

Carers' Café

A Briefing Report

“You need a connected neighbourhood to make a difference, or at least try”

Carers' Conversation Café participant

Introduction

The OCN team would like to thank everyone who contributed to our Carer Conversation Café. We would like to thank dementia activist Agnes Houston for facilitating the group for people living with dementia and Linda Gill (Tide's Carer Involvement Lead for Edinburgh, Lothian, The Borders and Dumfries and Galloway) for facilitating the carers' group. Thank you both so much for lending your time and expertise.

For this Café participants defined 'Neighbourhood' as a place; perhaps a local village, set of streets, shops or Stirling's city centre. We included people's experiences of activity groups, public services and recreational places. We also included the journey or space between places as neighbourhood.

We split the café guests into two groups: carers' and people living with dementia. Each group benefitted from a dedicated space to talk through the questions which drive the work of Our Connected Neighbourhoods. In particular, we set out to explore the barriers and enablers to neighbourhood engagement.

We took a creative approach to capturing the conversations, as pioneered by artist Jason Nelson*. For each group we prepared two 1 metre by 1 metre sheets of heavy gauge polythene.

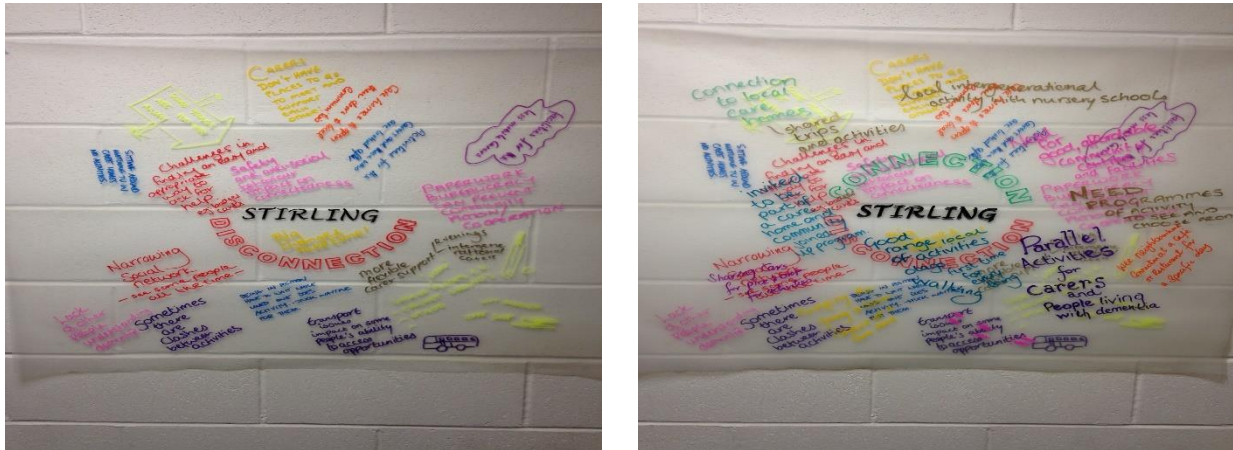


Figure 1: Pictures of the polythene feedback sheets completed by the people living with dementia group. First picture is DISCONNECTION. Second picture is DISCONNECTION and CONNECTION overlaid with each other.

Using paint-pens we stenciled the word STIRLING at the centre and DISCONNECTED in a semi-circle on one and CONNECTED on the other. When both sheets are overlaid DISCONNECTED and CONNECTED make a complete circle surrounding the word STIRLING. Participants could use the paint-pens to write and draw on the sheets. This format allows the sheets to be overlaid, compared and even developed into sculpture; which could be used for a creative exhibition or roadshow for the project at a later date.



Figure 2: Jason Nelson taking notes during the OCN Carers Conversation Café

*A big thank you to Jason for collaborating on and informing the creative format for this cafe.

Statistics

This is an overview of event statistics for the Carers' Conversation Café. The first chart provides a breakdown of participant numbers by group, while the second chart analyses the feedback we received from participants in response to our feedback form questions. These questions remain consistent throughout the Conversation Café series

Participant Numbers

We welcomed 29 people to the Carers' Café, the majority (17) of participants were carers' or people living with dementia.

