

How PRESENT improves the wellbeing of people living with dementia in East Dunbartonshire

Background: Living Well with Dementia in Scotland

Dementia is a complex condition that impacts on the lives of an increasing number of people in Scotland. East Dunbartonshire is the Scottish local authority area with the highest proportion of older people. Some 21% of the local population are over 60 years old and the population aged over 75 years old is set to increase by 71% by 2024. Around one person in 20 over the age of 65 is affected by dementia. There are approximately 2,086 people living locally with dementia as at March 2015.

Alzheimer Scotland has developed a comprehensive approach to ensure the well-being of people living with dementia. The current '5 Pillars Model of Post-Diagnostic Support' includes five key elements which are considered essential to supporting people after their diagnosis:

1. Understanding the illness and managing symptoms
2. Planning for future care
3. Planning for future decision-making
4. Supporting community connections
5. Peer support.

In particular, pillars 4 and 5 put the focus on community and peer support to promote the resilience of people living with dementia and to enable them to live in the community for as long as possible.

The project PRESENT, which is a joint initiative of East Dunbartonshire Council, the local Dementia Network, the Joint Improvement Team and Governance International, aims at strengthening pillars 4 and 5 through co-production. This means people living with dementia have a PRESENCE in their local community. Furthermore, it explores ways in which people living with dementia can be a 'pillar' to other people in their family, personal network and local community by enabling people living with dementia to make a CONTRIBUTION to their local community.



Starting points

PRESENT aims at establishing a new type of collaboration between people living with dementia and public services in East Dunbartonshire, based on co-production approaches and values.

“Co-production is about professionals and citizens making better use of each other’s assets, resources and contributions to achieve better outcomes or improved efficiency.”

Source: [Governance International](#)

The initiative developed out of the work of the East Dunbartonshire Dementia Network which was founded by East Dunbartonshire Council in 2002 as a forum that brings together organisations, groups, and members of the community, including people living with dementia, who are committed to improving the lives of people with dementia, their families and care-givers. The Network started with a core membership of around 10 people and originally functioned as a knowledge exchange among members but evolved over time to become a forum for collaboration. It now has over 50 members representing different groups and interests.

For example, in January 2014, East Dunbartonshire Council launched a dementia resource for schools targeted at upper primary and lower secondary children. People living with dementia contributed to the resource with stories of their experiences and reviewed the finished product before implementation. The local Dementia Network built on the school resource which is based on the “Curriculum for Excellence in Scotland” to provide hands-on training on dementia issues to senior secondary pupils in the eight secondary schools across East Dunbartonshire. A ‘Dementia Informed’ certificate is issued on completion to the pupil concerned. Furthermore, pupils in their senior year are offered the opportunity to participate in volunteering opportunities with people who have dementia. To date these opportunities have included

- Providing training on Skype to care home residents
- Assisting at a local Dementia Café.
- The creation and delivery of a new Community Café within a local care home.

Working together

PRESENT breaks new ground in applying the Governance International toolkit *Co-Production Star* to work towards co-production as default in the context of the challenges that dementia brings. So what did we do?

We began with an extensive mapping of existing and potential co-production initiatives (MAP IT – Step 1 of the *Co-Production Star*) building on East Dunbartonshire work on local asset mapping. We then prioritised areas to address. (FOCUS IT – Step 2 of the *Co-Production Star*).



Three issues emerged as key priorities for people living with dementia and service providers working in the public, third and private sectors in East Dunbartonshire:

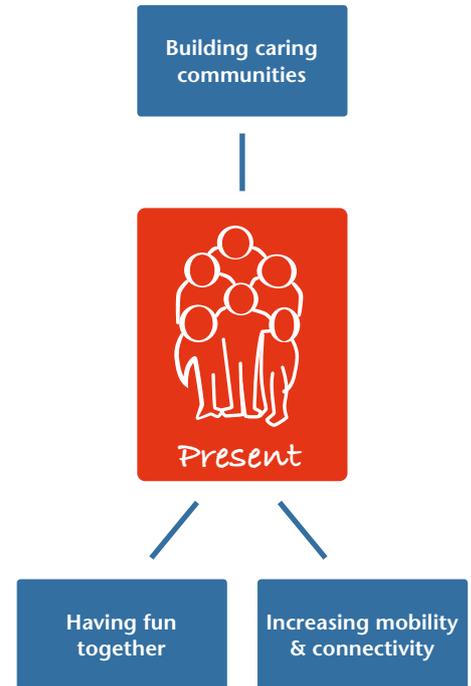
1. Building caring communities
2. Having fun together
3. Increasing mobility & connectivity

The next step (Step 3) of the Co-Production Star (PEOPLE IT) was about getting co-producers on board who have the enthusiasm, expertise and experience to turn the priorities identified in Step 2 into action.

The participants of the Co-Production Cafés included staff from public, third and private sector organisations, people with dementia and their care-givers. It was clear that PRESENT had attracted the interest of a wide range of people and services such as the police and staff from leisure and cultural services. Supporting change for people with dementia was no longer considered to be just the responsibility of the social work team.

