

*PRESENT.....*

# *Coproduction and dementia in East Dunbartonshire: experiences and outcomes*



people with  
dementia  
leisure  
NHS PRESENT carers  
social services housing  
communities Community Health  
Partnership





*"I thoroughly enjoy it and make a point of helping newcomers"*

*-Jim-*



*"I was glad today, you get the freedom to challenge it and I fight it"*

*-Mary-*



*"Often people are afraid of having it out in the open"*

*-Maggie, Wife and Carer for Jim-*

*"It's about developing people's capabilities and linking them to the community"*

*-Paula Brown Co-Production Co-Ordinator, East Dunbartonshire Council*



*"I feel as though you are better to get involved with something"*

*-Julie, Wife and Carer for Billy-*



*"Keep on doing your normal things as fully as you can.....You are the one that will pick yourself up"*

*-Harry-*



*"I'm going to fight it all the way...it makes me happy doing different things"*

*- Billy-*



*"the centre needs to be part of the community so the café is a link for the residents to the community"*

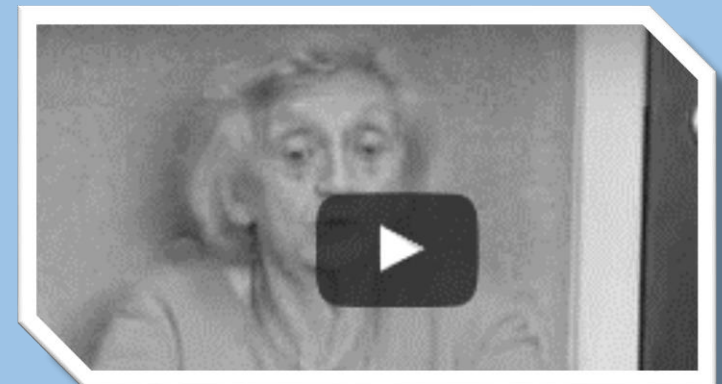
*-Alan MacDonald, Care Home Manager-*

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*A Message from Harry.*

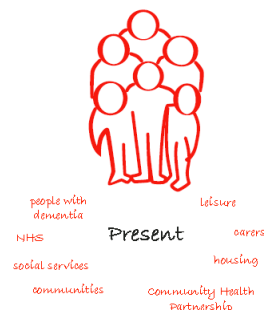


*Mary talking about  
being viewed as a  
“Whole Person”*

# Acknowledgements

*PRESENT” is a Co-Production project that establishes new ways of working between many different organisations, individuals and most crucially at its heart, people with dementia, their carers family and friends. All are focused on improving the lives and outcomes for people that live with dementia in East Dunbartonshire.*

*This project and the impact that it has would not be possible without the commitment, co-operation and support of a number of partner organisations. Our sincere thanks go out to them all.*



*“It's an equalising activity, puts dementia to the side, it normalises things”*

*-Sylvia Rossi, Dementia Champion, Eats Dunbartonshire Council talking about “Mind That Song”-*



*Jessie in full swing at Mind that Song in Kirkintilloch*

*“Bishopbriggs Academy are part of the Community Café, they sit with residents, do activities, serve tea and coffee. The Outcomes for them are, improved confidence, self-esteem, understanding, and overcoming stereotypes. For the older people, they feel valued, that the young people are interested in them, feeling part of the community, seen as a person, that their experience and life was important”*

*-Scott Lafferty, Youth Volunteering, EDVA, talking about the “Community Café”-*



*Eilidh, Caitlin and Sarah from Bishopbriggs Academy share their experiences of the Community Cafe*

# Executive Summary

PRESENT is a co-production project for people living with dementia in East Dunbartonshire. It is supported by JIT (Joint Improvement Team), Governance International and East Dunbartonshire Council and members of the Dementia Network.

PRESENT aims to give people with dementia, their carers family and friends a voice. To help them feel more empowered and have more choice and control over decisions which affect them and most importantly what they can do to have a better life.

The project, its aims and outcomes are part of a wider culture change for all, including; people living with dementia, carers, family and friends, third sector, health and social services.

It is about developing people's capabilities and linking them with the communities that they live within or want to be a part of. In East Dunbartonshire, the definition of community is very locale based and it is not a one size fits all approach. People want to be involved and co-production is better way to work with people, as it ensures effective communication and better outcomes for everyone.

For this change in culture to be sustained there needs to be a real infrastructure to enhance, support and facilitate the capability approach that PRESENT and co-production encourages

Some of the outcomes that PRESENT and its associated activities are delivering for people who live with dementia include:

Increasing fun and enjoyment in their lives

Increasing Awareness of Support Services and Activities

Helping people to stay positive and in control – better placed to take part and make informed choices

Making a contribution to their community and feeling valued

People living with dementia feeling they have a voice and can shape services

Keeping people more socially connected – making and maintaining friends and connections

Maintaining/increasing sense of self-worth – recognising what they can do not what they can't

Increasing Physical Activity.

Reducing anxiety



Paula Brown Co-production coordinator, East Dunbartonshire Council, talks about what PRESENT is all about.