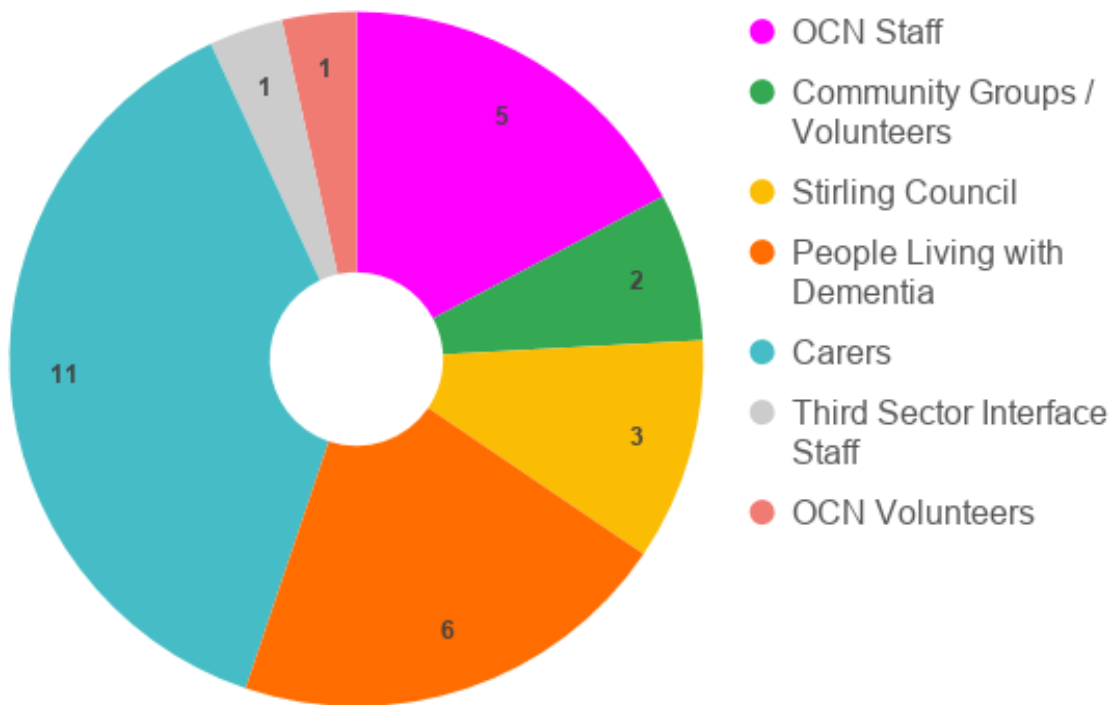


Figure 3: Pie chart showing a breakdown of participant numbers at the Carers Conversation Café.

Event Feedback

This is a breakdown of responses to the feedback forms for this event.

