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Stories from the Dementia Friendly Communities Evaluation

Evaluating the Impact of Life Changes Trust Funded
Dementia Friendly Communities in Scotland



‘The evidence outlined in this independent evaluation report demonstrates that although Scottish Dementia Friendly Communities are about enabling people, they are about more than removing barriers: they are about building bridges. Reducing isolation and loneliness is one aspect of the work of dementia friendly communities, but the foundation of their work is building strong, lasting relationships and making rights real for people with dementia and their families. It is our hope that this report will shape thinking on dementia friendly communities for a Fourth National Dementia Strategy and, most importantly, local dementia strategies.’

Anna Buchanan, CEO
Life Changes Trust

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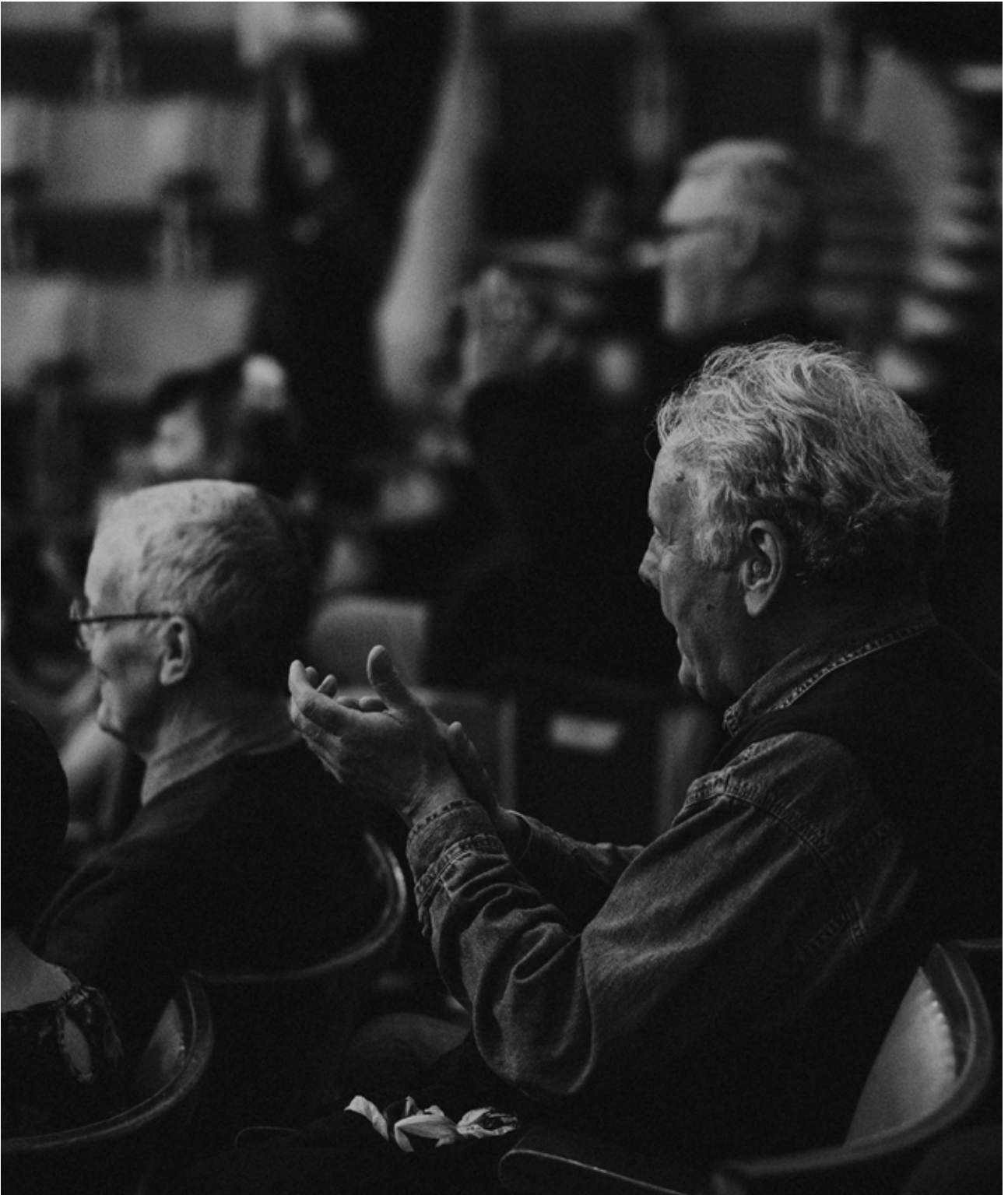
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Dementia Friendly Communities

About this report

This report is an abridged version of the Evaluation of Life Changes Trust Funded Dementia Friendly Communities in Scotland report. For more details on our methodology and data sets please see Christie, J., Yates-Bolton, N. and Thompson-Bradley, O. (2021) *Dementia Friendly Communities: Evaluating the Impact of Life Changes Trust Funded Dementia Friendly Communities in Scotland*. The Dementia Centre, HammondCare.

For the full SROI study, including justification of stakeholder inclusion/exclusion, financial proxies, sensitivity calculations and value maps, see Thompson-Bradley, O. and Christie, J. (2021) *Evaluating the Impact of Life Changes Trust Funded Dementia Friendly Communities in Scotland: Social Return on Investment Studies*. The Dementia Centre, HammondCare.



The joy of cinema, Movie Memories at Glasgow Film Theatre

Introduction

This report sets out the work of HammondCare's evaluation of the Life Changes Trust funded dementia friendly communities (DFCs). The Life Changes Trust (the Trust) was established in 2013 to support young people with care experience, people living with dementia and unpaid carers of people living with dementia. The Trust's mission is to drive transformational and sustainable improvements in the quality of life, wellbeing, empowerment, and social inclusion of its beneficiaries. A person-centred approach and the ability to live well with dementia are two central tenets of the Trust's approach, with a focus on the importance of the community to enable and empower people with dementia. Since April 2015, 40 DFCs have been funded across Scotland. This two-year independent evaluation began in June 2019. It explored:

1. The extent to which DFCs are creating better lives for people with dementia;
2. The extent to which DFCs are creating better lives for unpaid carers of people with dementia;
3. What has not worked and why?;
4. The benefits and challenges of a community development approach;
5. The extent to which DFCs can provide short, medium, and long-term post-diagnostic support for people with dementia and unpaid carers;
6. Whether these communities are able to complement and, importantly, inform national and local dementia strategies and action plans;
7. The extent to which the communities work in partnership and any significant benefits this partnership brings;
8. Any barriers and challenges that the communities have faced and how they, where possible, overcame them; and
9. The likelihood that these communities will be sustained in the long term.

Context

What is a dementia friendly community?

Many and varied DFCs have been funded by the Trust. The Trust recognises the role that these communities can play in meeting their priorities of promoting the independence of the person with dementia and creating a culture where people with dementia are valued, respected, and empowered to continue to do the things that are important to them. There are no fixed definitions of what constitutes a DFC. However, there are general common goals to support people with dementia to continue to be active and engaged community members, while increasing public understanding and awareness.

The Trust emphasises the importance of a community only being described as dementia friendly if it is identified as such by people living with dementia. The communities funded by the Trust place the person with dementia at the centre of the community. DFCs should have a focus on developing relationships, fostering inclusion and empowerment to enable the person with dementia and unpaid carers to be actively engaged with the community. Therefore, this is not limited to geographic communities, but also includes communities of interest, as this often draws people together and generates relationships that extend beyond physical location.

Why are dementia friendly communities needed?

