdeen, Care & Repair Angus and Care & Repair Locharaber.

The Trust published an evaluation report at the conclusion of the Scheme. We believe the evidence gathered from this scheme will help inform thinking about the use of small direct payments, through SDS, to better support people with dementia and unpaid carers. The evaluation report is on our website, along with a summary of two webinars which shared the learning: one focussed on the policy context and another focussed on individuals and personal budgeting: <https://bit.ly/3yPIzak>

Further reading on the pilot project can be found here: <https://bit.ly/2tv1HxL>

What we do

The Individual Awards Grant Scheme was available for people living with dementia or to unpaid carers providing four hours or more of unpaid care in three areas of Scotland: Aberdeen, Angus & Locharaber. The application period was open for a maximum of six months.

The aim of the scheme was to issue Individual Awards of up to £500 per person, providing financial assistance to:

- ▶ spend on something that will make life better
- ▶ enable them to do something that matters to them which, without the award, they would not be able to do

The Care and Repair projects were the lead partners for a consortium in each area linking with the Dementia Enablement service, also supported by the Life Changes Trust (see pages 91–93). Each area had between 2 and four partner organisations (with a background in dementia or unpaid carers) in their local consortium. They were represented on the panel considering applications, as well as an individual living with dementia.

Each area planned, structured and operated the scheme and administered the Individual Awards in a way which provided a positive experience for people living with dementia and unpaid carers. The scheme was promoted in different ways, taking into account operational issues, the local area and partners working with people living with dementia and unpaid carers.



Staff assisted applicants in the following ways:

- ▶ support people living with dementia to consider what would be beneficial, to make an application and to help with/make arrangements to spend their Award
- ▶ support unpaid carers to consider what would be beneficial, to make an application and to help with/make arrangements to spend their Award, if required
- ▶ work in close collaboration with the Care and Repair Dementia and Enablement Project operating in the same area, in order to maximise benefits for people living with dementia
- ▶ be flexible and support Awardees when circumstances change for people living with dementia and/or unpaid carers, and to make alternative arrangements if necessary so they can still benefit from their Award
- ▶ follow up with all Awardees and gather equal opportunity forms and receipts, as proof of Award expenditure, and obtain written feedback using a standard tool (a 'Guided Letter') provided by the Life Changes Trust

The Care and Repair projects administered the grants by:

- ▶ local promotion of the scheme
- ▶ participating in partners' planning and review meetings, convened by the Trust, to plan, review progress, share practical learning and problem solving
- ▶ participating in a wider evaluation process, involving an external evaluator/s
- ▶ facilitating panel meetings to assess applications, make grant payments, collect receipts and feedback from all Awardees

What we are achieving for people with dementia and unpaid carers

- ▶ a scheme which provides a positive experience for people with dementia and unpaid carers
- ▶ connecting people living with dementia to the Care and Repair Dementia Enablement Project in their area if a request relates to the home environment
- ▶ gathering evidence that can be used to inform and influence improvements in policy, practice and funding in the long term to benefit people with dementia and unpaid carers

If you want to know more, please contact:

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Facebook: www.facebook.com/LifeChangesTrust

Twitter: @LifeChangesTrst



Mobility and dementia

Go Upstream

Go Upstream

Scotland

- ▶ Go Upstream works with people living with dementia to improve mobility services
- ▶ Go Upstream provides a practical training and design programme for transport providers, helping to make services more inclusive for people living with dementia

We bring people living with dementia together with people who provide travel and transport services, through stories and shared experiences. We spend time together, learn from each other and explore ways in which transport can become more enabling, putting the voice of people living with dementia at the heart of future mobility service design. We create opportunities and conversations that everyone can contribute to.

What we do

Go Upstream's mission is to improve the travel experiences of people living with dementia by placing their expertise and experience at the heart of service design. Emerging from work supported by the Life Changes Trust, we are a new training and design consultancy. We create opportunities for travel and transport organisations to work with people with dementia to develop ideas for more enabling services, together. We've developed a practical training and design programme for service providers that builds a better understanding of the challenges of travelling with dementia, brings staff together with people with dementia to explore this in practice and prototypes ideas for change. We create collaborative groups, facilitate workshops and shared journeys and enable everyone to participate in building ideas for new services.