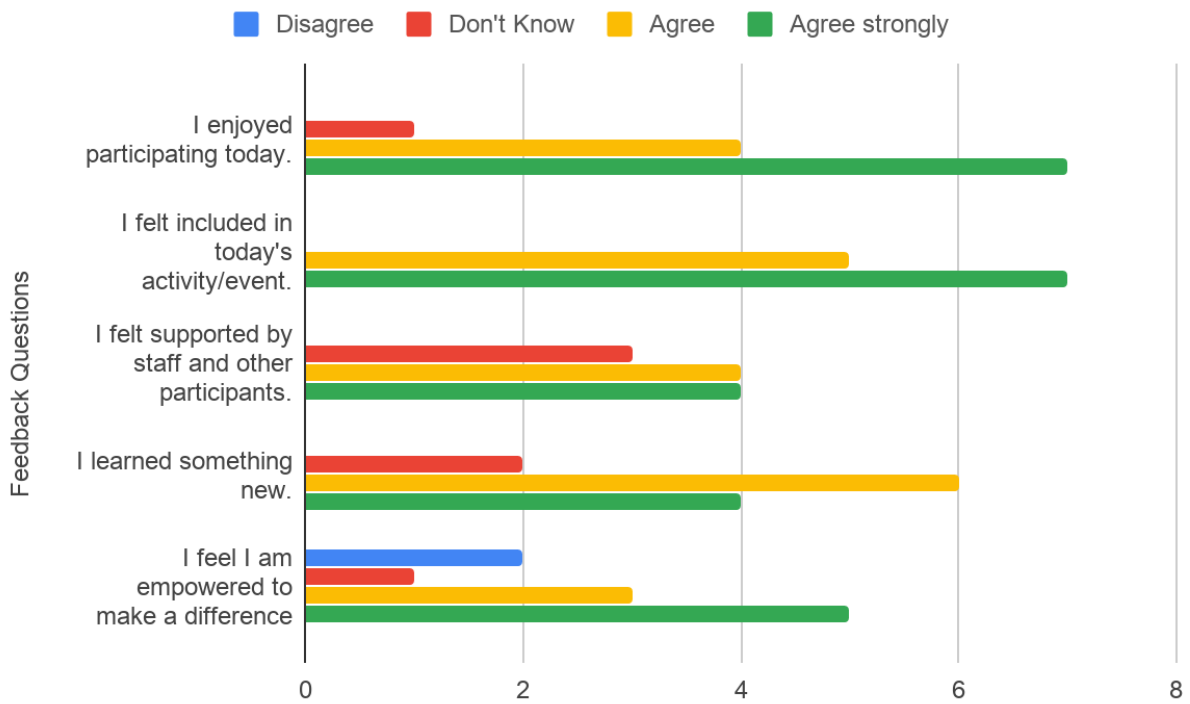


Figure 4: Comparative bar chart showing participant feedback to the Carers Conversation Café.

Findings - Carers



Disconnection and Challenges

Management of Information

Participants told us that the level of information given at the time of diagnosis could feel overwhelming. Some carers' spoke of feeling frozen at the prospect of knowing where to start. The indication here was that drip-feeding information over time may help people make better sense of it.

Some couples talked of drawing back from accessing services, at least initially, as they tried to digest news of the diagnosis to regain some kind of normality or routine. The decision to hold

back from accessing services could last for some time as couples try to just get on with life and this was an important insight given the time-limited post-diagnostic support currently offered to people with dementia in Scotland.

We also discussed patterns of referral. Participants noted that Third Sector organisations were often reliant upon referrals coming through from the public sector (especially the NHS). We discussed the potential benefits of self-referral where people with dementia and carers' could have control over when and where they connected with the variety of support options available to them locally. Some felt it would also be useful to provide opportunities for service providers to check-in with couples living with dementia after an initial period of finding their feet after a diagnosis.

Support options

Some carers' with experience of using local services and groups reported that support options were often very limited, especially at a local level. Some carers' indicated there was repetition in available activities, particularly from the Third Sector, and clashes in the timing of what was offered, with little evidence of co-ordination between different service providers. Carers' cited paperwork and red tape as possible causes that impeded community action and co-operation amongst organisations.

We received mixed responses when it came to the prospect of introducing informal local meetups. Many carers' welcomed the opportunity for more local contact while others described themselves as 'professional coffee drinkers' and were seeking a

greater range of support options. From a carers' perspective, community-based activities intending exclusively for people living with dementia could have the unintended effect of narrowing their social circle. When people with dementia were unable to travel independently to community activities, it took time out of the day for carers' to accompany them.

While there are free or discounted options available if a person requires bespoke or one-to-one support, it sometimes comes at a high financial cost that may be off-putting. For example, one carer spoke about the cost associated with befriending services. Most befriending services provide a 2-hour minimum visit meaning that costs per month could run to around £160. Many of those we spoke to indicated this pricing was prohibitive and even unaffordable for some. When adding in charges to attend other groups, such as arts and activities workshops, the cost of a loved-one participating in regular local activities can rise dramatically. Overall, participants felt there was a lack of access to affordable, reliable smaller amounts of respite care. A number of participants made the point that access to respite could help carers' keep the home going and reduce pressure on emergency services, and ultimately ensure they are well enough to continue caring.