There are approximately 90,000 people living with dementia in Scotland with the number expected to rise to 110,000 by 2030.¹

Scotland's National Dementia Strategies in 2010 and 2013 focused on timely diagnosis, better care and treatment, improving post-diagnostic support and strengthening integrated and person-centred support. In 2013, the Scottish Government made a commitment that by 2015/16, all people newly diagnosed with dementia would have a minimum of one year of post-diagnostic support coordinated by a Link Worker, including the building of a person-centred support plan. The most recent post-diagnostic figures, based on Local Delivery Plan (LDP) Standards, show that in 2018/19 around 6,000 people newly diagnosed with dementia received formal post-diagnostic support via a Link Worker and around 12,500 people did not.²

Alongside this formal policy-led offer of support are many other forms of support, such as DFCs.³ This community-led support is not counted in government data and not currently recognised by the Scottish Government as post-diagnostic support. This has led to debate about the need to broaden the definition of post-diagnostic support in Scotland to reflect the true extent, across the country, of the excellent support provided to people with dementia and their families after a diagnosis.

Scotland's Third Dementia Strategy (2017-2020) had a commitment to DFCs but this focused on promoting and supporting increased participation in befriending. Befriending is not the same as a DFC though it may be an element of support provided by communities.

¹ <https://www.dementiastatistics.org/statistics/prevalence-projections-in-the-uk/>

² In 2018/19 approximately 18,500 people in Scotland were diagnosed with dementia. 8,021 were referred for post-diagnostic support and, of those referred, approx. 6,000 (75.1%) received some form of post-diagnostic support. See <https://www.gov.scot/publications/nhsscotland-performance-against-ldp-standards/pages/dementia-post-diagnostic-support/>

³ <https://www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020/>

Why are dementia friendly communities needed?

Since April 2015, individual communities have completed six-monthly self-evaluations, and these have formed the basis of the annual DFCs summary reports produced by the Trust. These self-evaluations represent an extension of the grassroots approach of the communities whose members have been active participants in the planning and implementation of each project. In addition, the Trust has identified nine key principles which contribute to the success of the community (Fig. 1).

And now, 11 years on since the first Scottish Dementia Strategy in 2010, we have the challenges of COVID-19. A policy response to the pandemic has led to a new Dementia and COVID-19 Action Plan and a Fourth Dementia Strategy has currently been put on hold. The Action Plan was issued in December 2020 and explicitly mentions 'dementia-enabled communities' in Commitment 11:

Working with local health and social care partnerships and the third sector, community groups and businesses we will support and enhance local dementia-enabled communities and reduce social isolation and loneliness, as part of our shared action to strengthen and recover resilience in our communities.⁴

⁴ <https://www.gov.scot/publications/dementia-covid-19-national-action-plan-continue-support-recovery-people-dementia-carers/>


Life Changes Trust principles

Figure 1. Life Changes Trust key principles for dementia friendly communities



The expected benefits

All the funded DFCs must work to achieve five key outcomes for people with dementia and unpaid carers.




I have a significant say in how my dementia friendly community is run




I am empowered to do the things that matter to me



I am included



I know I have a community of support around me



I feel safe, listen to, valued and respected

Funding and impact at a glance

In 2015, Phase 1 DFC funding was launched with the aim of funding a wide variety of geographical dementia friendly communities and communities of interest, both large and small. Then, in 2018, building on learning from Phase 1 DFC funding, specific Development Funding was launched to support those who were already in the early stages of starting a community that is dementia friendly.

Total funding from the Trust 2015 – 2021:

£8,684,491

Total funding from other sources 2015 – 2021:

£3,010,758

This includes match-funding secured, plus, in-kind costs, at the time of application. It also includes funding to DFCs provided by the William Grant Foundation. It does not, however, include funding secured by the projects after the grant had ended.

Number of people with dementia reached:

12,374

Number of unpaid carers reached to date:

4,471

Average cost per head per year:

£694.29

This illustrates:

1. Projects ARE capable of securing match-funding even during economic stress and a competitive funding environment.
2. The important role played by the National Lottery Community Fund (NLCF), Robertson Trust and William Grant Foundation in particular.
3. The value of the investment with regard to the cost per head.

Source: The Life Changes Trust

⁵ Match funding came from NLCF, Robertson Trust, William Grant Foundation, Spirit of 2012.

The communities

DFCs are places where people with dementia and unpaid carers are included, empowered, and supported in every aspect of life, from accessing services to using public transport. Some DFCs are geographical communities related to a specific location. Others are communities of interest that bring people together because they are interested in similar activities, for example sports, art, walking outdoors, or dancing. DFCs also help to empower people whose lives are affected by dementia so that they can remain an active part of society, live as independently as possible and participate in decisions that affect their day-to-day lives. Appendix 1 details the Trust funded DFCs.

The communities



The communities

1. Aberdeen FC Community Trust
2. Alzheimer Scotland Dumfries & Galloway
3. An Lanntair
4. An Talla Solais
5. Badenoch Shinty Memories Group
6. British Deaf Association
7. Capital Theatres
8. Centrestage Communities – Gie it laldy
9. CrossReach Heart for Art
10. Dementia Friendly Aberdeen
11. Dementia Friendly Banchory
12. Dementia Friendly East Lothian
13. Dementia Friendly Highlands
14. Newmains Community Development Trust
15. Dementia Friendly Pentlands
16. West Dunbartonshire Council for Voluntary Services
17. Dementia Friendly Uists
18. DFC Helmsdale
19. Dementia Orkney
20. Dumbarton Dementia Café and Allotment Group
21. Dunblane Development Trust
22. Edinburgh Leisure
23. Glasgow Film Theatre
24. Glasgow Life
25. Glasgow's Golden Generation
26. Golf in Society
27. Queen's House, Kelso
28. Kinnections, University of the West of Scotland
29. Kirrie Connections
30. North Berwick Choir
31. Our Connected Neighbourhoods Stirling and Forth Valley
32. Partnerships for Wellbeing
33. Paths for All
34. Regional Screen Scotland
35. Scottish Ballet
36. Shopper Aide Ltd
37. Sporting Memories
38. St Andrew's Church, Carluke
39. Table Tennis Scotland
40. V&A Dundee

A note on diversity

The Trust encouraged applications from a wide range of organisations and interests across Scotland. They did not impose a template of a DFC but instead invited communities to create their own vision, stating what the problems were that they were trying to resolve, or what solutions they had which they could grow. Then, to focus on how these solutions could meet the needs of people living with dementia, and unpaid carers in specific communities. How would they do this in an organised, meaningful, and impactful way, and how could you recognise or evidence this? As a result, the DFCs vary in size, structure, membership, and focus. For example, the geographical DFCs range in the size and makeup of the areas covered, the type of setting that services are delivered in e.g., rural, urban, island communities, and sometimes a mix of these; and the types of activities they provide to meet the varied populations there.

What works in one geographical area did not then necessarily work in another. We will discuss this in more detail later in the report. The communities of interest are vastly different including sports, culture, wellbeing, and combinations of these. Communities of interest also evolve and branch into aspects of heritage, which can be geographically relevant, and intergenerational work, and so they grow and reach into other areas of life. In addition, geographical DFCs, and communities of interest can crossover in their descriptions and service development offerings. This diversity and freedom to create can be seen throughout this report as we discuss DFCs. We also look at this in detail within the added value section of the report.

Communities in focus

Two dementia friendly communities are included here to illustrate the different types of projects funded by the Trust: Dunblane Development Trust, which is a geographical community, and Scottish Ballet, which is a community of interest.

Dunblane Development Trust builds on the work undertaken by Dementia Friendly Dunblane, a collaboration of local organisations. The success of the collaboration led to them seeking funding and support to continue to meet the needs of the local community.

Scottish Ballet is a renowned national organisation which was able to transfer its approach to supporting dance and movement with people living with neurological conditions into opportunities for people living with dementia, to also participate in dance and movement activities.

Dunblane Development Trust

The Dunblane Development Trust developed from Dementia Friendly Dunblane. This collaboration is an informal working partnership including Dunblane Health Centre, all Dunblane churches, Dunblane High School, Dunblane Youth and Sports Centre, Stirling Carers Centre, Discover Dunblane Business Improvement District, Alzheimer Scotland, Randolph Hill Care Home and Dunblane Community Council.