PRESENT is now driving the integration agenda and enables the involved partners to see issues related to dementia from an overall 'outcomes' perspective and not just through the lens of 'their own' service. In particular, the third sector has had a strong presence in our East Dunbartonshire Co-Production Cafés.

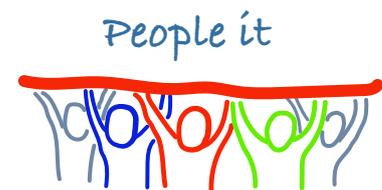
The participants in the Co-Production Cafés co-designed action plans to move the three PRESENT priorities from aspiration to reality. Three examples include development of supported walks with people with dementia, launching a new community café, in a local care home, supported by senior school pupils and hosting a 'Walk Your Neighbourhood' event with university partners.



Supported walks with people living with dementia

There are already health walks for local people in East Dunbartonshire. However, participants at the Co-production Cafés wanted to design walks suitable for people living with dementia and their care-givers. A focus group consisting of East Dunbartonshire's Walk Development Officer, together with local Dementia Cafés (known as DeCafés) attendees, and *Ceartas*, a local advocacy organisation which facilitates and supports DeCafés, got together in summer 2014. They agreed to start with taster walks to find suitable local areas to walk. The names of volunteers were taken and it was arranged to have a short walk at the beginning of the next scheduled DeCafé. A reminder was sent out before the DeCafé.

The taster walk in December 2014 went very well- it was a 20 minute walk near the DeCafé and was attended by 12 people living with dementia and 3 volunteers. Everybody enjoyed the walk as East Dunbartonshire is a scenic place. People have the freedom to attend as they wish. For example, over January walks had to be cancelled or rearranged due to bad weather but the feedback is already encouraging. The walks are promoted in the newsletter of the East Dunbartonshire Dementia Network which is co-produced by people with dementia.



DeCafés offer an informal setting to support people with dementia and their care-givers. Many people living with dementia in East Dunbartonshire think that “they are great places to go because you can meet people you know and it helps jog your memory”. For example, Billy came to DeCafé Kirkintilloch and met Jim. Billy knew Jim from over 50 years ago when Billy’s dad was on the committee at Baillieston Juniors which is a football team and Jim was one of Baillieston Juniors’ players. Billy said “It was great to see Jim again after all these years and get the chance to talk about the old days. I remember Jim was a cracking player, meeting him again gave us the chance to talk about folk we both knew back then and it brought back great memories.”



Another co-produced initiative was the ‘Walk Your Neighbourhood’ event.

‘Walk Your Neighbourhood’ – Memory Friendly East Dunbartonshire

East Dunbartonshire Council hosted a visit of delegates from the Memory-Friendly Neighbourhoods Network in September 2014. East Dunbartonshire Council is participating in a Scottish Universities Insight Institute-funded programme to share knowledge and expertise on how local communities can support people with dementia. Led by the Universities of Stirling and Edinburgh, this programme is called Memory-Friendly Neighbourhoods (MFN) and is working to provide insights into dementia-friendly communities. Delegates joined local people living with dementia, town planners and members of the Dementia Network to take part in a “Walk Your Neighbourhood” event in Kirkintilloch. The 40 participants split into small groups, tasked with using the [Age UK](#) ‘Walk in our shoes’ age-friendly resource pack in specified areas of Kirkintilloch. This helped the participants to understand what it is like to access the local area when living with dementia and to highlight areas for improvement (see Table 1).



Table 1: Areas for improvement identified during the ‘Walk Your Neighbourhood’ in Kirkintilloch

The Bridge	Steep ramp to high street, concern for wheelchair users Better signage to main town
Canal	Where to cross road – not clear – what way to the marina Designed for vehicles not pedestrians Benches could be better at the canal Pedestrians in competition with cycles
General	Are there seats in bus stops? Is transport well signed? Lots of coffee shops – but not “age or dementia” friendly Could a line be painted to direct people back to Marina or boats etc. Art as signage? Used during festivals, why not all the time? Different colours for different attractions? Or Pavement Foot Prints? Or Historical Trail – could a local society get involved? Lion Foundry/ Antonine Wall. Talking sign posts? How do we make the town work for pedestrians who can’t always rely on “local knowledge” due to memory problems

Source: *Dementia Voices* Newsletter, October 2014.

The findings will be considered by Council representatives over the next few months. Cllr Michael O’Donnell thought: “People who have dementia and their families are often subject to stigma and experience isolation and depression. Dementia friendly means improving opportunities for inclusion through awareness and dementia sensitive environments. This in turn will ensure that people with dementia enjoy the same quality of life as other East Dunbartonshire residents despite the challenges they experience.”

Professor Catharine Ward Thompson of the University of Edinburgh, said on behalf of the Memory-Friendly Neighbourhoods Network: “Our Network was set up to bring together researchers, practitioners and people whose lives are affected by dementia. We were keen to make these meetings as enjoyable and meaningful as possible. Getting out and about in Kirkintilloch was a great way of sharing knowledge and expertise through doing something practical.”