Many venues for activities were reported to be too far away from people's homes, underlining the need for great emphasis on local support and a neighbourhood-based approach to dementia care. Transport issues impact on some people's ability to access opportunities. This includes people no longer having access to a car or experiencing difficulties with public transport.

Community Assets

Many people reported limited access to local facilities that used to be at the heart of the community such as cricket grounds, community centres and halls. Often these had ceased to serve as local community hubs and were less likely to have an 'open-door' policy. People lacked opportunity for connection to others in their local community through community and social events that went beyond connections to fellow service users. The message here is that we need to consider the spaces and places within neighbourhoods that might serve as a focus for more opportunistic forms of sociability.

Awareness

People can find it hard getting the right help generally when out and about, as the general public often fail to recognise that carers' are guiding someone who has dementia. Lack of awareness of dementia amongst public, family and friends can cause a barrier as people draw back. Further work to improve public awareness of dementia would help to tackle this problem and lead to carers' and people with dementia feeling more comfortable to seek help when out in public.

Peer and Community Support

Many carers' reported they didn't have a dedicated place to meet up for peer support carers' thought that would be valuable but emphasised the importance of a venue that was local and easily accessible. Finding a mechanism for exchange (perhaps finding a digital solution) whenever time can be snatched, would also be valuable because a 'not coping crisis' can happen at any time.

A lack of opportunity for intergenerational contact and activities was also highlighted. Quite often families are geographically dispersed and carers' find they do not have opportunities to spend time with younger people. This adds to the feeling of being in a kind of 'dementia bubble'. Many carers' felt more intergenerational activities would contribute to them feeling better connected.

Respite and Care Support

Concerns about arrangements for the person with dementia if something happened to their primary carer was raised. One person asked: 'Who do you call if you're not yet at a full-blown crisis?' Emergency social work numbers usually result in leaving a message and response times can be slow, sometimes there is no response. Many reported the impression that Social Services only intervene at times of extreme crisis, whereas they wanted a point of contact to reach out to before things escalate to a crisis. One carer said: 'it would take a team of NHS staff to do what I do if I had to go into hospital in an emergency'. The message here concerns the need for more preventative support, which makes sense economically as well as reducing the human costs of reaching a crisis point.

Connection and What is Working Well

Support options

The range of support options appeared to vary quite dramatically according to where people lived. Many carers' felt under-served by local opportunities and choice of support options. Whereas, others noted there were a good number of activities to take part

in, including cafes, OTAGO Exercise programme (To prevent falls in older people), First Time for Everything (Free activities delivered by Royal Voluntary Services and Prudential) Walking Groups. However, even during the conversation about connection and what was working well, carers' spoke of the barriers to accessing these opportunities that included difficulties with transport and the distance they were required to travel.



Figure 5: The carers' group deep in conversation. Facilitated by Linda Gill from TIDE and scribed by Kevin Harrison from Artlink Central & Our Connected Neighbourhoods.

The carers' group deep in conversation. Facilitated by Linda Gill from TIDE and scribed by Kevin Harrison from Artlink Central & Our Connected Neighbourhoods.

In terms of more innovative developments in support, being invited to be part of a community and care-home joined up programme was mentioned as one way to support connectedness. This could include shared trips and activities.

Respite and Care Support

Day care type opportunities, such as those provided by organisations like Town Break, were highly valued by carers' and people with a diagnosis for carers', they provide an opportunity to get away for an hour or two and take care of chores or do shopping. More such groups, distributed at different sites across Stirling, would make support accessible at a local level.

People said provision of more co-located activity opportunities would also be valued. This has been something regularly raised throughout the course of the OCN community-development such as participant interviews, conversation cafes and home visits. The idea would mean that carers' could take part in an activity in one room with people living with dementia in another. This would provide reassurance for carers' and respite from care but also an opportunity for both partners to socialise with peers whilst knowing loved ones were safe and nearby.

Peer and Community Support

Having family to support a loved one living with dementia means carers' can get away for a bit, do chores and feel connected to the community. Of course, not everyone has family, or others who are available and willing to provide this kind of support. Having lived in an area for a long time, knowing the local people, carries benefits to feeling connected. At present, the wider support

networks available to people with dementia are not well understood or connected with formal service providers despite the role played by neighbours, fellow churchgoers or other neighbourhood support mechanisms. Much more could be done to support carers' to co-ordinate these different sources of support in their lives.