The Dunblane Development Trust was awarded development funding (2018-19) by the Trust. This funding has been used to employ a project coordinator and administrative support staff. A phased approach began by focusing on initiatives already launched through Dementia Friendly Dunblane before introducing new initiatives. The Dunblane Development Trust has focused on:

- Identifying opportunities and developing relationships with local individuals, groups, voluntary and commercial organisations encouraging them to 'sign up' to the DFC.
- Coordinating the involvement of people living with dementia and their family or carers in the development of new initiatives.
- Supporting the development of the Braeport Memory Café.
- Enhancing existing links with residents of the local private residential home; and
- Providing opportunities for volunteers to learn from local expertise, and opportunities for residents with dementia to join in community activities, e.g., meeting old friends at the memory café, attending the lunch club at the Dunblane Centre, playing indoor bowls, or attending church.

Scottish Ballet

Scottish Ballet received funding for a three-year (2017-2020) programme of dementia friendly dance activities, called 'Time to Dance'. Building on a community of interest based on dance and friendship, Scottish Ballet hosts free weekly drop-in classes for people living with dementia, carers, family members, friends, and dance professionals. Classes are intergenerational and, as well as being a place to come to dance, have fun, and socialise, Time to Dance participants can learn about Scottish Ballet's repertoire and attend theatre events. All Scottish Ballet's education and outreach work is linked to its repertoire. This is because feedback from previous projects highlighted that people feel more connected to Scottish Ballet as a whole, through these wider activities.

Time to Dance connects to Scottish cities that Scottish Ballet regularly tours to, or has a connection with, such as Glasgow, Edinburgh, Dundee, Aberdeen, and Inverness. Through a national programme of dementia friendly activity, the programme aims to unite, strengthen, and support an assortment of dance for dementia offerings into one national network of dementia friendly dance in Scotland.

As well as supporting paid and unpaid carers in class and afterwards at home, or in their care homes, Time to Dance supports a Scotland-wide network of dance education professionals by:

- Sharing the Time to Dance model and resources.
- Offering dementia friendly dance events in local areas that are connected to Scottish Ballet tours.
- Having a presence at creative festivals, such as Luminare; and
- Providing regional training opportunities for dance education professionals and partners such as Dance Base, Shaper Caper, Citymoves plus the unpaid and paid carers they work with.

Linking to Scottish Ballet tours provides people affected by dementia with an opportunity to participate in a dance class, watch a Scottish Ballet performance (or rehearsal) and engage with dancers and costumes.

Scottish Ballet



Time to Dance, Scottish Ballet

The Dementia Friendly Communities Model

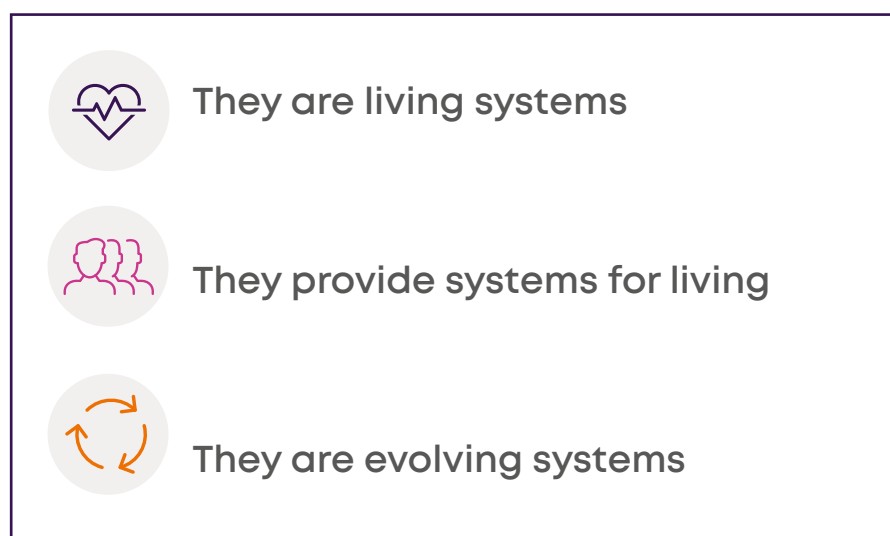
The evaluation of the Trust funded DFCs has drawn together a huge amount of information, stories and experiences. Our analysis revealed complex, interwoven themes and concepts. In order that this learning can be understood and used practically, for impactful, and sustainable DFCs moving forward, we developed a conceptual model which we have called the **Dementia Friendly Communities Model** (see Figure 2).

The DFCs in this study can be visualised as ecosystems. Ecosystems describe people, places and things that interact and have defined, recognisable boundaries. The **dementia friendly ecosystem** is built around geographical places, and domestic and shared spaces. These systems have a range of stakeholders, namely people living with dementia, unpaid carers, community groups, paid carers, statutory services and practitioners, local businesses and services, policy makers etc. These stakeholders can be active or passive and are not limited to any one group or role and include people living with dementia and unpaid carers. The stakeholders experience bonding around shared principles, values and objectives which are then strengthened through personal, neighbourhood, and community connections, practical and emotional support, and positive experiences. They reach out to new stakeholders, creating bridges with others to grow, to learn and to share. The dementia friendly ecosystem is, therefore, a complex, vibrant space, built on relationships and filled with potential, functioning as both a nurturing and an influencing body.

The Dementia Friendly Communities Model

Sustainability

To be sustainable, DFCs must be resilient in the face of practical, financial, and political challenges. Social capital is essential for resilience and refers to the presence and quality of relationships, connections, and networks.⁶ There are two types of social capital referred to here: bonding and bridging. Bonding social capital is the sense of connection we share with the people that we know. This is built around our similarities and acts of reciprocity which affirm these similarities. Bridging social capital describes support which makes it easier to access information and resources outside of the person's usual network, community, or communities. This can be described as asset-building and can be thought of as growing resilience. Linking social capital, which we referred to earlier in the report (page), is an element of bridging capital, specifically describing the relationships with people and organisations in power. The successful DFCs in this study appear to have three ecosystem elements which can foster social capital. These are:



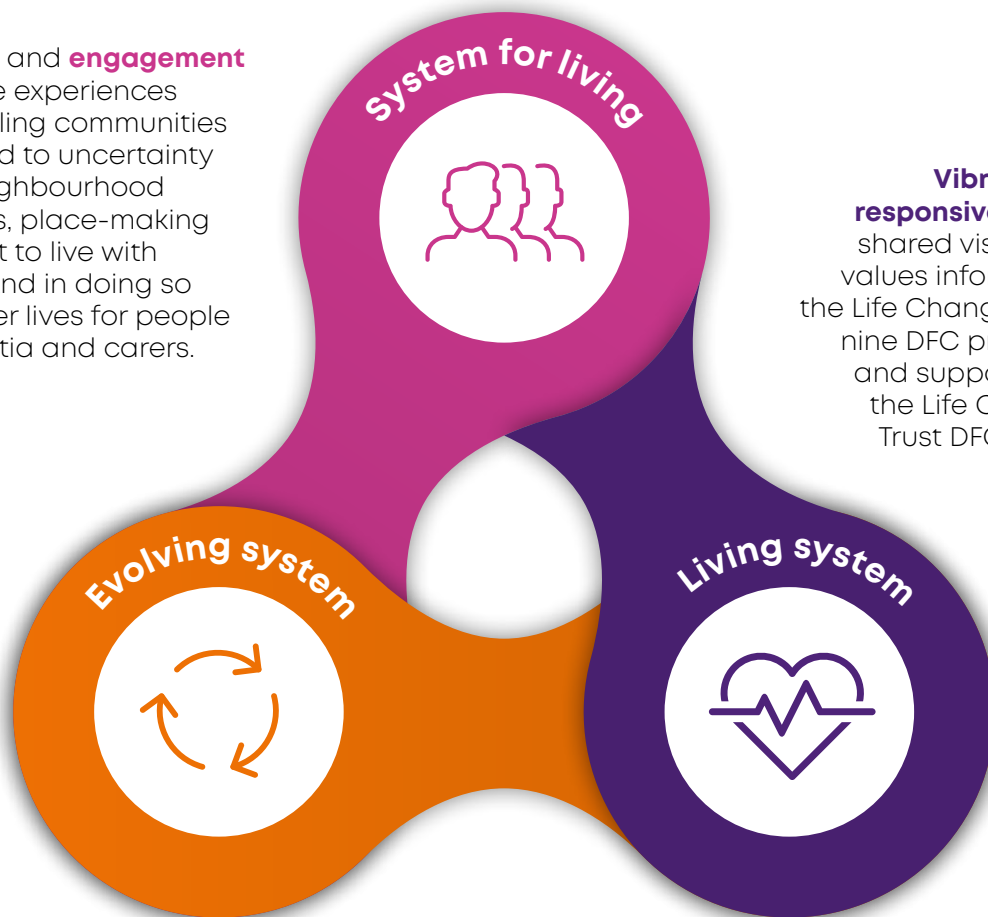
⁶ Putnam, R.D., 2000. *Bowling alone: The collapse and revival of American community*. Simon & Schuster, New York.

