Dementia Friendly Communities in Scotland
Report 2 - The First Year
April 2015 - March 2016
“This is brilliant. What would I have been doing? Sat at home staring at the bloody walls. It’s given me a new lease of life.”
(Person with dementia)

“Older persons should remain integrated in society, participate actively in the formulation and implementation of policies that directly affect their well-being and share their knowledge and skills with younger generations.”
(UN Principles for Older Persons, Principle 7)

People with dementia have the right to help to attain and maintain maximum independence, physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.
(Charter of Rights for People with Dementia and their Carers in Scotland, Paragraph 9)

The Life Changes Trust was established by the Big Lottery Fund with a National Lottery grant of £50 million to drive transformational improvements in the quality of life, well-being, empowerment and inclusion of people affected by dementia and young people with experience of being in care.
In April 2015, the Life Changes Trust invested £3.4 million in fourteen dementia friendly communities across Scotland, over a period of three years. These communities are all very different. Some are geographical communities, that is, they relate to a specific location like West Dunbartonshire or Dumfries and Galloway. Others are communities of interest that bring people together because they are interested in similar activities, for example, sport, art or walking outdoors.

When deciding how to fund, the Trust felt it was important to look at ‘community’ from the perspective of people living with dementia and carers. People often describe the area in which they live as their community, but they also talk about the closer communities they belong to – the places where they go to do things that matter to them, such as the bowling club, the theatre or the allotment. Therefore, the Trust has taken a broad definition of ‘community’ when funding dementia friendly communities because we believe this better reflects the reality of people’s day-to-day lives.

Each community was chosen because it understood that people living with dementia and carers have to be central to the development and growth of a dementia friendly community. They need to have a significant say in how it is run, to the extent that they are able. Otherwise it is not their community. The people who lead these communities understand this and demonstrate it on a daily basis. They see the person more than they see the dementia.

Many of the communities funded by the Trust were chosen to be exemplars to others of how normal practice and activities can be adjusted so that people with dementia and carers are not excluded, but included. The communities are led by people who are strong-minded, determined and willing to learn. Since the funding began, the communities have met once every three months to share learning and network with each other. They have given and received an enormous amount of help and support from each other, and many new partnerships have been formed between the communities and with other organisations.
This second report has been compiled using evidence gathered from the first year’s monitoring and evaluation reports of the communities. It is not intended to give an in-depth account of all the activity the communities have undertaken or all of the wonderful things they have achieved, but to draw out learning and points of note. There are some particular quotes and case studies that give a glimpse into the ways in which people living with dementia and carers are involved in the communities, and how they are assisted by them.

The first report, that covered the communities’ first six months\(^1\), showed that it can take some time to really ‘get going’. The bigger the community, the longer it can take to establish work that makes a real impact. This does not mean that the bigger communities have less value, it just means that those who choose that approach need to be aware that, where there are multiple partners, decision making can be more complex and time consuming.

It will be very clear from this report that ‘small’ projects can have very wide impact as they grow and develop out into the community, and this can happen quickly. The growth in reach of some of these projects in the space of just one year has been tremendous. The leaders of these dementia friendly communities would say that being flexible and responsive to the needs and opinions of people living with dementia and carers has been challenging, motivating and necessary.

The observant reader will note that the title of this report has changed slightly from the title of the first report. It now reads “Dementia Friendly Communities in Scotland”. This is not because we don’t want to be associated with other similar communities across the globe, but because we believe that many of the communities developing in Scotland are qualitatively different from those following a more traditional Dementia Friendly Community model. This has been commented on by a number of people and organisations from the rest of the UK and other countries, who are noting the grassroots, community-led approach of the Trust-funded communities, as opposed to the top-down statutory-sector-led approach of many other DFCs.

Lastly, this report – and subsequent reports – will begin to highlight the role that dementia friendly communities have in making rights real for people living with dementia and for unpaid carers. In the past few months there has been increasing discussion about dementia and human rights. This was a key issue at the Dementia

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Scotland 2016 conference held in Edinburgh in September; the same was true at UK Dementia Congress in Brighton in early November, at which the DEEP network launched their booklet ‘Our Dementia, Our Rights’.2 At the recent 26th Alzheimer Europe Conference in Copenhagen Helen Rochford, Chair of the Irish Dementia Working Group, called for a European Dementia Strategy that is human rights based. In Appendix 1 of this report, links are provided to some key human rights conventions, charters and principles that are applicable to people living with dementia and carers.

We hope that you will enjoy reading this report and will find it both informative and inspirational.

Anna Buchanan

Director, People Affected by Dementia Programme

Life Changes Trust

Aberdeen FC Community Trust

This is a dementia friendly health and well-being community initiative which began in Aberdeen. Funding is being used to develop activities such as walking football, gym activities, health walks and park based activities in Aberdeen public spaces, to make them dementia friendly. The project promotes good health, inclusion and learning and raises awareness of dementia within the wider community, as well as providing respite opportunities for carers. The project has grown considerably in its first year and now operates in Aberdeenshire as well as in Aberdeen. It works in partnership with many other organisations, including Alzheimer Scotland (reminiscence sessions and Dementia Friends).

AFCCT’s dementia friendly community finished in the top four of the European Club Association Awards 2016, in the Best Community and Social Responsibility Programme Award Category. They also recently won the Committee of the Faculty of Public Health in Scotland Community Award for 2016 in recognition of outstanding initiatives delivered in relation to Public Health.

http://www.afcccommunitytrust.org/home.php
Arora bilingual dementia friendly community initiative
(Stornoway, Isle of Lewis)

@dfclanntair

A Gaelic and English languages project, run by the an Lanntair Arts Centre, Arora uses combined local knowledge, local language, and memory tools to support people affected by dementia in a culturally specific way.

This initiative looks at the role that bilingualism plays in the delayed onset of dementia and the benefits that an oral tradition can have in retaining good memory skills, providing a generational bridge and a sense of belonging.

The project takes arts into the community across the Western Isles and also works in care homes, day centres and hospitals. The an Lanntair Arts Centre is being made dementia friendly to create more accessible cinema, festival and exhibition experiences.

A number of people with dementia on the island have reverted to their first language of Gaelic, and so the project has created recordings of Hebridean life in both English and Gaelic (which helps preserve oral history and also aids reminiscence). They have produced podcasts to help staff learn Gaelic.

Arora won the Best Dementia Friendly Community Initiative category in the Scottish Dementia Awards 2016. They also gave a poster presentation at the recent Alzheimer Europe conference in Copenhagen.

https://dfclanntair.wordpress.com/
**Centrestage Communities and Music Theatre**

Centrestage Communities and Music Theatre is an arts organisation founded on the ethos that anyone – regardless of age, ability, background or experience – can gain life changing social benefits through active participation in the arts. The project, called ‘Gie it Laldy!’ aims to facilitate conversations and connections through musical themed memory activities, and people living with dementia, carers, family members and other participants come together for companionship, entertainment and community in a positive and supportive setting. Around 50 people with dementia attend 'Gie it Laldy' and a Skype link is used to stream weekly cabarets to residents in care homes who cannot attend in person. Centrestage has also tailored its productions for general audiences so they are dementia friendly, for example, Robert Burns cabaret, Little Women, A Night with Gilbert and Sullivan, and The Full Monty.