We're learning a lot and our aim is to turn this into action. Go Upstream is already initiating and supporting a number of projects, including the development of a service to support people who stop driving as a result of a diagnosis of dementia. We're exploring the suitability and provision of toilets on travel services and the use of technology to make rail travel easier for people with dementia. As with all of our work, these begin with the participation and contribution of people with dementia. We regularly engage with groups of people with dementia across Scotland and beyond, with links to various Alzheimer Scotland and DEEP groups around the country.

Go Upstream isn't simply a catalogue of answers to 'dementia friendly transport'. We're developing a network of people and organisations, raising the importance of travelling well with dementia and seeking opportunities to place the experience and expertise of people with dementia at the heart of transport service design.



What we are achieving for people with dementia and unpaid carers

We want people with dementia and unpaid carers to feel able to travel independently and confidently, enabling them to continue to participate in, and contribute to, their communities. We believe that participation in, and contribution to, the exploration of travel challenges and service design can be empowering and enabling too.

Training

Go Upstream's core commercial offer is a training and design programme. The materials and processes that we use in workshops with people living with dementia can be used by anyone to facilitate conversations about getting out and about – these are freely available from our website <http://www.upstream.scot/workshop-resources-1/>

If you want to know more, please contact:

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Further reading

- ▶ Travelling with dementia (2019, Go Upstream)
<https://bit.ly/3dyw8VT>
- ▶ Travelling with dementia (2013, Scottish Dementia Working Group)
<https://bit.ly/2SbVcuJ>
- ▶ Voyage of discovery, working towards inclusive and accessible travel for all (2018, Amadeus)
<https://bit.ly/34yoxS4>



Dementia inclusive symbols

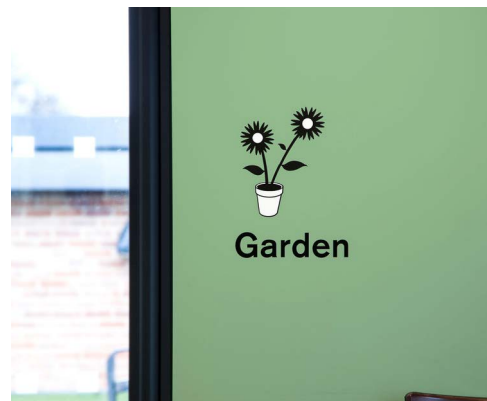
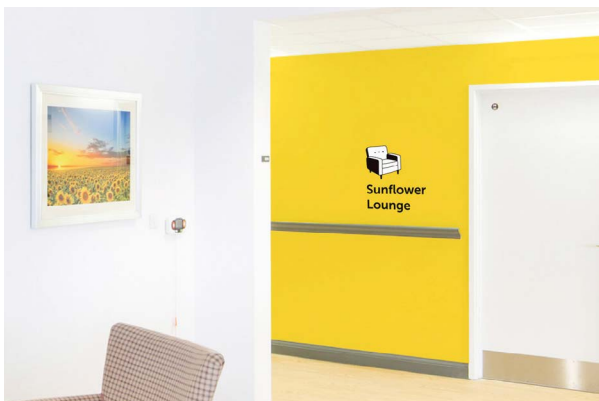
Inclusive Symbols: StudioLR

StudioLR
Making the Difference

Scotland

StudioLR is a design studio that works to make people's everyday experiences better. Even if it's just a little bit at a time.

We work hard to spark something in people. We take complex problems and make them simple – using empathy, surprise and humour. And we don't use any jargon.



What we do

In 2015, the design team identified a lack of effective signage in dementia care environments and initiated a project, working with the Universities of Edinburgh and Stirling, to use insights from people living with dementia to develop signage that was both effective and attractive. The work was made possible with a Scottish Funding Council Innovation Voucher through Interface.

Building on the success of this, and with funding from the Life Changes Trust, StudioLR looked to repeat a similar review with a particular focus on ‘symbols’ that appear on everyday signs.

This research project explored the feasibility of developing a new ‘inclusive’ set of 15 commonly seen symbols that will appear on signs in order to improve the independence and confidence of those living with dementia as they go about their everyday lives.