The Dementia Friendly Communities Model

All three system elements, a living system, a system for living, and an evolving system must be present in a sustainable DFC, and the quality of each can act as a relative indicator of sustainability and success in the longer term. This is important if stakeholders are to have trust in the permanency of the DFC.

Connection and **engagement** and positive experiences within enabling communities that respond to uncertainty through neighbourhood connections, place-making and support to live with dementia. And in doing so create better lives for people with dementia and carers.

Vibrant and **responsive**, with a shared vision and values informed by the Life Changes Trust nine DFC principles and supported by the Life Changes Trust DFC toolkit.



Create, grow and mobilise assets, and manage change for growth (resilience). Successful DFCs expect to face challenges and they build trust and confidence in their ability to respond over time. DFCs are cooperative and learning communities. They offer a point of continuity through the experience of change.

Figure 2. Dementia Friendly Communities Model

The stories

Better lives for people with dementia and carers

DFCs create better lives for people with dementia and unpaid carers. Participants spoke about the positive impact of being a member of a DFC on their identity, and the quantity and quality of their relationships within the DFC. Being part of a DFC led to a sense of living a better life, with potential. The brightness of people's accounts of their involvement with the DFC contrasts markedly with the 'dark places' some community members described having experienced psychologically prior to being involved.

The key themes highlighted are:

- **Living again – life again means everything.** This statement sums up the impact of DFCs on the lives of people with dementia who were part of the communities.
- **Fulfilling my potential.** This was a clear statement that emphasised that people were not just receiving support. People living with dementia and unpaid carers stressed the potential 'to be' and the opportunities that the DFC presented to be proactive in their lives, as opposed to being passive.
- **I have choices – my life and my choices are valued (and valid).** Exercising autonomy and proactive engagement in their daily life.
- **Meaningful relationships.** Relationships which feel different. .

The stories



Paths for All

The stories

The conversation below provides an insight into how DFCs contribute to better lives for people with dementia and unpaid carers. Both Carol, who has dementia, and her husband Malcolm describe how they benefit from being part of a DFC.

A conversation with Carol and Malcolm

Malcolm: My name's Malcolm. I'm a full-time carer for my wife Carol who has got young onset dementia and we attend St Andrew's drop-in café twice a month.

Carol: I'm Carol

What do you think people with dementia would say is the most important thing about a dementia friendly community?

Carol: You feel safe. Because you've got Honor and her team are looking after us and we can tell Honor and her team everything and they'll listen to you. You feel like a part of a... I don't know, a family. And that's the first thing I felt when I walked into the hall, I felt safe, and I could just be me.

Malcolm: I know because I see the reaction on Carol; we get up and the timetable is

The stories

up above the calendar in the hall and it says 'Drop-in' day today, her whole face lights up because she knows what we're going to and actually really looks forward to it.

And it's opened new avenues as well for her. Just this year she's met the Queen. She's been on the radio. She's been interviewed for Glasgow Live. And this has all come from the Drop-in centre.

So, Carol, why did your face light up when you realise it's Drop-in day?

Carol: Oh, I just absolutely love it. I'm always first in the hall and I'm usually last to leave it. And it's so hard to explain. We do fun things. You never feel stupid. It takes me a while to make decisions about things, so even tea or coffee, and she'll say, 'I'll come back to you' and I'm like 'Aye, right'. And even wee stupid things like that, but it makes me not flustered and it gives me time to think about what I'm going to do. And the children come,

and they sing to us and oh, it's amazing.

And my life has totally changed for... I've started coming in December and I was so nervous about going, but now I'm... like I say I'm the first in the door and oh we do lot of different things. And I'm going to be doing art and I'm being asked to be the ambassador for Playlist for Life. And like Malcolm said, I met the Queen. Oh my God, that was so exciting. I can remember telling her she was so very beautiful. I told her about the Drop-in, and I told her about Playlist for Life.

But honest to God it [DFC] has totally changed my life and you don't feel stupid. You don't... it's hard to explain. When you have had a hard day or you need a cuddle, you can get a cuddle.

Malcolm: At our Drop-in, the second in the month, which is the last Friday of the month, is when the professionals come in; they'd sit and talk to you.

The stories

You have people coming from other organisations and they will introduce what they do. We've had the local leisure people; we've had Scottish Power. And all these different people coming in and it makes it a lot more interesting for the person with dementia.

What about the mental health aspect of being a carer?

Malcolm: Yes, absolutely. It takes everything away from you. I have acquaintances that I see on a regular basis when I'm walking the dog. I have no friends in the village. My circle of friends are all at the Drop-in and they may not be the carers. It may be the person with dementia. And I've got three or four that I've got really close to, and we have a ball. We really do.

I lost contact with nearly all my friends, you don't have time to see them, but I've got a new group. I've got a new group of people who I look forward to seeing [at the DFC]. There are other carers out there who

must feel the same and who need these groups.

Carol: That's when you get the cuddles. That is when they do the cuddles.

Carol: When I was diagnosed with dementia I was like, oh my God, I'm dying. That's your first initial thought and it's so terrifying. It's really, really scary. And I was like, I didn't want to cook. I didn't want to see people. I was making silly mistakes. I was doing all these things and I was more and more and more not wanting to go anywhere or do anything, because I just felt so stupid. And this is what St Andrew's has done for me. I go and I'm out enjoying myself and I'm involved in everything, and I can talk to anybody at St Andrews and well, I call Helen superwoman.

But I really that's how I feel, as if I'm living and not just vegetating. **I'm actually living.**

Post-diagnostic support, influencing and decision making

In Scotland, which has published three national dementia strategies (in 2010, 2013, 2017), everyone newly diagnosed with dementia can expect to receive appropriate support following diagnosis. Post-diagnostic support (PDS) is a Scottish Government guarantee to anyone receiving a diagnosis of dementia. The experience and availability of support is based on the 5 and 8 Pillars Models and varies across Scotland. This support, in the main, is coordinated by a health or social care professional and, initially, support may be provided with reference to the 5 Pillars Model of Post-Diagnostic Support. This model, developed by Alzheimer Scotland, focuses support on the immediate impact of a diagnosis. So, help to understand the illness and manage symptoms, and think about planning for the future, but also to stay connected and make the most of peer support. A named person is available to the person and their carer for a minimum of one year following diagnosis with the aim of building a person-centred plan. The 5 Pillars Model is represented in the image below.