[http://www.centrestagecommunities.org.uk/gie-it-laldy](http://www.centrestagecommunities.org.uk/gie-it-laldy)
‘Creating Dementia Friendly Communities’
Dumfries and Galloway

This extensive dementia friendly community supports, empowers and involves people affected by dementia across Dumfries and Galloway so that, regardless of where they live, they feel valued and understood and are part of a supportive and enabling community.

The initiative is a result of a partnership involving NHS Dumfries and Galloway, Dumfries and Galloway Council, Alzheimer Scotland Action on Dementia, and User and Carer Involvement.

The community has a growing range of activities for people with dementia and for carers. It is also carrying out specific work with minority ethnic communities, adults with learning disabilities or brain injuries, people who are homeless and the LGBT community.

Work has started with schools, colleges and universities to reach people at the start of their careers and teach them about being dementia friendly, for example, students who will go into hospitality, catering or hair and beauty careers. The DFC has delivered multiple awareness raising sessions in shops, businesses, schools and public service organisations, such as Fire Scotland. They are also working with social housing landlords across Dumfries and Galloway.
Dementia friendly allotment group in Dumbarton

This is a dementia friendly allotment project which is run by people with dementia and carers and allows them to make use of the allotment and be outdoors. The project was set up by Alzheimer Scotland in partnership with local people with dementia and families.

The allotment is available for people with dementia and their carers either to work in the garden or just spend time there. It acts as a focal point and those who run it are ambassadors for learning about dementia. However, the work of the allotment is also more widespread with those who attend going out into the broader community to spread awareness about dementia. Similar projects in the area are learning how to be dementia friendly, for example, a larger community garden at a local park and local gardening groups.

At the request of people with dementia who attend the allotment, four tea dances have been held and a music group is being planned. A number of people who attend have formed the DAWDLE group (Dementia Awareness West Dunbartonshire Learning and Engagement), which is looking at ways of making Dumbarton even more dementia aware.
Dementia Friendly Communities Helmsdale CIC

Dementia Friendly Communities Helmsdale is a social enterprise which is committed to leading work that puts awareness and dementia friendly activity at the heart of remote rural communities. It works in partnership with businesses, service providers, voluntary groups, community organisations and individuals who share their ambition to create a dementia friendly community.

Funding is being used to increase local opportunities for people with dementia so that they can continue to enjoy their interests and hobbies, things that are meaningful to their lives, for as long as they wish to. It is also used to raise awareness and challenge the myths and stigma associated with dementia.

As well as providing regular activities during the week for people living with dementia and carers, the community provides specific services such as 'Dinner to Your Door' and 'Bridge Over Troubled Water', which offers flexible short/mid-term support to people with dementia and/or carers at a time of unexpected stress and transition. For example, carers can find themselves without support when a care package is pending but not yet in place, or when they fall just short of the strict criteria for receiving support from statutory services.

http://www.adementiafriendlycommunity.com/
Dementia Friendly Community, West Dunbartonshire

This is a dementia friendly community partnership project encompassing 22 separate neighbourhoods across West Dunbartonshire. They are showing local businesses, GP’s, health care professionals and service providers across the region how to become more dementia friendly.

They are also addressing the social needs of people with dementia and their carers to make sure their quality of life and activities are not reduced and they can continue to do the things that matter most to them.

Each member of the dementia friendly partnership has made a strategic pledge to become dementia friendly, and this has been endorsed by the local Community Planning Partnership. During the three years of funding, a model for training and awareness raising will be rolled out in the 22 neighbourhoods of West Dunbartonshire. The model will be used to equip organisations (statutory and private), individuals and businesses to become dementia friendly. At the end of Year 1, the work had been established in 6 areas and was being actively evaluated.

This project also promotes particular sessions on dementia and sight loss in partnership with the RNIB.

www.dementiawestdun.org
The ‘Heart for Art’ project, run by CrossReach (the Church of Scotland Social Care Council) is a creative arts community operating across Scotland. It offers opportunities for people living with dementia and their carers to learn new, or reawaken existing, artistic skills, build confidence, and develop social relationships through creative arts, as well as providing access to support and advice. The project challenges the stigma and discrimination associated with a diagnosis of dementia, by promoting positive images of people living with the condition. It also helps improve personal relationships, promote mental and creative stimulation and create a community where members can participate in something that is meaningful to them.

There are now Heart for Art groups in Glasgow, Stonehaven, Dundee, Edinburgh, Kirkcudbright, Garelochhead, Bankfoot and Musselburgh, with more planned in 2017. This arts community is exploring the use of new arts media, methods and materials with people with dementia (e.g. pottery). The artists’ work was shown at four exhibitions in 2015-16, including the Kirkcudbright Arts and Crafts Trail. The project is building a number of interesting partnerships with organisations such as the Queen Margaret University (receiving art students on placement) and local schools.

http://www.churchofscotland.org.uk/serve/the_guild/projects/current/heart_for_art
King’s and Festival Theatres, Edinburgh

Two of Edinburgh’s most famous theatres - the Festival and the King’s – are becoming dementia friendly venues. The theatres are ensuring that people with dementia and those who care for them can continue to be part of the theatre-going community, enjoy participating in the arts and mix with their peers. They are also acting as exemplars for other, similar venues.

In 2015-16 an audit of the Festival Theatre and Studio space was completed which resulted in a number of physical adaptations. The Festival Theatre café has been refurbished to be more dementia friendly and a new ‘venues group’ was established (mainly people living with dementia) so that other venues can be adapted. The next challenge will be auditing and adapting the King’s Theatre (opened in 1906).

The Theatres’ dementia friendly programmes have grown in number, shaped by the input of people with dementia and carers. 104 theatre staff have been given dementia awareness training and this is having a real impact.

The community was a finalist in the Best Dementia Friendly Community Initiative category of the Scottish Dementia Awards 2016 and also presented at the 26th Alzheimer Europe Conference in Copenhagen.

Kirrie Connections (Kirriemuir & Dean Area Partnership)

@kirrieconnect

This is a small rural, intergenerational dementia friendly initiative in Angus which aims to raise awareness, change attitudes and promote inclusion throughout the community. They are developing a dementia friendly garden close to the town centre, an information hub for support, information and advice, improving signage around the town centre and providing awareness raising sessions for schools, businesses and community groups.

The Kirrie Connections community hub is now open in the centre of Kirriemuir and is very easily accessed. As well as being a meeting place for people with dementia and carers, it is being used by a number of other organisations. A baseline attitudes to dementia survey was undertaken with the wider community and a number of dementia awareness sessions have been held with volunteers and schools, in partnership with Alzheimer Scotland.

They have almost finished the dementia friendly garden, which is usefully situated near a care home and sheltered housing.
Paths for All, the nationwide champion of walking for all in Scotland, is developing a dementia friendly walking community. Paths for All aims to create a happier, healthier Scotland where increased physical activity improves individual quality of life, health and well-being.

The funding is helping ensure that everyone affected by dementia also has the opportunity to take part, enjoy the benefits of walking, improve their health and well-being and be part of a larger community.

In 2015-16, Paths for All carried out wide ranging consultation in order to develop effective guidance and training for those who will lead dementia friendly walks across Scotland. They also awarded six grants to the first dementia friendly walking groups. As well as promoting walking for people with dementia, the groups are introducing other activities such as walking football, and strength and balance work. They are using photos taken on walks to create exhibitions.

This walking community has developed an accreditation process for Walking for Health projects to become dementia friendly. Two "1st Steps in Dementia" training courses were run, attended by 31 walk co-ordinators and a training course for dementia friendly walk leaders has been completed.