Findings - People Living With Dementia

Disconnection and Challenges

Support options

For people with dementia there were also mixed responses when it came to the question of accessible support options. Some people living with dementia felt there was a good choice of activities in and around Stirling but not enough in their local neighbourhood. Barriers included the lack of available spaces for different groups or activities, with people often going onto waiting lists and not being sure when they might be able to access a particular activity. Participants often felt they didn't know what activities were available at any given time and by the time they did find out it was too late and the activity had finished. People with dementia noted they experienced a lack of confidence following their diagnosis. A particular need for more intergenerational opportunities was voiced.

At present it seems there is no single system or easy way to find out what dementia inclusive groups or activities are available. Sometimes there can be a lack of available spaces and the cost to attend becomes prohibitive. People end up on a waiting list or self-excluding on the grounds of cost. One message from our discussion concerns the need for great accessibility of more mainstream groups and community resources and the need for local providers to take responsibility for becoming dementia inclusive and advertising this so people are aware of what's available to them.

Sensory

We also learned a lot about the sensory impact of dementia. It can for example impact on visual perception and on how people experience the acoustics of public venues and spaces. The design, layout, light levels and acoustics of a venue or environment can have a big impact on accessibility and much can be done to help people map out dementia-inclusive spaces in their local communities to help others find suitable venues and tackle social isolation when people become confined to their home.

Awareness

People experienced feelings of isolation as members of the public, neighbours, family and friends drew back after receipt of a diagnosis of dementia. Perceptions of dementia can be misguided or driven by stigma toward the condition. Participants made it clear that much could be done to familiarise their local communities with dementia that will enable them to feel more confident to venture out and about.



Figure 6: Participants, Staff and volunteers enjoy refreshments, conversation and interaction during the café.

Community Assets

Some members of the group felt there was a diminished community spirit along with diminishing community facilities. There was a perception of an increase in housing but no increase in facilities or facilities being taken away. A lack of local community halls and places to meet and high rental rates to use them can mean local groups don't happen like they used to. Lack of access and affordability of local venues such as halls and community centres means a lack of available spaces to provide support and engagement locally.

Transport

Difficulties in accessing public transport and more dedicated disability transport services came up several times and this is feedback the OCN team have heard repeated often. This can mean people can't attend activities further away and become disconnected. The key message here is that support needs to be reachable – either in being walkable or easily reached via accessible transport. Working with local transport providers seems a useful starting point to enable people to reach the support they need.

Connection and What is Working Well

Support options

The group of people living with dementia reported that the clubs and groups they attended helped them feel connected to their local neighbourhood. Activities involving local history, memory and sharing really helped. Intergenerational opportunities were also valued. Art groups, cafes and libraries were also acknowledged as important to day-to-day living.

Awareness

People with dementia valued support from family and from their partners. People felt dementia awareness training was important, so they were not treated differently. In some villages people felt well supported by local shops, a post office, and news agent staff who knew them. This helped with a positive feeling of understanding and connectedness. People who had dogs very much valued the connection they had from walking them. They have a set route and it makes them happy to walk their dog.

Having understanding friends and supportive neighbors helped with feeling connected.



Figure 7: Dementia assistance dog (and OCN mascot) Rufus attending the café.

New Connections: Recommendations

Management of Information

Carers' and people living with dementia need access to information about what services and groups are available at the right place at the right time, but without becoming overwhelmed. A concise information guide or directory for people at the point of diagnosis could help. It should detail activity and service contact information. This verifies and supports the feedback from OCN participants, feedback from third sector plus health and social care that everyone would benefit from such a resource.