The 5 Pillars Model of Post-Diagnostic Support © Alzheimer Scotland 2011

Post-diagnostic support, influencing and decision making

Following the period of post-diagnostic support, 'care coordination' can be available to support the person with dementia and their carer to live with dementia as it progresses. The aim of this work is to build resilience through attending to the symptoms of dementia, and its effects. This support is focused on an 8 Pillars Model of Integrated Community Support where a 'Dementia Practice Coordinator' can be appointed to coordinate areas like general and mental health care and treatment, carer support, environmental factors and community support and connections. This model is represented in the image below.



The 8 Pillars Model of Integrated Community Support © Alzheimer Scotland 2015

Post-diagnostic support, influencing and decision making

There are two important strands to post-diagnostic support (PDS), the first is the experience of receiving support. This covers issues of availability, accessibility, suitability, and impact. The second is the ability to influence the PDS agenda and to shape it.

DFCs undoubtedly provide PDS for people living with dementia and unpaid carers across the 5 Pillars Model of peer support, community connections, understanding the illness and managing symptoms, and planning for future decision making and care. This happens in a way that is dynamic and highly personal. Post-diagnostic support is not prescriptive or fixed; it is organic, gained through connection, engagement, and everyday experiences. People living with dementia and unpaid carers are not passive recipients of support in a traditional patient/practitioner relationship – they are valued members of an evolving community, highly involved, contributing solutions and shaping support, and often providing support to others. DFCs also work across several strands of the 8 Pillars Model, primarily supporting community connections, personalised support, support for carers, and contributing to an enabling local environment. Some communities also deliver support within the strands of health care and treatment and therapeutic interventions, to deliver cognitive stimulation and mental wellbeing interventions.

We also found evidence of engagement in decision-making, awareness raising, and relationship building and political influence at a local and national level.

Post-diagnostic support, influencing and decision making

Breda's Story: Influencing policy and decision making

DFCs were able to use their connections and networks to interact with and influence political decision makers at national and local levels. Breda, the coordinator of the Dunblane Development Trust, a role that was funded by the Trust, explains how they influenced political decision makers. We introduced the Dunblane Development Trust on page 18.

Breda describes key activities of awareness raising, and local and national influence.

Awareness raising

We presented to 100 senior managers of Stirling Council at their 'Big Huddle' event. Colin shared his lived experience of dementia and how supporting the Dunblane Development Trust has given him a new purpose in life. The feedback we received was that **'his words and approach are inspirational.'** We are a member of Stirling Dementia

Post-diagnostic support, influencing and decision making

Friendly Multi-Agency steering group and have contributed to the development of their action plan. We participate in the subgroup looking at People and Places, this forum allows for our influence on local plans and strategies to better meet the needs and aspirations of people living with dementia and unpaid carers. We always demonstrate we work on a partnership basis, as we work with other dementia friendly communities; we share and learn a lot. Networking is essential to get to know other people working towards becoming a dementia friendly community.

Local

We have influenced the local health and social care strategy. We attended a presentation event of the Patient and Public Forum of NHS Forth Valley where the CEO of our NHS Board outlined the draft Health

& Social Care Integration Strategic Commissioning Plan. Dementia was not included in that version of the plan. We contributed to a discussion about this with the CEO and subsequently dementia and mental health appeared on the plan. We also attended the budget consultation at council chambers and a consultation event to feed into the NHS Forth Valley Strategic plan. The CEO invited us to give a presentation to NHS Forth Valley Board on our journey towards creating a dementia friendly community. Following this the CEO attended the Braeport Memory Café and said that it was the best afternoon at work she had in a long time. She now wishes to attend a Dunblane Development Trust steering group meeting. Dunblane and the dementia friendly community is now specifically referenced in the NHS Forth Valley Strategic Plan as an example of a successful

Post-diagnostic support, influencing and decision making

DFC. The CEO of the Health and Social Care Partnership also attended the café, and she was very supportive of the social model of post-diagnostic support we offer. Local councillors of all parties have attended the Braeport Memory Café, communicating and networking with them has been very beneficial. Two councillors from Stirling Council attended with a view of supporting the establishment of 'Tea's Company' in Bridge of Allan. We have successfully mentored and supported the leaders of this initiative.

National

Two of our DFC members (a person with dementia and a carer) and I attended Scottish Parliament as guests of TIDE (Together in Dementia Everyday) to learn how parliament works and how to influence our MSPs; that was a fabulous training event. We learnt a lot there. I think we need to influence dementia strategy very, very strongly and give policy makers the real lived experience of individuals with dementia and their unpaid carers. Our local MSP attended the Braeport Memory Café on several occasions and interacted with attendees. He subsequently gave a speech in the House of Commons on volunteering and the Braeport Memory Café (see HANSARD 13/02/2019).

The influence and impact of the communication and engagement of DFCs at a wider societal level illustrates how meaningful engagement with decision makers was also a significant achievement for staff, volunteers, and community members.

Challenges and overcoming

This section focuses on the hurdles and challenges faced by DFCs. We discuss the issues raised and the ways in which these were addressed and resolved, or not, highlighting the use of community assets and resourcefulness. We also reflect on experiences of the pandemic. A range of challenges were experienced and, in most cases, overcome by DFCs. These ranged from external factors such as the weather impacting on activities, practical issues of transport or premises, to relationships and issues of funding and sustainability. Some challenges were expected, and others were unexpected. How the DFCs anticipated, planned for, and responded to challenges was a key factor in the ability to overcome or to try something new. We have created a word cloud of the issues raised by DFCs as they explored challenges.



CrossReach Heart for Art DFC funding began in 2015 and provides creative art sessions for people with dementia across Scotland. Heart for Art seeks to bring creativity and connection to people affected by dementia. Free, community-based art classes cater to individuals, providing choice and support. The programme focuses on the creative skills that each person brings.

In other circumstances, Heart for Art would have created a bespoke exhibition of art created by the artists of the programme but the pandemic meant that creative solutions were needed. Heart for Art has adapted to offer free one-to-one online art sessions with a professional art tutor. For those preferring to work offline, art packs were provided by post.

In May 2021, Heart for Art launched a new online art gallery showcasing the work produced by the artists through these virtual sessions and art packs. Created using a variety of mediums and featuring a wide range of styles and subject matter, each piece is a testimony to the extraordinarily creative abilities of the artists.



'Sunset'
John MacIntosh, Carlisle
Acrylic on canvas

Throughout his life John's main hobby has been sport particularly football which he played professionally with Hearts for 6 years. Painting was a whole new activity for John and he took a big interest in the impact the colour had as the painting progressed. Acrylic medium was completely new to John, but he is very proud of the end process.



'Spring tulips'
Carol Topper, Carluke
Acrylic on canvas

Carol joined Heart for Art with no previous art experience after being recently diagnosed with dementia. Since then Carol has discovered a talent she never knew she had and continues to develop her skills at every class. Carol has a wonderful vibrant personality which is visible in this painting produced with acrylic on canvas. Gaining a sense of achievement and joy with every painting produced Carol loves to engage with our sessions and looks forward every week to producing something new for her family.



'The Glen'
Ken Grey, Bankfoot
Acrylic on canvas

Ken enjoys landscape painting and particularly Scottish landscapes. Ken's painting of "The Glen" was produced during lockdown with the support of our art packs and his daughter Diane

"We're so grateful to you for sending the art pack. I have spent many a happy hour with him painting and making lovely memories"

Diane Clow, Ken's Daughter

Challenges and overcoming

Kirrie Connections: Responding to the challenges of COVID-19

The challenges of the COVID-19 pandemic have been responded to by many DFCs by readjusting to a new way of connecting with people, connecting in new ways and traditional ways such as personal letters and newsletters. Where DFCs have been able to continue to provide support and connect with people with dementia and unpaid carers, the impact has been described as a lifeline.

Eight weeks into the first lockdown one of the leads for a DFC shared how they were responding to the challenge of the COVID-19 pandemic.