Sporting Memories Network
@SportsMemNet

This dementia friendly sports network promotes physical and mental wellbeing through activities at 55 groups across Scotland. It originally began with the intention of helping people with dementia reminisce and tell their own stories of watching or participating in sports, and provide opportunities to try out playing new sports. It has now grown and developed to include a much wider range of activities, informed by the aspirations of people living with dementia.

As well as meeting in public and sports venues, the groups also meet in care homes. The project has a strong intergenerational focus (see later in this report) and in 2015-16 around 70 young people were involved in helping to deliver Sporting Memories groups in Scotland.

The network holds regular awareness-raising events and is exploring what it could be doing to better support and include carers.

http://www.sportingmemoriesnetwork.com/d1079/scotland
Groups no longer receiving funding

Centrepiece, the small dementia friendly choir funded in East Lothian, is no longer receiving funding from the Life Changes Trust. The choir is still running very successfully but was able to fund its activities from its own funds, which meant they did not have to report on the use of funding as required by the Life Changes Trust Award.

Deaf Connections no longer receives funding but the Trust is investing in raising awareness about dementia in the Deaf Community in other ways, for example, through peer-to-peer resources that are under development.

Development funding

Two areas with real potential received a small sum of development funding to help them strengthen their approach towards becoming dementia friendly - Dementia Friendly East Lothian and Dementia Friendly Aberdeen. Further development funding for other areas is available through the Trust’s current open call for funding of a second phase of dementia friendly communities in Scotland.³

³  [http://www.lifechangestrust.org.uk/people-affected-by-dementia/funding-opportunities](http://www.lifechangestrust.org.uk/people-affected-by-dementia/funding-opportunities)
Background

In 2014, the Life Changes Trust made a commitment to funding the development of dementia friendly communities across Scotland. Dementia Friendly Communities, whether large or small, recognise and embrace the challenges that a life with dementia presents to people with dementia and their carers, enabling them to live life to its full potential.

Dementia friendly communities also help raise awareness about dementia and tackle myths and misunderstanding. They empower those whose lives are affected by dementia so that they can remain integrated in society, live as independently as possible and participate actively in decisions that affect their day-to-day lives. Through the funding awarded, the Trust aims to:

1. Improve the quality of life and well-being of those whose lives are affected by dementia (both people living with dementia and their carers).

2. Support more rapid and effective development of Dementia Friendly Community projects and practices across Scotland so that:
   - people will be aware of, and understand more about, dementia;
   - those whose lives are affected by dementia will seek the help and support they need; and
   - people affected by dementia feel included in their community and are enabled to be more independent and exercise more choice and control.

3. Share findings and learning from Dementia Friendly Communities funded by the Trust in order to improve dementia friendly practice across Scotland, and elsewhere.

4. Support the development of positive relationships, mentoring and learning between Dementia Friendly Communities in Scotland, and also between Dementia Friendly Communities and similar initiatives that support the empowerment of those affected by dementia.
The Trust was looking to fund projects that would contribute to the following outcomes for people living with dementia and carers:

- I have a significant say in how my dementia friendly community is run
- I know I have a community of support around me
- I am included
- I feel safe, listened to, valued and respected
- I am empowered to do the things that matter to me

Seventy-two applications were received and fourteen were chosen for funding. The decision-making process actively involved people living with dementia and carers – their input and insight was invaluable.

Each funded project agreed to self-evaluation and participation in the wider Community of Learning and Practice run by the Trust, meeting on a quarterly basis. This report is based on the findings of each project’s monitoring and self-evaluation reports during the first year.
Self-evaluation

Although many of the projects funded by the Trust will be externally evaluated, the Trust believes that self-evaluation of a project, from the very outset, is very important. Good self-evaluation requires dementia friendly communities to reflect on their activities, progress and outcomes for people living with dementia and carers. Doing this on a regular basis means that adjustments to ways of working can be made quickly and, if the project starts to lose its focus or purpose, this can be rectified before it is too serious.

The quarterly gatherings held by the Trust, which all the dementia friendly communities must attend, provide an opportunity for the communities to share learning and reflect on their own practice. A recent evaluation of these gatherings showed that the communities greatly value these gatherings and, if anything, want even more time to network and learn from each other.

Every dementia friendly community has a thorough evaluation plan which has been drawn up with support from the Social Value Lab[^4] and the Trust. They have been provided with tailored self-evaluation guidance and also have access to the Trust’s online evaluation toolkit.[^5]

Each community is required to submit a six-monthly monitoring and evaluation report to the Trust. This is to satisfy financial reporting requirements, but it is also to report on progress, learning and outcomes. Communities have been assured that these reports are not deposited in a dusty drawer and forgotten about, and this report is evidence that this does not happen!

Each community reports against the five outcomes for people living with dementia and carers, listed above. They also report on a range of statistics such as the number of people attending sessions, number of awareness raising events and the number of new partnerships formed. They provide qualitative evidence of how the organisation itself is growing and developing. These statistics are important because they provide some indication as to how likely it is that the work will be sustainable in the longer term. The Trust would want to take early action and, if appropriate, provide support if a project appears to be struggling. Evidence from people with dementia and carers is gathered by a variety of methods – feedback after the session (written or verbal), informal discussion groups, impromptu feedback recorded by either writing it down or using a phone to capture it in audio/video. Each community has its own way of hearing from its members and continues to review this.

Sometimes, pictures can tell a powerful story when an individual no longer can. Often, when a person has more advanced dementia, a carer will be able to judge whether or not the dementia friendly community is having a positive effect. Communities seek consent before personal information, such as photos or stories, are published.

The remainder of this report draws on the self-evaluation of the dementia friendly communities between April 2015 and March 2016.
### Overview of progress - From April 2015 – March 2016 (The First Year)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Number</th>
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<tbody>
<tr>
<td>992* people living with dementia were actively involved in Trust-funded dementia friendly communities</td>
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<tr>
<td>681 carers of people with dementia were actively involved in Trust-funded dementia friendly communities</td>
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<td>176 awareness-raising events were held by the communities</td>
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<tr>
<td>2,447 members of the public attended awareness-raising events</td>
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<td>505 workers or volunteers attended events to raise awareness</td>
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<td>158 new organisations pledged to become dementia friendly as a result of the communities’ work</td>
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<td>10 facilities were adapted to become dementia friendly</td>
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<td>1,078 reminiscence/memory sessions were delivered by 6 Communities</td>
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<td>152 new partnerships were developed</td>
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<tr>
<td>There were 113,617 media interactions, e.g. media releases, retweets, TV appearances</td>
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*There is a small drop in this figure since Report 1 because two DFCs are no longer operating.*
Learning for the dementia friendly communities

People with dementia and carers are essential in shaping the dementia friendly community

If people with dementia and carers are given a significant say, they will take the opportunity to express their thoughts and opinions. In order to do this in a respectful and non-pressured way, there needs to be sufficient time set aside to do so. Someone living with dementia may not always remember by the end of a session that they wanted to suggest something, so real-time feedback and conversations that spark the memory are important. People also need to be given the confidence that their suggested improvements or changes will be acted upon wherever possible.

Some of the communities have found that it is not always easy to obtain feedback, thoughts and opinions. People can be reluctant to say anything negative, and some are just so surprised to be asked that they don’t know what to say at first. Almost every community has found that time must be factored in or valuable input will be lost. In addition to time set aside for conversation, each community has found different ways to help people have a say.