This was also reported in our local co-produced newsletter the *Dementia Voices Quarterly*. Some of the members of the group *Dementia Voices* took part in a ‘Walk Your Neighbourhood’ event. This is what Margret, one of the members, thought of the event: “There were lots of people taking part, including people from Stirling University, architects and people from other parts of the country. Some of the groups walked to the Library and others walked

to the Marina. We discussed what was good about the area and what needs improved. One of the suggestions is we need more lowered kerbs for people with walking aids. The event was well organised and it was good to get the chance to take part”

(*Dementia Voices Newsletter*, October 2014)

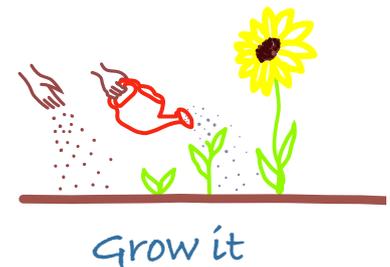
Challenges

The project PRESENT benefits from robust partnerships between East Dunbartonshire Council, East Dunbartonshire Community Health Partnerships, people with dementia, carers and third and private sector organisations, founded through the Dementia Network.

A challenge remains in building a sustainable infrastructure for co-production. This requires the support of senior managers across health and social care to ensure the staff, and the services they manage, co-produce health and well-being in day to day practice. PRESENT would not have been possible without strong senior management support from Social Work within East Dunbartonshire. The integration of health and social care taking place this year will be an ideal opportunity to build on this approach. Moving to a consistent approach which is based on capabilities depends on meaningful culture change, for which there is a strong commitment: specifically, all partners sign up to the fact that people who work and live in East Dunbartonshire need to know how and where they can contribute. A time banking model could help to match people, groups and organisations which want to make a contribution.

Furthermore, there is a need to ensure that capabilities have a role in assessment, in addition to the attention traditionally given to needs.

A local co-production charter will put dementia and co-production on the agenda of all local services and provide people living with dementia with a tool to have their voice heard and, where required, to challenge partners and service providers if pledges and standards are not met.



Outcomes

As this project is still ongoing no formal evaluation has been undertaken yet. In order to sustain the new co-production initiatives resulting from the Co-Production Cafés, elected members of East Dunbartonshire Council adopted a Co-Production Charter (this is part of Step 4 of the Co-Production Star – MARKET IT) on 5 March 2015. The Charter sets out both rights and responsibilities of all stakeholders, including service providers and people living with dementia, and will constitute a solid commitment to continue the co-production journey in East Dunbartonshire. The monitoring of the implementation of this Charter will provide the opportunity to evaluate key elements of the PRESENT project.



Why is this co-production?

Assets – People living with dementia are the experts in their own lives. They can help improve public services and also help each other.

Capacity – In East Dunbartonshire, many local practitioners are developing skills in communication (including the communication tool Talking Mats) and Person Centred Planning to ensure people living with dementia can tell them what they can do as their condition progresses. People who live in care homes are also as important as people who are living at home.

Mutuality – PRESENT is where public services and citizens work together to harness each other's expertise, skills and resources. This is not just about giving people living with dementia a voice but enabling them to make a contribution.

Networks – PRESENT aims at

1. Enabling people affected by dementia to make a contribution to their families and local community;
2. Giving people living with dementia a greater presence in caring communities;
3. Providing public services with incentives, tools and networking opportunities to work in more enabling ways with people living with dementia.

Catalysts – PRESENT builds on the work of the East Dunbartonshire Dementia Network and other local co-production champions. In particular, PRESENT has embedded new co-production activities with people living with dementia within clearly defined strategic priorities and supported through explicit expectations of behaviour in the Co-production Charter.

Lessons and learning

PRESENT has provided East Dunbartonshire Council with a step-by-step approach for harnessing the professional expertise, commitment and energy of public service providers and the expertise, experiences and skills of people living with dementia and wider communities, so that the social and personal outcomes for people living with dementia can be improved. However, people who have dementia and their families are often subject to stigma and experience isolation and depression. This experience and coping with the changes that dementia brings can be extremely disabling.

Co-production is also a journey. In order to make co-production effective for people living with dementia a three-tiered approach is needed which enables

1. Personal relationship changes within households and families;
2. Peer support in the local community;
3. Organisations to help communities to help themselves.

Further information

This case study was produced as part of the resource

‘Co -production – how we make a difference together’

developed by the Scottish Co-production Network, the Joint Improvement Team, the Health and Social Care Alliance Scotland and Governance International.

A full description of the project “PRESENT” is available on the [Governance International publications webpage](#).

You can find out more about this case study from Julie Christie, Dementia Partnerships Lead, East Dunbartonshire Council (email: julie.christie@east-dunbarton.gov.uk), Gerry Power, Deputy Director, Joint Improvement Team (email: Gerry.Power@scotland.gsi.gov.uk) or Elke Loeffler, CEO, Governance International (email: elke.loeffler@govint.org).