Kirrie Connections community members

Challenges and overcoming

Readjusting to the new way of connecting with people

'We are still trying to push on as much as we can. Increasingly, what we're finding in lockdown, in the feedback that we're getting from our members, is just how much it meant to people coming in every day. We are busier than we've ever been since lockdown. We're engaged on all sorts of different levels with everybody. We're still in contact with all of the members. Unfortunately, some of them really are struggling just now. It is an incredibly difficult time just now for people who are struggling to understand what's happening. We took probably two weeks after lockdown to really think about what support we could offer and what support the members needed. One of the first things we did was an audit of technology of who had either computers or tablets or smart phones and were able to use them. We phoned everyone up and spoke to them about whether they needed support with shopping or a trip to the chemist. Over the past couple of months there's been a huge amount of work and it's just really been in the past couple of weeks we've found our groove for what seems to be working.'

Connecting in new ways

'It's getting back to that person-centred approach again. We're not doing the same thing with any two people. We've got a whole suite of different things that we're doing ranging from just simply phoning people up and speaking to them, whether that's the person with dementia or family carers. Some people with dementia really struggle on the phone but family carers generally appreciate it. We're using Zoom in a wide variety of ways. We're doing group Zoom sessions; however, one of the things we found is that some people find them really, really confusing; but if you do a one-to-one with them, actually they can handle that really well because [it's] one face they're looking at, they can really manage that.'

Challenges and overcoming

Written communication

'We are also doing four different newsletters that people are getting every week. We're doing a general one; our community choir (with a song sheet); our music project newsletter (with a craft pack); and our farming memories group. Staff and volunteers are handwriting letters to people as well, which has probably got the best response out of anything that we've done. We're actually getting letters back; there are kind of 'round robins' happening with people writing to one another.'

Being able to continue with your support

'One of the things we did prior to lockdown was a regular carer support group that we ran in collaboration with the local carer centre. We've kept that going; at the meeting family members spoke about how much they appreciated the fact that we had remained in contact with them, saying things like, "You've been an absolute lifeline and the only service that has remained in contact with us." Locally the post-diagnostic support service (which admittedly a lot of our people are out of that service now anyway) are all nurses. They've been reallocated back onto the front line, so that service has just disappeared overnight. We're hearing similar things from other services, such as where they've furloughed staff. The fact that we're still here and still reaching out to people, I think, has been hugely, hugely appreciated.'

Relationships

'There's a huge amount of peer support, and that's one of the things that is very difficult to replicate virtually, unfortunately. But when we're physically open, that kind of peer support is just huge, absolutely huge. The love and care they all show for one another is just incredible. That's replicated throughout volunteers and the staff team; the relationships that form are a huge part of it, they really are.'

Challenges and overcoming

As the COVID-19 pandemic continued the DFCs continued to respond in ways that ensured relationships and connections were maintained with people with dementia and unpaid carers. The sustainability of the DFCs in the face of a global pandemic is a testament to the commitment and motivation of staff, volunteers, and community members. It also provided an insight into the self-organising, and individual support responses that were possible when other more formal services were unavailable. These communities have offered a lifeline to people with dementia and unpaid carers during this pandemic.

Some of the topics were crosscutting. One such example is communication. Communicating well with stakeholders and partner organisations requires patience and planning. On occasions there could be a different focus and priorities even where there were shared goals of providing quality support to people living with dementia. Negotiations and respectful approaches had to be developed. This is all part of the process of social bonding where stakeholders work to ensure their values and aims are aligned. A lot of this work is attended to in the application for Trust funding, but as the programmes set out on their respective journeys, membership changes, and objectives might adapt. COVID-19 is also the most obvious example of an unexpected challenge. The self-evaluations cover challenges. However, social bonding helps us to see the ways in which DFCs use their pooled resources to both identify challenges and address them.

Challenges and overcoming

There are also very practical considerations, such as supplying a service where there is a limited transport infrastructure or harsh weather. Frequently cited challenges included the time involved in the recruitment of volunteers and engaging potential community members. The biggest challenge had been how to sustain the DFCs over time. This challenge has been replaced by the more immediate challenges that have resulted from the COVID-19 pandemic which brought into stark focus delivering in the present. The DFC stakeholders have been measured and focused on their responses to both. The Trust produced a report in 2020⁷ which told stories of responses to COVID-19. The COVID-19 response shows how the different stakeholders contribute to their community. For example, distinct groups made suggestions or offered resources to support isolating members and used the crisis to make themselves known to others who could use their help. The ecosystem structure of the DFC makes this possible as the members have a shared vision and within this can act as individual agents in confidence that they are aligned to the DFC as a whole and its purpose.

Communities faced challenges at various stages of their programmes, for example, in starting their planned activities, recruiting volunteers and members, sustaining activities day to day, practical delivery, and sustaining relationships with key stakeholders and members. This included cementing the DFC as a fixed resource and finding and securing funding for the longer term. These experiences of challenge and overcoming, as the community developed, illuminate the communities as 'living systems' that respond to, reflect and embrace the geographical, social, cultural, political and economic aspects of their environment. This provides an opportunity to expect tasks and challenges for distinct stages of the DFC lifecycle, and for neighbouring DFCs to help each other with geographical challenges, such as reaching communities and practical issues, such as shared resources/transport links etc. Successful DFCs also learned from challenges.

⁷Life Changes Trust. 2020. Covid-19 Learning Report. https://www.lifechangestrust.org.uk/sites/default/files/publication/files/BOTH%20PROGRAMMES%20COVID-19%20LEARNING%20REPORT_0.pdf

Added value – Social Return on Investment

Much of the value associated with activities that take place in the real world is not easily measured in financial terms – things like happiness, dignity, respect. This can mean that outcomes which are important to people and communities are overlooked, or discounted. Social Return on Investment (SROI) is a method of evaluation developed by the New Economics Foundation⁸ that aims to measure and communicate this broader value. SROI measures change in ways that are accepted by the people or organisations that experience the change (stakeholders) and articulates this from their perspectives. Importantly, relevant outcomes are identified by the stakeholders themselves.

Social Return on Investment
helps to tell the story of how
an activity, programme or
organisation **makes a**
difference in the world

⁸ <https://neweconomics.org/2009/05/guide-social-return-investment>

Added value – Social Return on Investment

SROI assigns a monetary value to these outcomes by identifying indicators which can be allocated a financial value (or proxy). Comparing this value to the investment required to achieve that benefit produces an SROI ratio. SROI takes standard financial measures of economic return a step further by capturing social as well as financial value.

Stakeholders provide information about what changes and what matters for them



The research team gathers data from the projects to help evidence this change



SROI assigns a financial value to these changes using standard rates (or proxies)



SROI presents these values in relation to the cost of the activity

Added value – Social Return on Investment

Dementia Orkney:

A Social Return on Investment case study

Dementia Orkney

Dementia Orkney, a geographical DFC funded for three years by the Trust, commenced in August 2017. Dementia Orkney was developed by Age Scotland Orkney, NHS Orkney and Dementia Friendly Orkney, with local people living with dementia and unpaid carers actively involved in helping to shape the community. Dementia Orkney aims to promote health and wellbeing, resilience, access to support and inclusion through activities which include local hub drop-in sessions, support for unpaid carers, information and advice, training and education, and signposting and referral.

This case study analysis focuses on the impact of Dementia Orkney on the lives of people living with dementia and unpaid carers. The analysis adopted a SROI methodology to measure the impact of Dementia Orkney activities and to place a monetary value on them. It focuses on the value gained from involvement with Dementia Orkney for people living with dementia, unpaid carers, Age Scotland Orkney, local volunteers, NHS Orkney and Orkney Islands Council.

Added value – Social Return on Investment

Laura's story

The Hub has been a warm, welcoming place to come during difficult times. A place where we are understood, accepted and supported.

We have made new friends who, by the nature of the disease, remain nameless but familiar. We find ourselves to be not alone; amongst others experiencing similar challenges on a daily basis. We have picked up tips on coping with an ever-changing way of life.