Satisfaction conversations

This technique has been used by the Sporting Memories Network. The satisfaction conversations are predominantly carried out in pairs so as to be less daunting for the people involved. The conversations take place at the group but away from the main activity. This ensures that they are in context.

Questions are asked and then the ‘pairs’ talk about them. The advantage in this is that each person responds to the other and does not feel they are talking alone to a big group; it affords a sense of privacy.

Conversation also allows for deeper exploration of the answers rather than one or two sentence responses. The answers given during the conversations are recorded – this could be in writing or it could be using a voice recorder/phone.
Examples of questions:

- Why do you come here/to this group/this place?
- Would you change anything about this group/place?
- Do you have any advice for the workers here?
- Do you feel that coming here does you any good?
- What would you tell a friend about this group/place?

Helping to shape my community

It is clear from the evaluation reports submitted by the communities that those who attend the communities are helping shape them week after week. At the Dumbarton Allotment, people have a very significant say through the DAWDLE\(^6\) group, as one person has commented:

“Joining this group has given me so much confidence – I was very nervous at the beginning but everyone has been so friendly. I never knew I could stand up in front of a room and talk to people about dementia”.

The evaluation evidence submitted by the Dumbarton Allotment shows that those who attend the allotment are free to make suggestions that are acted upon. For example, one carer felt that people who visit the allotment may not always feel fully supported because regular members are also caught up in maintenance work. She suggested a dedicated maintenance day without visitors over the spring and summer to free up time for providing more support to particularly frail visitors, e.g. from care homes. Another person suggested a chalk board for people to write and draw on with waterproof chalk (it rains a lot on the west coast of Scotland!).

Discussion between some members of the Helmsdale community resulted in the revival of visits to the golf course. Two people with dementia had said that they didn’t think they could play anymore. The local golf club donated two sets of clubs and, accompanied by a supporter, people have begun playing golf again. This has developed into an intergenerational activity.

At Gie it Laldy, they ensure that every session allows sufficient time for conversation and not just activities like singing. The learning gathered from these conversations and interaction forms their plan for the next week’s sessions. This means that the sessions are responsive rather than prescriptive.

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\(^6\) Dementia Awareness West Dunbartonshire Learning and Engagement group
One person who attends one of the Heart for Art projects said:

“I wasn’t happy with the way my table was set up last week, but I felt comfortable to change it”.

This may seem a small thing but it meant a lot to this person that they could change things to suit - that the activity fits around them rather than vice versa. The Festival and King’s Theatres have been including people with dementia in the dementia audit of their buildings. One lady provided some helpful observations:

“The toilets are so dark I don’t want to lock the cubicle door, because I’m afraid I won’t be able to get out…improving lighting and putting on new door handles would be much better”.

During one of the theatre’s “It’s a Funny Old Story” sessions, one man pointed out that he would like to contribute:

“Where’s the donation box for teas? I’d have liked a second cup, but didn’t feel I should as I wanted to make a donation”.

The theatre now has a donation box for people who want to contribute, although second (and third) cups of tea are available to anyone who wants them.

Having a significant say also opens up the opportunity to be more involved in the community, as Aberdeen Football Club Community Trust reports:

“(He) stated previously that he would like to help more with sessions, so he helped with setting up the session today by carrying the kit bag and helping the coaches”.
Having a say in a larger community

Some of the larger Communities have had a daunting task on their hands to help people with dementia and carers have a significant say. Dumfries and Galloway covers an area of 6,426 km\(^2\). It is widespread and very rural in parts. They have divided the region between four DFC locality workers who have been going out to meet people with dementia and carers in order to understand what would make Dumfries and Galloway more dementia friendly. This work has been supported by work carried out by User and Carer Involvement, which has also focused on reaching minority ethnic communities.

As a national organisation which is implementing dementia friendly walking through a number of local projects, Paths for All wanted to hear from people living with dementia and carers about what they thought the benefits of a health walk might be. They also wanted to know whether the walks should be restricted to people with dementia or ‘mixed’, including people without dementia. They had many conversations with people with dementia and carers; they also spoke to walk leaders.

Those spoken to were very clear that there would be benefits to them: “blows away the cobwebs”, “gets fresh air in your lungs”, and weight loss. People spoke about making sure the walks were suitable for various fitness levels and that they could build confidence gradually in those who had lost confidence, e.g. because of a fall. There was a real focus on the sociable aspects of walking with others, especially if you have a dog with you.

There was considerable agreement that dementia friendly walking groups should ideally be mixed, i.e. that walks should not be exclusively for people with dementia and carers, but should involve people from the wider community, more generally.

“That’s a huge thing. I don’t think you should keep dementia in a group.”

“I think a mixed group is good. It’s a mixed society.”

As the communities continue to grow and develop over the next two years, we are interested to see how they adapt because people with dementia and carers are shaping them. The evidence to date shows that in order for people to have a significant say in how their community is run, they need to feel confident to speak up and confident they will be heard. For people with dementia, this also needs to be in the moment or at least in an environment that sparks the memory or re-creates past feelings that can be articulated.
The circle of support needs to be wide, and support needs to be timely

One of the primary purposes of a dementia friendly community is to ensure that people living with dementia and carers know where to turn for help; that they have a circle of support around them. Both National Dementia Strategies published by the Scottish Government to date have given a commitment to improving post-diagnostic support in the year after diagnosis. Both strategies placed great emphasis on the provision of information and training, and aim to support, enable and empower people with early dementia, and their carers. It is in this context that all of the dementia friendly communities operate.

The communities provide information and advice, but also refer to others who can provide further or specialist information and advice. A number of them, such as West Dunbartonshire, are providing training to professionals so that there is greater understanding of dementia in the wider community. In the first year of their existence, the communities have held 176 awareness raising events but awareness of dementia is raised in other ways as well.
The DFC in Helmsdale has held dementia awareness afternoons for staff at a local hotel and pupils and staff at the high school. They have spoken about their work at the local Highland Games, Community Council meetings and local third sector/charity events. Their work is publicised in a regular newspaper column. They have also produced publicity materials, such as a booklet setting out the challenges of establishing a rural dementia friendly community.

The communities have varied views on the benefits of asking organisations in their area to sign a pledge promising to become dementia friendly. Some see it as a definite statement of intent which is to be welcomed and then monitored. There are also differing opinions on whether or not ‘dementia friendly’ shops, cafes, etc, should display signs in the window and what those should look like. Should the signs be decided locally or should one national symbol be adopted? Most agree that they do not want the words ‘dementia’ or ‘Alzheimer’s’ on the sign – they would prefer it to be recognisable but subtle.

“We have been talking to agencies, organisations and businesses around the adoption of a certification scheme to show dementia friendly status. (There has been) a positive response to rolling out a model which involves training a Dementia Champion, providing awareness sessions for staff, displaying a window sticker/certificate to acknowledge the support offered... also ongoing participation in a process of mystery shopper type visits annually to ensure the organisation is living up to its pledge. We have worked through the PAS 1365 DFC standards and outlined a checklist for this process, which we will pilot in Year 2...”

The communities are committed to partnership working, as is evidenced by the fact that 152 new partnerships were formed in 2015/16. Some have reported that people who attend the DFC for the first time are pleased to learn that there is help they can access in the wider community and from specialist charities.