The summary of the feasibility phase demonstrated an inconsistency in responses across a number of focus groups – confusion and a variance in opinion was evident with a literal translation frequently observed. As a consequence, further funding from the Life Changes Trust was secured to design and evaluate a new, effective set of symbols.

Ongoing testing was facilitated by Steve Milton, Director of Innovations in Dementia, to evaluate the legibility and understanding of each of the concept designs developed by StudioLR with feedback from groups of people living with dementia across the UK.

There’s been an enthusiasm from participants to feedback their views on something ‘practical’ rather than policy-based that will impact positively on people’s everyday life.



What we are achieving for people with dementia

The fresh new set of symbols is part of the drive to encourage independence for people living with dementia. Beyond this, the new ***inclusive*** symbols will be more effective for *everyone* right across society, in all public places – clear, easy to understand and relevant to people’s everyday lives.

The symbol set can be found at: www.studiolr.com/inclusive-symbols

The ‘any disability’ symbol was launched at the UK Parliament on 5 June 2019 and is free for download.

The ultimate goal is that the British Standards Institute (BSI) adopts these as the standard British symbols. Subsequently, the symbols could make significant impact globally as the International Organisation for Standardisation (ISO) International standard.



Training

We'd don't have the expertise to offer training at StudioLR but we can offer guidance and advice regarding the principles of wayfinding and signage design.

If you want to know more, please contact:

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Blog: <http://blog.studiolr.com/category/inclusive-symbols/>



End of life and palliative care



Donald MacAskill, CEO Scottish Care

Over the last few years there has been an increased awareness of the importance of developing palliative and end of life care services. We have seen a welcome awareness that palliative and end of life care should not be limited to those who are living with cancers. There has been a growing desire to ensure that those who are reaching the end of their lives are able to be supported, as well as they can be to end their days in a way which upholds their dignity and sense of humanity.

Palliative care is all about helping someone with a life-limiting condition to retain the best quality of life and to be as free as possible from pain and distress. Palliative care is not just the support that we give in the last few days and weeks of a person's life but for many with dementia it is a support that can last months and years. In fact, one of the many distressing and really difficult things about dementia is that the decline and changes in mobility and communication, the growth of frailty and frequency of infections, can make the sense of knowing when someone is reaching the end of their life very difficult to determine. Palliative care is therefore about living life to the full, to the very end of life and at that end to ensure that someone is able to have a 'good' death and that they and their families are supported as well as possible.

Dementia affects every single person in a unique way. However, there are general patterns, which indicate that someone is reaching the later stages of their illness and there are things we can do to help at that stage. Palliative and end of life care needs to be as person-centred as possible. Effective palliative care helps us to plan, prepare and to care with dignity. I suggest that there are some key themes, namely, planning, communication, environment and relationship.

Planning

When someone who has dementia is coming to the latter stages of their illness, it is inevitably a time of great stress and upset within a family and amongst friends. It is not the best time to be making significant decisions or having hard conversations. For the end of our life to be as supported as the start of our life we need to plan and prepare as best we can and as early as we can. This is especially true of dementia, where anticipatory care planning helps to make sure that a person with dementia retains as much control and choice in the way in which they want to end their life. It is so important to have conversations about wishes and beliefs, about desires and hopes before an individual's disease begins to more profoundly affect their capacity to communicate and to make decisions.



Communication

How we make our desires and needs known, how we speak to the world and to others is unique to each one of us. Dementia as it progresses changes the way we communicate and this can be extremely distressing for both the person themselves and those close to them. Dementia leads in many instances to changes in the way that we relate even to those who are close to us and this often means we use vocal language less and less. Good palliative care and support helps those who care for someone with dementia to re-learn the language of communication. There is a recognition that we need to gain the ability to read the body, as well as hear the words and sounds a person makes. This is so important especially in the recognition of how a person might feel pain or express distress. Being with another teaches us the powerful impact of touch and caress, of gazing and consoling, of reassurance and presence. Communication happens when we read the small signs an individual is showing and when we don't jump to assumptions that someone is being difficult or challenging in their behaviour. As someone talks less and less, as they become more detached and distant, then palliative care is there to uphold, comfort and guide.