In Mum's own words, "It's right fine when you can have a laugh and fun with everyone. What a lovely bunch of folk." She never remembers anything that has happened or anyone's names but knows she enjoys herself and has a good feeling about going to the Hub. She is always keen to go.

Attending the carers group meeting is a great opportunity to share experiences, gain an insight into what may lie ahead and how to cope with anything that crops up.

The Stress and Distress course was another helpful tool to have to hand when faced with new challenges but also knowing that self-care and preservation are vital too.

Added value – Social Return on Investment

Scope of the study

This analysis aims to understand the value created by Dementia Orkney in supporting people living with dementia and unpaid carers. The SROI analysis is based on Dementia Orkney investment, activity and outputs between August 2017 and October 2019.

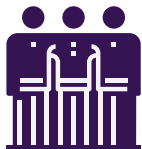
See Thompson-Bradley, O. and Christie, J. (2021) *Evaluating the Impact of Life Changes Trust Funded Dementia Friendly Communities in Scotland: Social Return on Investment Studies*. The Dementia Centre, HammondCare for the full SROI study, including justification of stakeholder inclusion/exclusion, financial proxies, sensitivity calculations and a complete value map.

Dementia Orkney outcomes

Outcomes are the changes experienced by stakeholders as a result of being involved in an activity. Through interviews and informal conversations with stakeholders, we identified a range of positive outcomes for people living with dementia, unpaid carers, Age Scotland Orkney, volunteers, NHS Orkney and the Orkney Islands Council related to Dementia Orkney.

Positive outcomes identified for a range of stakeholders related to Dementia Orkney

People living with dementia



Feel part of something/have a place to go/feel a sense of belonging

Connect with others

Have fun/enjoy themselves

Unpaid Carers



Develop supportive relationships with other carers, staff and volunteers

Increase capacity to cope through peer support, information, training and signposting

Reduced feelings of loneliness

Relieved of stress/burden

Know where to go for information

Age Scotland Orkney



Raised profile of Age Scotland Orkney

Build relationship with local partners

Challenge stigma/raise profile

Volunteers



Increased wellbeing

Increased knowledge

Improved capacity to support more people/a broader reach

Orkney Islands Council



Improved capacity to provide a personalised and responsive dementia support service

NHS Orkney



Reduced emergency hospital admissions (through early identification of infection/delirium)

Added value – Social Return on Investment

The reported outcomes are based on our engagement with the Dementia Orkney project team, people living with dementia, unpaid carers, volunteers, NHS Orkney and Orkney Islands staff.

Data on inputs (investment of time and money), activities and outputs relate to programme delivery between August 2017 and October 2019.

Within the SROI analysis, these outcomes are valued utilising a financial proxy representing the benefit accrued by the stakeholder involved.

The social value

The SROI analysis demonstrates that Dementia Orkney activities contribute positive social value for multiple stakeholders that is greater than the cost of the investment.

$$\text{SROI} = \frac{\text{Present value}}{\text{Value of inputs}} = \frac{\pounds 1,036,819}{\pounds 200,764} = \pounds 1: \pounds 5.16$$

The social value contribution for every pound (£) of investment is estimated to be £5.16

In summary, there is clear evidence emerging from this SROI analysis that sustaining the involvement of people with dementia in their communities has positive outcomes for the person involved, and for unpaid carers. Dementia Orkney is an integral part of facilitating this community involvement and maintaining community connections.

Badenoch Shinty Memories Group: A Social Return on Investment case study

Badenoch Shinty Memories Group

Badenoch Shinty Memories Group (BSMG), a dementia friendly community of interest, received a development grant from the Trust in June 2019. The group is part of the wider shinty community under the umbrella of Shinty Memories Scotland, a network of groups set up in shinty-playing communities that uses the sport's archives and resources to support people with dementia and people experiencing isolation, mental health challenges and loneliness. These Shinty Memories groups have evolved from a Sports Heritage Scotland initiative, involving shinty's governing body, the Camanachd Association and Alzheimer Scotland. BSMG works in partnership with the Highland Folk Museum, using a shared project officer post to support the objectives of the two organisations in developing a compassionate, inclusive community.

Prior to March 2020, when COVID-19 restrictions began, BSMG hosted one community event per month. These events focused on engaging the community, particularly people living with dementia and older

people at risk of isolation, over shared memories of shinty. The group also hosted rotating, biweekly 'Time Travellers' reminiscence sessions in four local care homes and sheltered housing schemes. The last of these sessions was held on 11th March 2020.

Since pandemic restrictions began, BSMG volunteers have maintained regular contact with people who had been attending the events, as well as care home and sheltered housing staff. The group has found new and creative ways to connect with people, including accessible, USB

film compilations and a quarterly paper and digital newsletter featuring shinty memories, photos and stories, as well as quizzes, community news and recipes. Local people are invited to contribute content to the newsletter. In addition to care homes and sheltered housing, BSMG has developed a working relationship with the local high school. In the absence of face-to-face events, high school pupils wrote letters to local residents identified by BSMG, aiming to reduce feelings of isolation and to maintain a sense of connectedness within the local community.



Former shinty rivals and long-time friends, John and Donnie, touch camans

See Thompson-Bradley, O. and Christie, J. (2021) *Evaluating the Impact of Life Changes Trust Funded Dementia Friendly Communities in Scotland: Social Return on Investment Studies*. The Dementia Centre, HammondCare for the full SROI study, including justification of stakeholder inclusion/exclusion, financial proxies, sensitivity calculations and a complete value map.

Added value – Social Return on Investment

Scope of the study

This SROI analysis is based on BSMG investment, activity and outputs between June 2019 and December 2020. It focuses on the value gained from involvement with BSMG for people living with dementia, unpaid carers, care home residents and sheltered housing tenants, local volunteers, and the Highland Folk Museum.

Badenoch Shinty Memories Group outcomes

Outcomes are the changes experienced by stakeholders as a result of being involved in an activity. Through interviews and informal conversations with stakeholders, we identified a range of positive outcomes for people living with dementia, unpaid carers, care home residents and sheltered housing tenants, local volunteers and the Highland Folk Museum related to BSMG.

Most people living with dementia who were involved with BSMG were care home residents or sheltered housing tenants. The outcomes for people with dementia were similar, regardless of where they lived, therefore, the stakeholder group 'People living with dementia' includes these care home residents and sheltered housing tenants. All other care home residents and sheltered housing tenants are considered together, since the outcomes for these stakeholders were also the same.

Positive outcomes identified for a range of stakeholders related to BSMG

People living with dementia



Feel part of something/have a place to go/feel a sense of belonging

Connect with others/share stories and experiences through reminiscence

Unpaid Carers



Develop supportive relationships with other carers, staff and volunteers

Have time for own lives

Carehome residents/sheltered housing tenants



Re/connect with others, talk and share stories/memories

Feel connected to wider community/sense of belonging

Volunteers



Increased wellbeing

Get to know people in community better

Increased knowledge about dementia

Highland Folk Museum



Museum more dementia enabling

Buy-in for ongoing community outreach based on partnership

Informs museum shinty collection

Added value – Social Return on Investment

The social value

The SROI analysis demonstrates that Badenoch Shinty Memories Group activities contribute positive social value for multiple stakeholders that is greater than the cost of the investment.

$$\text{SROI} = \frac{\text{Present value}}{\text{Value of inputs}} = \frac{£388,392}{£80,389} = \text{£1: £4.83}$$

The social value contribution for every pound (£) of investment is estimated to be £4.83

Social bonding and social bridging

BSMG illustrates well how a DFC can help to build social bonding capital across a range of stakeholders. Older people, with and without dementia, connect with others and share their stories and experience through reminiscence sessions and local newsletters. Whilst these activities initially focused on shinty memorabilia and memories, they have evolved to include resources that more broadly represent life in Highlands communities, thereby drawing more people in; one person described the activities as ‘community memories’. Members of the community living in supported housing or care settings are involved and feel remembered and reconnected to the community beyond their accommodation. Contrary to what might be expected of a DFC, it is people living in care and support settings who make up the majority of the BSMG stakeholders. Unpaid carers develop supportive relationships with others based on mutual experiences. Volunteers also benefit by getting to know people in their community better.