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7 See [https://adementiafriendlycommunity.com/our-publications/](https://adementiafriendlycommunity.com/our-publications/)

“Jim⁹ and his wife hadn’t been in contact with Alzheimer Scotland before the theatre tour...”

In Dumfries and Galloway, some people with dementia and carers who attend activities have shared for the first time the things that have caused them trouble and distress, for example, issues with the local bus company or a high street chemist who does not understand dementia.

Others are content with the help they have but are looking for friendship, relationship and meaningful activity. Carers greatly appreciate the respite that they receive when their relative or friend is attending an activity but they also benefit from peer support and enjoy having company and the chance to talk.

“I felt at ease for the whole time. It was much needed respite for me. I just love coming along and chatting, probably too much. My brother (living with dementia) always asks how my walk was and we now have something new to talk about. It does me the world of good.”

“It’s nice just to come and have dinner out together like we used to. Socialising, you know. We’re quite isolated really. I struggle to even do the shopping.”

“The walking group keeps you active and I have met interesting couples and exchanged views with them. I have learned from their experiences in caring for their partners and valuable information. This helps me cope and deal with situations that I will inevitably face in the near future.”

For some, knowing they have a community of support means emotional support. The Gie it Laldy project reports: “If someone misses a session we will call them to double check that everything is alright...if it is a wedding anniversary, we will have a card for them and play their first dance from their wedding. On the anniversary of her husband’s death we invited Elaine¹⁰ to stay behind...and (one of us) danced with her to their wedding song”.

“...the people here are great. Cannaе get better than that. We get to know the guys. If you see a guy and something is bothering him, loads of guys would help him.”

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⁹ Not real name
¹⁰ Not real name
Many of the communities offer practical support. In Helmsdale they offer ‘Bridge over Troubled Water’, a service designed to provide short/mid-term support direct to the person with dementia and/or provide respite to carers when no other help is available.

**Case study: Bridge Over Troubled Waters, Helmsdale**

A desperate call was received by the DFC office from a lady concerned about her father’s well-being since the passing of her mother. At the time, her father lived in London and her plan was to move her father to the Highlands. Her father had clearly not been well for some time, a fact which had been concealed from family members by her mother. His condition had worsened and become much more apparent as a result of his wife passing away. While clearly distressed by the loss of his wife, he was placed in care, where he was labelled as ‘violent’ by care staff. The dementia friendly community assisted his daughter by providing a listening ear and practical advice to help with the move from London to the Highlands.

This gentleman now needs a greater level of care. The move to the Highlands was a time of great upheaval for him, and for his daughter. DFC support workers provided immediate care, twice a day, until a support package could be put in place by social care. They have since continued to support both the gentleman and his daughter, in addition to the social care package currently provided. He was introduced to the Helmsdale Well-Being HUB, where he is now a regular member three times a week. The introduction to the HUB has made him feel welcome in the local community, keeps him physically, mentally and socially active, and provides his daughter with valuable respite during the week.

This gentleman is not violent; he is a man of 90+ who has benefited from caring and compassionate staff, who have taken the time, and used their vast experience to understand and address his specific needs. Now fully understood and listened to, he is fully integrated into his new environment and has responded well to the routine that the Well-Being HUB provides.
Training often needs to be bespoke

Almost all of the Communities have taken a while to establish exactly what kind of training is right for their project. Not everyone working in the DFC needs the same depth of training, but some need greater understanding than others. Some projects are quite specific and so specialist training is needed, which does not always exist.

Paths for All explored a range of options and training providers to deliver dementia training to their volunteer walk leaders. They weighed up the cost, content, relevance and delivery styles of a number of providers and chose the 1st Steps in Dementia Training provided by Later Life Training. After the delivery of the first two sessions, Paths for All evaluated the course using feedback from those who attended. They are now working with Later Life Training to develop a half day Dementia Friendly Walking Training package for volunteers in order to make walks more accessible to people living with dementia. The course will be delivered by Paths for All and will become one package in their suite of training programmes.

http://www.laterlifetraining.co.uk/courses/dementia-1st-steps/about-dementia-1st-steps/
Paths for All have also incorporated elements about dementia into their other training courses, for example, into their Safety Outdoors training course and general Walk Leader training. Information about dementia and the benefits of walking for people who live with the condition are included in the walk leader manual, which every newly trained walk leader receives.

“When we were initially planning the project we had planned to use Dementia Friends sessions as the training for our volunteers. However...we realised that the volunteers would need training about what they practically need to consider...and while simply being more aware is a positive change, there is greater depth of understanding required...our volunteers do not need to be experts in dementia, however they do need to know how to support someone with dementia in a walking group.”

Centrestage Communities DFC had a bespoke training package designed for them based on the Promoting Excellence in Dementia Care training programme. This was initially for all key staff involved in the project but is now being adapted and extended to junior leaders and schools volunteers to ensure that even the youngest has a good understanding of what dementia is and the importance and privilege of care-giving.

West Dunbartonshire DFC has held a number of awareness raising sessions as well as providing more in-depth training, based on Promoting Excellence, to specific community partners, for example, the Fire and Police Services. They have recognised the need for the general training to be adjusted to the audience receiving it, for example, by eliminating NHS jargon and making it more relevant to the trainee’s day to day working environment.

Work with hospitals and NHS staff is developing, but it is not always easy to get a route in

A good number of the communities are working in hospitals or with hospital staff. This is largely a result of them making themselves known to hospitals or meeting NHS staff at awareness raising or training events, but also because others are letting hospitals know about the work that is taking place. Some of this awareness has been difficult to achieve, not necessarily because of an unwillingness to engage but because the processes that have to be gone through to obtain access to hospitals are very lengthy. Some hospital policies seem designed to keep people out and appear to be very risk averse. GPs have been hard to engage with and the idea of ‘social prescribing’ seems foreign to many.

Delayed discharge from hospital, for whatever reason, means that there are people who have recovered but who are sitting staring at the four walls of the ward for weeks and even months. One DFC reports that staff freely admit that they see cognitive function declining the longer someone with dementia is in hospital. Those who have gained access to hospitals have been warmly welcomed back and many new activities have been provided to people with dementia who are in hospital. An Lanntair’s DFC offered Memory Café pop-up sessions which met NHS requirements. This was done by partnering with Alzheimer Scotland through a service level agreement approach.

“I took some activities from an Lanntair’s programme to a hospital ward so that people could enjoy the Herring Girls exhibition by Katie Scarlett Howard. One lady remembered the Herring Girls and told me all about the rags around their fingers. Another modelled a Herring Girl out of art grade plasticine with me, while we talked about the playful nature of Katie’s sculptures, the big lips and thick legs.”

In Dumbarton, people with dementia and carers from the DAWDLE Group have delivered awareness sessions to hospital staff, and in Helmsdale the DFC has been liaising with a nearby hospital so that long-term inpatients with sufficient mobility can come to activities at the DFC’s Hub. Patients enjoy having a change of environment and meeting new people.

The Festival and King’s Theatres run a storytelling project called “It’s a Funny Old Story”. This is run at the Scottish Storytelling Centre and features the “Festival Theatre spinning some tales, reading some poetry and even adding in some songs as well”. Another organisation, Artlink14 heard about the storytelling project and introduced it to the dementia wards at an Edinburgh hospital. All four wards are now part of the project, which is being expanded. This kind of activity is crucial to maintaining a sense of identity and connectedness, as another community reports:

“In the hospital people were unable to gather and chat, which was very much needed for social interaction…such a simple thing to gather people for a cup of tea and a chat but so very important. People chat with each other so eagerly, each wanting to know where the other is from, their family name and chatting about shared friends, neighbours and relatives. One lady and gentleman grew up together and sit next to each other every time, leaning towards each other to hear properly, talking animatedly about their week and their family news and so grateful for the opportunity.”