OCN GOAL

OCN have connected with PhD student Claudia Edwards, who also identified the need for such a resource during her placement with NHS Forth Valley Community Mental Health Team for Older Adults. That team identified value of such a directory for signposting people at diagnosis. Working collaboratively with Claudia OCN shared all our activity mapping via our online events calendar. OCN also suggested auditing the directory using the OCN printed media guidance audit tool. It will be important to find ways to future proof this resource. It will need to be updated and maintained. The administration of this will need to be as easy as possible. OCN commits to liaising with partners to help develop this resource with the aim that it can be used as a template to support similar resources in other areas.

Single Point of Referral

A single-point referral process could also provide a solution to couples being able to manage information overload and allowing them to selectively request specific information at different stages of the journey. This could potentially make it easier to (re)-engage with dementia organisations when and where they need and want to. It could also assist Third Sector organisations to connect with people if there's been a gap in contact.

OCN GOAL

OCN partners have started work on co-producing a single point of referral process for services in the Stirling area. As proof of concept, OCN will look to pilot this at the Bellfield Centre in the first quarter of 2020.

OCN MILESTONE

OCN have been working on building an events calendar on the website. This can be used to view activities (as scheduled on the calendar) for saving as a PDF. It is intended to compliment the directory.

OCN Activities Calendar <https://bit.ly/38Mzjr5>

Co-located activities

There is a desire for activities where carers' and loved ones can do meaningful activities in different rooms at the same time. This would provide much needed opportunity for meaningful involvement and respite, especially for carers' who find it challenging to find time to do such activities.

OCN MILESTONE

Since the OCN partnership meeting on the 19 November 2019 Alzheimer's Scotland and Town Break have planned to provide co-located carer and person living with dementia groups on the Stirling Community Hospital Campus. This is a fantastic example of co-production and partnership working in action.

Peer and Community support

The co-delivered carers' group, provided by Alzheimer's Scotland, aims to fulfil this. The group met for the first time on 4th December 19. The carers' decided frequency, purpose and timings for the group.

OCN GOAL

With a focus on partnership work and avoiding duplication, OCN will receive an invite to this carers' group to discuss developing local neighbourhood cluster support groups.

Libraries could be investigated as venues to host the groups and each group could define its own format.

Respite and Care Support

This is something commissioning services need to consider making available. This could be by commissioning new services or expanding and developing existing successful provision. OCN project findings and recommendations will be shared with the different strategic groups across Forth Valley. This would include, but not limited to, Dementia Friendly Stirling meetings, the About Dementia forum and dementia strategy reviews. We will add reports to our website.

OCN GOAL

Partners need to lobby and campaign for this to be put in place. This suggestion can be added to Forth Valley dementia strategy review consultations in April next year.

OCN have made a commitment to feed project findings into About Dementia: Shaping Our Worlds Together – Scotland’s forum for improving lives.

OCN regularly attends Dementia Friendly Stirling meetings and will make these findings available for discussion.

Additional Information Links

Scotland's National Dementia Strategy

<https://www2.gov.scot/Resource/0052/00521773.pdf>

Standards of Care for Dementia in Scotland

<https://hub.careinspectorate.com/media/1487/dementia-standards.pdf>

Charter of Rights for People With Dementia and Their Carers in Scotland

<https://nhsforthvalley.com/wp-content/uploads/2014/12/Charter-of-Rights-for-People-With-Dementia-Careres.pdf>

Mental Health (Scotland) Act 2015

<https://www2.gov.scot/Topics/Health/Services/Mental-Health/Law/2015Act-provisions>

A handy pocket guide to human rights for carers'

<https://www.bihhr.org.uk/carersguide>

Our Dementia Our Rights - A DEEP guide to the rights of people living with dementia

<http://dementiavoices.org.uk/wp-content/uploads/2016/11/Our-dementia-Our-rights-booklet.pdf>

About Dementia – Scotland's form for improving the lives of people affected by dementia. The human rights of unpaid carers' is one of 15 sub-groups. OCN will be feeding its findings into the forum. <https://www.ageuk.org.uk/scotland/what-we-do/dementia/about-dementia/>

TIDE <https://www.tide.uk.net/>

Agnes Houston https://twitter.com/agnes_houston

Jason Nelson <http://www.jasonnelson.co.uk/look-and-learn.html>

For more information about this report and the Our Connected Neighbourhoods project please use the following contact details.

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