Added value – Social Return on Investment

BSMG is woven into the wider community through its volunteer network but also a wide range of partnerships, including the local high school, the Highland Folk Museum, Church of Scotland, and Alzheimer Scotland. The group has made considerable contributions to raising awareness and understanding of dementia in the community, while generating buy-in from the local high school and museum in terms of sustained community outreach activities. The group facilitates access to the wider community and the available resources, support, and information, acting as an important social bridge for many.

Figure 3 summarises the estimated social value contributions of BSMG in terms of how the group builds social bonding and bridging capital for community members.

£344,084 Social bonding value

- People living with dementia feel a sense of belonging/ involvement in community and connect with others/share stories and experience through reminiscence
- Unpaid carers develop supportive relationships with other carers and staff and have time for own lives
- Care home residents and sheltered housing tenants connect or reconnect with others, talk and share stories/memories, and feel connected to their wider community /have a sense of belonging
- Volunteers have increased wellbeing and get to know people in community better

£44,308 Social bridging value

- Volunteers have increased knowledge about dementia
- The Highland Fold Museum is more dementia enabling, has buy-in for ongoing community outreach based on the partnership with BSMG and has an informed shinty collection

Figure 3. BSMG contributes significant social bonding and social bridging capital to the local community.

Key learning points

- Impactful DFCs are vibrant spaces made up of lots of different people, groups, ages, views, opinions, and interests. They are inclusive and there is space for everyone.
- People living with dementia and unpaid carers make DFCs happen. They are not simply recipients of support. The act of giving support and having purpose is as important as receiving support in DFCs, and brings the community to life as a responsive, reciprocal system. It is a way of being, as well as a recognisable place and/or space.
- DFCs are not static and change over time. There is no time limit to membership of a DFC and roles can change over time.
- Harnessing skills, knowledge, time, relationships, and connections makes use of everyone's potential, and the potential of the DFC. This is vital for growth and sustainability.
- DFCs bring about real change and deliver practical and substantial support as part of Scotland's ambitions for post-diagnostic support and personalised, community-based support. As such they should be recognised as a model for delivering co-produced health and social care, and opportunities found to embed this in policy and practice, using the learning from this report.
- DFCs have a role in supporting people with dementia and unpaid carers as part of COVID-19 recovery planning.

Recommendations

- Dementia friendly communities create better lives for people with dementia and unpaid carers. Policy makers and commissioners should ensure that the things valued by people with dementia and unpaid carers are at the heart of support programmes and policy actions.
 - **Living again and fulfilling my potential**
 - **Choices: my life and my choices are valued**
- Policy makers should consider the **Dementia Friendly Communities Model** model as a means of delivering post-diagnostic support closer to communities and using community development approaches that are diverse and meaningful. Think about creating a new PDS framework which can accommodate the learning from DFCs.
- Policy makers, funders and commissioners should acknowledge the role that people living with dementia and unpaid carers make to their communities and create opportunities to facilitate this through the **Dementia Friendly Communities Model**.
- Policy makers should consider the full range of services and interventions that DFCs can deliver, including alternatives to traditional health and social care services as the focus for care coordination.
- Policy makers should embed the **Dementia Friendly Communities Model** as a template for emerging DFCs across Scotland with support from the Trust and their legacy partners.
- Policy makers, funders and commissioners should create opportunities for local organisations to access funding for periods of time which take account of the need for sustainability and growth potential, including simplified funding application processes.

Recommendations

- Funders and commissioners should think about value and impact from the perspective of community stakeholders using the SROI examples in this report as an example of what is possible. Consider different funding streams for different stakeholder impacts. Use the social return on investment approach to focus on outcomes and value.
- Commissioners should consider the potential for growth of DFCs including time to build. Look for opportunities to learn from community development approaches alongside traditional health and social care support.
- Integration joint boards (IJBs) should find ways for health and social care structures to make space for community development approaches to dementia care and support. DFCs provide a forum for consultation, generating innovative ideas, and finding solutions. This can be better utilised to inform policy and create new partnerships that are the right fit for the communities that they serve.
- IJBs should consider the full range of services and interventions that DFCs can deliver in partnership with traditional health and social care services, and make a commitment to invest in local initiatives, taking into account the need for sustainability and growth.
- DFCs can maximise their potential success, impact and sustainability by using the **Dementia Friendly Communities Model** to focus on the three elements of being a living system, providing a system for living, and being an evolving system.
- DFCs should use this focus to plan for distinct stages of the life of their programme with specified tasks and objectives, including recruitment and funding.

Recommendations

- DFCs should prioritise bridging activities to build a robust network that focuses on the support that people living with dementia and unpaid carers want, need, and can contribute to, and that can share (and draw on) assets and resources with a diverse range of organisations and businesses, across the community locale.
- DFCs should celebrate their diversity and recognise the strengths of their collective knowledge. They should make time to record the growing community resilience reserves that they build and have access to (Christie, 2020)⁹ for their own use and for future commissioners and funders (a community Resilience Reserve[®]).
- As part of their legacy, the Trust should ensure the **Dementia Friendly Communities Model** influences programmes such as bold (Bringing Out Leaders in Dementia) and About Dementia, and the findings from other relevant initiatives, such as the Small Grants Programme.
- As part of their legacy, the Trust should make opportunities available for DFCs to continue to develop and network. This can help facilitate a collaborative, learning approach to seek help, find solutions, and access peer support, beyond the life of the Trust.
- As part of their legacy, the Trust should facilitate the development of other practical resources and connections that can contribute to the continued development and networking of DFCs.
- The Trust should share the **Dementia Friendly Communities Model** with the current DFC community to use as a framework for measuring current impact and embedding future sustainability.

⁹ Christie, J. 2020. *Promoting Resilience in Dementia Care. A person-centred framework for assessment and support planning*. London: JKP.

In conclusion

This evaluation has found many examples of the positive impact of DFCs in the lives of people with dementia and unpaid carers. DFCs come in different shapes and sizes, delivering a range of diverse services and support networks across Scotland. They contribute to better lives for people living with dementia and unpaid carers. They can deliver post-diagnostic support and create opportunities for influencing local and national policies through partnerships, and direct political activity. They deliver added value to the communities they serve. We have used social return on investment analysis to explore this in some detail, bringing to life the community development focus which makes these projects so unique and diverse. Challenges are part of life and a daily part of the DFC experience. However, this evaluation has shown that so too, is the experience of overcoming challenges. Successful DFCs are resilient, they expect challenges, and learn from these experiences and from each other.

The network experience of DFCs, created by the Life Changes Trust, provides both a catalyst and a support structure, which is then sustained by the DFCs themselves. We have categorised DFCs as complex ecosystems which allows us to visualise the active and evolving nature of the communities and their component parts through our **Dementia Friendly Communities Model** (Fig. 2). Situating this model within discussions on dementia friendly communities could help communities to focus on the future whilst delivering reliable and meaningful support in the present. We conclude this report with the recommendation to situate this model as the focal point for policy and action in making dementia friendly communities a reality, as part of the Scottish Government's commitment to strengthen and recover resilience in our communities.

In conclusion

And finally

We want to thank all the DFCs for their contributions to this work and their commitment to supporting people living with dementia and unpaid carers across Scotland. The combination of nurturing support, care, and friendships, and influencing activities, of awareness raising and the amplification of the voices of people with dementia and unpaid carers in both the everyday and in policy discussions, has provided the rich content detailed in this report and featured within the **Dementia Friendly Communities Model**.



An Talla Solais



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