Stigma, stereotyping and low expectations still exist

A few of the Communities reported that stigma and stereotyping have posed challenges. These stereotypes are not just dementia-related but often older-person-related.

“Working in rural Aberdeenshire has proved to be different compared to the city, with far more people concerned about the stigma of dementia and less willing to engage - those with dementia as well as older adults without dementia. This has been the biggest barrier to attracting more people, but by using our own social media channels and working with the local press we are constantly challenging people’s perceptions and showing that people can live well with dementia.”

One of the Communities has noticed a marked change in the language used about dementia on their social media platforms. There are now fewer negative comments about dementia and more comments that recognise that people can be supported to live well with dementia. Heart for Art observed, when holding awareness-raising events, that many people express surprise when they learn that dementia is not a natural part of the ageing process.

14 http://www.artlinkedinburgh.co.uk/
The community in Dumfries and Galloway has been doing work with some minority ethnic groups and have found a very significant level of stigma around dementia. This seems to be the result of lack of knowledge and an ability to accept the condition. The community will be carrying out work to address this.

In one or two communities, staff have overheard people talking about a leaflet they have just picked up which advertises some of the community’s activities: “You wouldn’t be able to do that, Dad”; “Someone with dementia couldn’t do that… my mum could barely lift a tea cup when she had dementia”. There is then the opportunity to gently address some of these misconceptions.

One project reports that they are constantly asked how they are dealing with the risks, challenges and potential problems with running a dementia friendly community. They explain very clearly that all sessions are risk-assessed but that they do not operate on a risk-averse basis.

Some of the projects that conduct activities outdoors have noted that carers worry when their relative is outdoors and prefer structured activities that are indoors. There is also an expectation that walks will start and finish promptly. This is not an unreasonable expectation but one walk leader has pointed out that for the walk to really be dementia friendly there has to be a little leeway with the time. Someone may be having a difficult day and walking more slowly than usual; sometimes routes have to be changed if a path looks dangerous, which might extend the length of the walk slightly. Walks are checked beforehand, but an unexpected and heavy shower of rain can have an effect.

Aberdeen Football Club Community Trust gave these examples:

“A gentleman attended an Aberdeen FC game as a guest in a box. His wife told us that he probably wouldn’t manage the full first half, but he stayed from 1pm until full-time, which was incredible.”

“He was told by his carer that he wouldn’t manage walking football, but he had played earlier in a football memories session. The carer couldn’t believe it.”

Clearly this does not mean that the advice of carers should be ignored or disbelieved – far from it – but it does mean that sometimes aspirations for people living with dementia should be higher.
Some care homes need to raise their aspirations for people living with dementia

Several of the Communities have reported that they have had the opportunity to challenge the assumptions of care home staff about the abilities and aspirations of care home residents. This ranges from demonstrating that individuals can safely leave the care home to attend an activity and also return safely, to showing that people can still talk, sing or dance and enjoy creative activities. There are a number of care homes that still will not open their doors to the dementia friendly community but, in others, once the barriers are broken the door remains wide open.

“When we first visited…the paid carers wouldn’t join in with singing, dancing and were generally very detached…now (they) are just a proactive as we are. We have witnessed paid carers going from not singing or participating to dancing around the room with (residents)...The staff have commented that the feeling within the care home is more positive since we started attending weekly. They note the difference in each individual and as the project progresses the partnership is only growing stronger.”

Communities have reported that this kind of activity breaks down barriers to conversation and has extended conversation beyond the usual care-oriented conversations.

Aberdeen Football Club Community Trust has been asked by residents to provide sessions in care homes, and has also brought a number of care home residents to events at Pittodrie Stadium, such as the Golden Games festival15 held in June 2016.

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15 [http://www.sportaberdeen.co.uk/activities/be-active/active-ageing/golden-games/](http://www.sportaberdeen.co.uk/activities/be-active/active-ageing/golden-games/)
One community reports:

“With restrictions on staff numbers and the tendency to take the path of least resistance and least risk, many care homes do not offer very much in the way of outings and visits. With support from (our) project...people become used to going out, the risks seem to diminish and care teams are more open to the idea. One gentleman visited a café and was able to use his good hand to press down the cafetiere plunger with great relish, explaining that he really appreciated good coffee”.

“Older persons should be able to pursue opportunities for the full development of their potential.”

UN Principles for Older Persons, Principle 15

Housing partners are important when developing a dementia friendly community

The Life Changes Trust has funded two projects related to housing. The first is being undertaken in partnership with numerous housing partners and the University of the West of Scotland. It seeks to draw together a wide range of information and resources on housing and dementia across Scotland and will culminate in a Housing and Dementia Conference in Perth on 15 May 2017 (sign up for the Life Changes Trust ebulletin via www.lifechangestrust.org.uk for updates).

The second project is the Dementia Enablement Pilot Project which involves Care and Repair in early intervention in the home for people with dementia. This project is running in Aberdeen, Angus and Skye/Lochaber/Kyle of Lochalsh until 2019 and it is expected that there will be a wide range of learning for the entire Care and Repair network as well as local authorities and Integration Joint Boards.

Many of the communities have become involved with this work in different ways, primarily by contributing learning that they have gained in their own geographical areas. The community in Dumfries and Galloway is holding a number of awareness raising sessions for social landlords and staff working in sheltered housing.
Sporting Memories has set up a new group in a sheltered housing complex in Midlothian and is working with seven housing association groups in Glasgow. A number of people living with dementia and carers who are involved with the Helmsdale DFC have been working with a social housing provider by co-designing sixteen assisted-living units, ensuring they are suitable for someone living with dementia.

**Older persons should be able to live in environments that are safe and adaptable to personal preferences and changing capacities.”**

**UN Principles for Older Persons, Principle 5**

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**Dementia friendly communities are intergenerational**

Almost all of the Communities have an intergenerational aspect to the work they do, particularly linking young people and older people. There is a considerable amount of volunteering by younger people in their teens and early twenties, as well as strong links between schools and a number of the communities.

A large number of school pupils help out, particularly with sporting activities like football or golf. Sporting Memories has linked with Street League\(^{16}\) so that walking football can be facilitated by young unemployed men. They have produced a video that shows how this operates\(^ {17}\) and are currently building a separate evaluation framework around all their intergenerational work with people with dementia. Aberdeen Football Club Community Trust has begun work with young carers, some of whom care for a person living with dementia. This is work they would like to build on.

Not all the young people who volunteer are confident in doing so, but they quickly learn how to engage with people who have dementia.

*“We have witnessed...incredibly vulnerable and disadvantaged young people show patience, empathy and understanding...They no longer see ‘a grumpy old man’ or a nameless ‘old woman’...they see real people with real stories...a history, but also a present and a future.”* 

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\(^{16}\) [http://www.streetleague.co.uk/](http://www.streetleague.co.uk/)

\(^{17}\) See [https://vimeo.com/182835766](https://vimeo.com/182835766)
In Dumbarton there was a wonderful example of generations sharing an experience of the dementia friendly allotment. Local school children came to the allotment to plant onions along with residents of the local care home.