Environment

Part of the process of planning in palliative and end of life care is to support someone in a way that helps to use the environment which they are in to maximise their care and comfort. It also means that we have conversations and make decisions about where it is that someone with dementia wants to spend their last few weeks and days. All too often people end their life in a place they do not want to be. For instance, for many a busy, unfamiliar, noisy and impersonal environment, such as a hospital – despite the quality of care offered – might not be where an individual would want to spend their last few days.

Palliative care can help us to plan for the space and place that we die. It can help us to appreciate that comfort is often brought by someone being in a place they call home, listening to their favourite music, hearing the sounds of their garden, seeing through a window the rhythm of their community as it passes by. Palliative care can help us create a space where dying is nurtured and where loss is cradled in a personal, familiar and comfortable place.

Relationships

Palliative care is first and foremost about relationships. It is about placing the person living with dementia at the heart of all focus and attention. But there is also a deep awareness that those around the person are profoundly affected by the dementia and by its progression. It is the recognition that dementia changes relationships and that the sense of loss and change can be extremely hard to deal with. Good palliative care does not just, therefore, focus on physical health and pain management, but upon supporting the dynamics of emotional, psychological and spiritual integrity and wellbeing as they affect the individual and the family. Good palliative care seeks to do all it can to support and renew relationships as they are changed.

So, through appropriate planning, developing communication, appreciating environment and renewing relationships there are great strengths offered by palliative and end of life care for someone living with dementia.

Every ending of life is the parting of uniqueness. No two lives are the same, however similar. Good palliative care is about offering people, paid and unpaid carers, to have space and time, simply to be, to be present, to console and calm, to reassure and listen. At such moments it is not the actions that we undertake or the tasks that we perform, but the presence we offer and the simple act of being-with that makes an ending into a good death.



Bereavement Charter for Children and Adults



Scotland's first Bereavement Charter for Children and Adults was launched on 15 April 2020. The charter was developed over an eighteen month period in consultation with individuals and groups across Scotland.

This Charter, together with Guidance notes, has been developed by a coalition of individuals and organisations.

It contains 15 statements which describe what the best bereavement care and support should look like. It has been developed to support individuals and communities who struggle with the death of someone they know or someone in their community.

The Charter is designed to help us understand not only the importance of bereavement support, but what that support needs to look like.

Whilst accepting that every death is unique and that the way we each come to terms with a death is individual, this Charter and Guidance attempts to describe what good bereavement support can look like and what difference it can make.

The authors of the Charter hope that it will begin to appear in locations across Scotland and will be used by diverse groups and individuals. It is therefore hoped that the Charter will help us as a nation become more effective at supporting people to grieve.

A short film has been produced which establishes the contextual background, rationale and intended outcomes for the development and implementation of a human rights based Bereavement Charter for Scotland. This and a link to the Charter, Guidance notes and FAQs can be found here: <http://www.sad.scot.nhs.uk/bereavement-charter>



Bereavement Charter FOR SCOTLAND

A Bereavement Charter for Children and Adults in Scotland

This Charter provides a set of statements which describe how in Scotland we can support a person or a group of people experiencing bereavement. Good bereavement care is a human right. This Charter is underpinned by a desire to make sure that in Scotland, we can do all that we can to support people who might be experiencing difficulties following the death of someone they know or somebody in their community. It is the responsibility of everyone within Scotland to ensure that this is achieved. These are our statements:

IN SCOTLAND, PEOPLE WHO HAVE BEEN BEREAVED SHOULD:

- be treated with compassion, empathy and kindness
- have their wishes, choices and beliefs listened to, considered and respected by all

SCOTLAND SHOULD BE A PLACE WHERE:

- grief, bereavement and death are recognised as a natural part of life
- there is an open culture which is supportive of people having the opportunity to grieve
- accessing support (including emotional, practical, financial, social, and spiritual) is seen as a right
- efforts are made to ensure that adequate bereavement support is accessible for everyone
- people have space and time to grieve
- it is recognised that bereavement might affect all aspects of a person's life (e.g. relationships, school, workplace)

IN SCOTLAND, PEOPLE ARE SUPPORTIVE OF FRIENDS, FAMILY AND COMMUNITY MEMBERS WHO HAVE BEEN BEREAVED, WHICH MEANS THAT:

- people's needs and grief reactions are recognised and acknowledged as being different at different times
- grief and bereavement can begin before death and can be lifelong
- people who have been bereaved should feel supported to talk about the person who has died if they wish to
- bereavement and grieving can be experienced by the whole community and not just by individuals
- there is help to know where to refer or signpost people to for additional support

The Charter and additional information can be found at www.scottishcare.org/bereavement

This Charter was developed by a coalition of individuals and organisations including:





Dundee Palliative and End of Life Care Project

Dundee

Introduction

The symptoms of dementia for individuals as the condition progresses can be complex and often require skilled health and social care input. Despite this, people with dementia are less likely to receive palliative care than people with other conditions, such as cancer, and those who do receive palliative care tend to receive it much later. This can lead to poorer experiences and outcomes, such as stress and distress, poor pain management and unnecessary hospital admissions.

It has been recognised that people with dementia are often not identified as having palliative and end of life needs, and their care can be poorly coordinated.

What we do

The Dundee Project is one of a number of sites working with Healthcare Improvement Scotland's Improvement Hub¹³ (ihub) to support the implementation of The Scottish Government's Strategic Framework for Action on Palliative and End of Life Care, which states that everyone who needs palliative care will have access to it by 2021. Commitment 1 of the Framework is to focus and improve the earlier identification and coordination of care for those who have palliative care needs. Commitment 6 and 7 of the 3rd Dementia Strategy 2017-2020¹⁴ looked to test and evaluate Alzheimer Scotland's Advanced Care Dementia Palliative and End of Life Care Model¹⁵ and identify ways to make improvements in palliative and end of life care for people with dementia.

13 <https://ihub.scot/>

14 <https://www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020/>

15 https://www.alzscot.org/campaigning/advanced_dementia_model

Alzheimer Scotland's Advanced Dementia Practice Model provides a framework so that the care and support given to people with advanced dementia and at the end of life is integrated and comprehensive. It incorporates the 8 Pillars Model of Community Support¹⁶ and introduces an Advanced Dementia Specialist Team for optimum care.

The project in Dundee is looking specifically at the identification of palliative and end of life care needs and care coordination of people with dementia living in care homes. This involves supporting care homes to test a number of tools to help support the identification of palliative and end of life care needs and uses the Advanced Dementia Practice Model as a framework to coordinate people's care.

The Dundee site has been working with people to capture the experiences of individuals and unpaid carers. The project also engages with those who deliver and provide services to understand issues and challenges for those living and dying with dementia to inform how their local services can be improved.

The Project was completed in November 2019, and the resulting case study is available on the ihub website: <https://ihub.scot/media/7274/dundee-palliative-care-case-study.pdf>

What we are achieving for people with dementia and unpaid carers

The aim of this project is to improve the quality of care for people living and dying with dementia in care homes through:

- ▶ focus on a person-centred and flexible approach
- ▶ timely and skilled coordination of End of Life and Palliative Care
- ▶ best support – Advanced Dementia Practice Model and End of Life Care
- ▶ focus on carers and family
- ▶ working together to achieve outcomes that matter to the individual

¹⁶ https://www.alzscot.org/campaigning/eight_pillars_model_of_community_support



While this work relates to the ihub's Living Well in Communities¹⁷ and Focus on Dementia¹⁸ portfolios, it is also relevant to other groups, such as people with frailty and those living with multiple long-term conditions. It is also hoped that the project will impact on unplanned admissions to hospital, reduce delayed discharges and highlight the importance of conversations regarding wishes and preferred place of care.

If you want to know more, please contact:

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17 <https://ihub.scot/improvement-programmes/living-well-in-communities/>

18 <https://ihub.scot/improvement-programmes/focus-on-dementia/>

Further reading

- ▶ Communicating with people with dementia – Allan K & Killick J, (eds) Hughes J, Lloyd Williams M & Sachs G Supportive care for the person with dementia. (2010, Oxford University Press)
<https://bit.ly/2MGwJJH>
- ▶ Living Grief and Bereavement (2019, **tide** Carers Network)
<https://bit.ly/35M10yt>
- ▶ ‘Trees that bend in the wind: Exploring the experiences of front line support workers delivering palliative and end of life care’ (2017, Scottish Care)
<https://bit.ly/2t0RN6L>

Getting in touch

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

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