“These school teacher was the daughter of one of the care home residents... The allotment provided the opportunity for the teacher to introduce her dad (living with dementia) to her pupils, and the opportunity for a man living in a care home (her dad) to see his daughter at work as a teacher. For the children, it was a moment that hopefully gave them an insight into dementia which could not be taught in a classroom.”

**Partnership working is the key to sharing learning and growing a movement for change**

At the end of their first year, the communities had formed 152 new partnerships (in addition to those they had formed in order to become a dementia friendly community). Some of these partnerships are with each other, for example, Paths for All has worked with a number of the other communities. Others are with dementia-related organisations such as Alzheimer Scotland, or Age Scotland’s Early Stage Dementia Team.

Overall, the partnerships are wide ranging – with local authorities, health boards, sports clubs, day centres, museums, cafes and local businesses. In some areas there are good working relationships with the health and social care partnerships. Links are being made with older people’s groups who have not previously explored why people leave their groups if they are diagnosed with dementia.

In one area, a productive relationship has been built with the Community Payback Team which offers offenders the chance to make amends for their offences by doing unpaid work to benefit communities. Paths for All have recognised a need for befrienders for some of the people who attend their walks, therefore they are linking with existing befriending projects and networks to develop these relationships.

Very importantly, the communities are building partnerships with those who want to learn about the work they are doing. These partnerships are not just in Scotland but also further afield, for example, in Wales. The Life Changes Trust has recently opened up a second phase of open call funding for Dementia Friendly Communities and it is clear that learning from the first phase of Communities is being built into the thinking of those applying in the second.
Working in rural areas has unique challenges

Three of the key issues that have come up in relation to rurality have been isolation, communication and transport. The response from the communities has been twofold: first, to find ways of transporting people to events/activities/services; second, to find ways of bringing the events/activities/services to people. Heart for Art meets in a number of rural areas and reports:

“Each group has a named co-ordinator so participants will know who will be there each week. In some areas this has been a little bit challenging so we are looking to recruit part-time creative arts co-ordinators in the more rural areas”.

Communication with remotely-located staff can also be a challenge and the use of good quality phones and tablets that get good reception is a ‘must’. Skype is a huge benefit if there is good internet access.

The very rural community in Helmsdale has been making use of 65” interactive Smart screens since September 2015. The screen is used by both staff in conjunction with people with dementia, and people with dementia on their own. It is user friendly, and complements other IT activities that use smaller tablet devices. Using the large screen has helped some people develop enough confidence to try using a tablet - often very successfully.

This increased exposure to IT has increased people’s capability to investigate topics of personal interest as well as helping them connect with family and friends over Skype, and ordering and shopping online. There are now five Smart screens in use, which are installed in community halls, a care home and a hospital. Future plans include networking the screens so that activities such as Chair Based Exercise and Tai Chi can be coordinated and transmitted from one location for participation by all.

The screens have been used for cognitive games. This has proved beneficial as a tool to measure the change in members’ capabilities. They have also been used for tutorials on art and exploring the technique of other artists. This has inspired people to go and try out tips and ideas at home.
Access to YouTube through the large screen has been useful and the community uses it regularly to find footage of local villages and countryside. This starts up conversation and reminiscing. Vintage comedies can also be found on YouTube and one 93 year old member requested a few of his favourites.

The screens also provide an efficient way of gathering feedback on things that matter to people with dementia, without having to travel far to a meeting. For example, feedback was provided to NHS Highland on its webpage on Falls Prevention. By using the Smart screen to view the webpage, feedback was given that the webpage was not user friendly, which was helpful information since NHS Highland had considered it to be so.

A large number of the Communities have engaged with the dementia and transport work being carried out by Upstream\(^\text{18}\), funded by the Life Changes Trust. Upstream is holding a ‘Travelling Well with Dementia’ Conference at the Festival Theatre in Edinburgh on 7 December 2016. Upstream has been exploring a number of the challenges around transport and rurality with people who live with dementia in rural areas, as well as in cities. We look forward to the findings of their work and then exploring what further work needs to be done. The Upstream blog makes very interesting reading: \[\text{http://www.upstream.scot/blog/}\].

\[\text{“To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures...shall include the identification and elimination of obstacles and barriers to accessibility...”}\]

\[\text{UN Convention on the Rights of People with Disabilities, Article 9}\]
Communities need to be flexible to support people at varying stages of dementia

A question which a few of the Communities have been asked is, “What will you do once people can no longer come to your community?” Whilst this is a valid question, it shows a misunderstanding of the communities and their ability to grow with people with dementia and meet new needs. It also overlooks the varied relevance of the communities. For example, a person who can no longer play walking football can still be part of a reminiscence session or general time spent together. Many of those who attend Sporting Memories groups refer to them as their ‘club’; for some, the club has replaced the pub. A person who has attended a supported art session in Stornoway, held by an Lanntair, may, if they have to go into hospital, find that an Lanntair is on the hospital ward providing activities.

Dementia is a progressive condition and this will always be a challenge for the communities; there will come a time when people can no longer participate, but this should not come sooner than is necessary and is not a reason to put limits on what people with dementia can do.

Some carers who have lost relatives or friends find that remaining involved in the dementia friendly community can help them with their grief. As the communities enter their second year of funding, many of the them are turning their attention more closely to the needs of carers. From the feedback provided to communities to date, carers may not be looking for activities or even new friendships – although peer support relationships do appear to develop very quickly when carers have the opportunity to meet.

“Carers can be difficult to engage with as they often leave to do other tasks such as shopping, resting and housework...ensuring they feel supported can be difficult.”

There is a sense from carers that they feel a measure of support through the respite they receive, but a number of the communities want to do a lot more to help carers.

“We made attempts to set up specific carer activities (fitness and pampering sessions)...but they were reluctant to commit to regular activities and preferred to use the opportunity for respite. We will be continuing to talk with carers and investigate other opportunities to offer (support).”
For some people there may come a time when a particular dementia friendly activity is no longer suitable. The dementia friendly community itself may have to make the decision that the activity is no longer meeting a person’s needs.

“...as local professionals increasingly recognise the value (of the DFC), they refer more people to us. Sometimes the advanced nature of the person’s dementia and the wish of the carer to have respite time poses a risk by putting an undue degree of responsibility on our volunteers.”

Risk assessment is a day-to-day activity of all the communities and they carefully consider how risk can be reduced, doing all they can to keep people involved. Volunteers are crucial to providing extra capacity, which is sometimes what is needed to keep people involved.

One of the key themes that emerges from all of the communities is that they promote the “can do” rather than the “can’t do”. As Paula from Heart for Art says on the film the Trust had produced for its Community and Dementia conference¹⁹, “We focus more on the person than on the dementia”.

**Good volunteers are worth their weight in gold**

Most community projects - not just dementia friendly communities - struggle to recruit and retain volunteers on a long term basis. Some of the communities find they have a steady flow of short-term volunteers who complement their ‘core’ volunteers who are involved on a longer term basis. Others have struggled to recruit; one reason given is uncertainty about what working with someone with dementia might involve, another is the belief that only ‘experts’ can work with people with dementia.

Training is the key to success where there are willing volunteers, particularly practical training that is relevant to the volunteer’s specific context. As stated earlier in this report, the evidence shows that Dementia Friends is a good introduction to dementia, but more in-depth, bespoke training is needed for those working in a dementia friendly community context so that they feel confident and empowered.

¹⁹ 21 September 2016 [https://www.youtube.com/watch?v=zrvRBYEJYfM](https://www.youtube.com/watch?v=zrvRBYEJYfM)
Volunteers also need clarity about their role and the level of commitment expected of them. Job descriptions and ongoing training and development opportunities for volunteers are as important as for paid members of staff.

**It is not always easy to build links with Dementia Link Workers and Dementia Ambassadors**

One common theme raised by several of the communities was the difficulty of building relationships with the Dementia Link Workers in their area. The Scottish Government has guaranteed a year’s post-diagnostic support for everyone diagnosed with dementia from April 2013. In many areas this is provided by Dementia Link Workers on behalf of the NHS. In other areas post-diagnostic support is provided by NHS staff.

A number of the communities have tried to seek out link workers but found that contact lists were out of date and, if they did manage to make contact, emails were not responded to and phone calls were not returned. Some communities have said that they believe the link workers are so busy with work that they do not have time to engage. A number fulfil the link worker role in conjunction with another role.

There are also two communities who were relying on Dementia Ambassadors to assist with awareness raising and training, but a good number of Ambassadors have had to withdraw their initial support due to other work pressures.
Next Steps

This current cohort of dementia friendly communities is funded by the Life Changes Trust until March 2018. The Trust will continue to report every six months on their progress and learning. This is so that others who want to carry out similar work can learn from them and with them - in Scotland and in other countries. There are many organisations from across the world who have said that they are following the communities’ development with real interest.

Each community will also produce its own evaluation report, which will explore their particular project in more depth, and this will be published towards the end of the funding period. The Trust will be discussing with communities their plans for long term sustainability and we imagine that they will take varying routes to achieve that sustainability.

As mentioned earlier in the report, the Trust currently has an open funding call for a second cohort of dementia friendly communities, which are likely to begin their journey together in the summer of 2017. This allows a period of time when the first and second cohorts will overlap and we expect that a number of mentoring relationships will develop between the existing projects and new ones. For more information about the funding, see the Life Changes Trust website: www.lifechangestrust.org.uk.

It is important to remember that the communities are one element (albeit it a crucial one) of the work funded by the Trust in Scotland in order to achieve transformational and sustainable change for people whose lives are affected by dementia. They do not work in isolation but are part of a bigger picture and wider partnerships.

The third report from the dementia friendly communities will be published in Spring 2017.
Appendix 1

Some useful Human Rights documents

United Nations Convention on the Rights of Persons with Disabilities


The Convention on the Rights of Persons with Disabilities (CRPD) sets out what human rights mean in the context of disability. The first human rights treaty of the twenty-first century, it represents a major step towards realising the right of disabled people to be treated as full and equal citizens.

The Convention states ‘persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’. There can be little doubt that persons with dementia are included in this definition and have always been potential beneficiaries of the Convention.

By ratifying the Convention in 2009, the UK committed to promoting and protecting the full enjoyment of human rights by disabled people and ensuring they have full equality under the law. The Convention covers a wide range of areas including:

- health
- education
- employment
- access to justice
- personal security
- independent living, and
- access to information.
The Convention is not directly enforceable in any UK court, but it does constitute a binding obligation in International Law. This means that the UK has pledged to make sure its domestic laws and policies comply with it. The Equality and Human Rights Commission, Parliament and civil society can hold the Government accountable against the terms of the Convention.

The UK has to report on how it is implementing the Convention. The next year in which the UK will be examined against the Convention will be 2017. The previous report on the UK related to the 2014 examination and dementia was not mentioned once.

**United Nations Principles for Older Persons**

These Principles do not carry the same weight as a Convention, though there is a growing movement to have them turned into a Convention with accompanying reporting requirements.

They can be found here: [http://www.ohchr.org/EN/ProfessionalInterest/Pages/OlderPersons.aspx](http://www.ohchr.org/EN/ProfessionalInterest/Pages/OlderPersons.aspx)

They are very relevant to the work of dementia friendly communities and talk about independence, participation, care, self-fulfilment and dignity.

In 2014, the Welsh Government made the decision to embed these Principles in its new Social Services and Wellbeing (Wales) Act, requiring all public bodies to have regard to them.

**Human Rights Act 1998**


Note that this Act does apply to Scotland. The Human Rights Act 1998 came into force in October 2000. It enables individuals to enforce 16 of the fundamental rights and freedoms contained in the [European Convention on Human Rights](https://en.wikipedia.org/wiki/European_Convention_on_Human_Rights) (ECHR) in British courts. This makes Parliament and public bodies more accountable to citizens through the courts. There are fundamental rights that impact directly on service provision in the health and social care sector, others support family life and the right to privacy.
Rights particularly relevant to people living with dementia include the right to life (Article 2), the right not to be subjected to inhuman or degrading treatment (Article 3) and the right to a family life (Article 8). A balance has to be reached between rights and responsibilities. Not all rights are absolute and frequently decisions have to made about how to balance competing rights.

Section 6 of the Human Rights Act 1998 is particularly important because it places a duty on public bodies to avoid acting in a way that is incompatible with the rights contained in the European Convention on Human Rights. If a public body does act in a way that is incompatible, it may find itself subject to judicial review.

**Equality Act 2010**


Note that this Act does apply in Scotland. The Equality Act protects people from being treated unfairly because of any characteristics that are protected under the legislation. The ‘protected characteristics’ are:

- age
- disability
- gender reassignment
- pregnancy and maternity
- race – this includes ethnic or national origins, colour or nationality
- religion or belief – this includes lack of belief
- sex
- sexual orientation.

The Equality Act 2010 defines a disability as a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities. This clearly covers most forms of dementia.

Direct discrimination occurs when someone is treated less favourably than someone else in similar circumstances on the grounds of a protected characteristic. Indirect discrimination occurs when a condition or requirement is applied equally to everyone but some are unable to comply because of a protected characteristic. This would be unlawful unless the condition or requirement is objectively justifiable.
The Equality Act 2010 places an Equality Duty on public bodies; it came into force on 5 April 2011. The Equality Duty intends to ensure that public bodies are proactive in eliminating unlawful discrimination, advancing equality of opportunity and fostering good relations. They must consider equality issues in everything they do with regard to the protected characteristics.

The Equality Act applies to all those providing goods, services and facilities in Scotland, England and Wales. An individual claiming discrimination can go to court and the judge would decide whether discrimination has occurred. The Equality and Human Rights Commission has some enforcement powers in certain situations under the Equality Act because it is a non-departmental public body which oversees equality and human rights law and practice. It has the ability to investigate public bodies and go to judicial review if necessary. There are strict time limits on bringing discrimination cases to court.

Charter of Rights for People with Dementia and their Carers, Scotland

See: http://www.dementiarights.org/charter-of-rights/

This Charter aims to empower people with dementia, those who support them and the community as a whole, to ensure their rights are recognised and respected. It is not enforceable and public bodies in Scotland are currently not required to report against it.

However, it sets a standard for the rights of people with dementia and carers in Scotland and is guided by a human-rights-based approach (known as the “PANEL” approach, endorsed by the United Nations).

It emphasises the rights of everyone to:

- Participate in decisions which affect their human rights.
- Accountability of those responsible for the respect, protection and fulfilment of human rights.
- Non-discrimination and equality.
- Empowerment to know their rights and how to claim them.
- Legality in all decisions through an explicit link with human rights legal standards in all processes and outcome measurements.
Getting in touch

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

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