*John and Kathryn are married and both well into their 70's now. They don't get out much these days as a couple, Kathryn has Dementia and John finds it more difficult to cope and has to spend most of his time caring for Kathryn. Today was the first time they had attended "Mind That Song"*

*They had both enjoyed the afternoon, meeting new people and having a chat and a laugh over coffee. They were both a little uncertain and apprehensive about what "Mind that Song" was all about but quickly relaxed and joined in the singing and discussions about the music.*

*As they sang along to the old Elvis hit "Falling in love with you", Kathryn turned to John and with one of the biggest, warmest most loving smiles, took his hand in hers. He then responded in the same way, clasping her hand in his and smiling they both then laughed together sharing a special moment as a couple again.*

# Executive Summary

Some key learning that has come from the project and its activities, participants and key stakeholders include:

*"We feel like someone is listening and can help us"*  
Doreen and Bill.



The trick is to engage people in activities not about dementia

Co-production and an infrastructure for co-production will lessen some of the duplication that happens in localities and can lead to better use of resources

There is a willingness from people to be involved and it is a better way to work with people, as it ensures effective communication and better outcomes for everyone

Barriers need to be removed to allow them to contribute and set the agenda. They should help shape the agenda. Dealing with some of the underlying assumptions about vulnerable people. They can still contribute.

Community resources are needed that have an overview of what's available

A rethink is required on how to engage and consult with people and communities where they drive the agenda. To achieve this required a different mind-set and new skills

They just want to live life normally. Control is taken away from them, independence is being stripped away from them. We need to help them restore some of this

People want opportunities to get together

Community Café is an approach that could be developed further and rolled out to other Care homes and schools.

For this Culture change to be sustained there needs to be a real infrastructure to enhance and encourage the capability and encourage the capability approach that PRESENT and co-production encourages

# What we are doing.

PRESENT is a co-production project for people living with dementia in East Dunbartonshire. It is supported by JIT (Joint Improvement Team), Governance International and East Dunbartonshire Council and members of the Dementia Network. It began in August 2013 and from then there have been a number of workshops engaging people in the community, living with a diagnosis of dementia or living with a person who has dementia. Other groups include police, fire and rescue, care agencies, care home providers, park rangers, walk development officers and housing have been involved too.

Living with dementia can have a big emotional, social, psychological and practical impact on a person. Many people with dementia describe these impacts as a series of losses and adjusting to them is challenging.

The way a person with dementia feels and experiences life is down to more than just having the condition. There are many other factors aside from the symptoms of dementia that play a huge role in shaping someone's experience. These include the relationships the person has, their environment and the support they receive

PRESENT aims to give people with dementia, their carers family and friends a voice. To help them feel more empowered and have more choice and control over decisions which affect them and most importantly what they can do to have a better life.



Paula Brown Co-production coordinator, East Dunbartonshire Council, talks about having a role and a purpose



Paula Brown Co-production coordinator, East Dunbartonshire Council, talks about Co-Production and listening to people with dementia



*"I don't feel confident enough to go out much these days"*

-Bill-



*"I felt I was slipping away"*

-Jane-



*"Felt isolated on my own"*

-Mary-



*"People don't talk about it, like cancer 10 years ago"*

-Julie and Billy-

Through a number of Co-Production events, held with service partners and people living with dementia, 4 Priorities were identified.



**Creating an Infrastructure for Co-production**



**Building Caring Communities**



**Having Fun Together**



**Increasing mobility and connectivity**

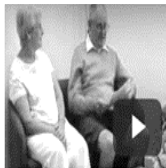
# What we are doing.

A Series of Co-Production “Labs” then allowed people living with dementia, their families and carers to develop a series of action plans and activities based around these 4 priorities.



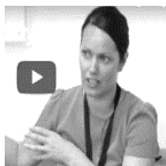
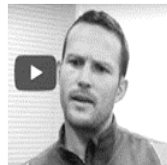
**Intergenerational  
Community Cafe**

**Dementia  
Network Website**



**Newsletter**

**Supported Walks**



**Music Network**

**Sharing Stories  
and Experiences**



Leisure

Community Health  
Partnership

communities

people with  
dementia

carers

social services

NHS

housing

## Intergenerational Community Cafe

The Community Café takes place at the Mavis Bank Care Home in Bishopbriggs. It is run in partnership with the Dementia Network, East Dunbartonshire Council and Bishopbriggs Academy and is all about promoting dementia awareness. The pupils from Bishopbriggs Academy spend time with Residents and reminisce over memories and the times gone by. Residents show pupils old memory items and explained their significance to them.

Anticipated outcomes for pupils include increased confidence, self-esteem and understanding, overcoming stereotypes. For the residents, they feel that the young people are interested in them and feel valued, part of the community, are seen as a person, and that their experience and life was important.



## Dementia Network Website

East Dunbartonshire Council have an established Dementia Network which has a long history of co-creation and co-production.

People living with dementia are experts in their own lives. With the partners in the Network, together with dementia voices we have created a dementia partnership website. This will be an online source of information starting with local, to national and international details about dementia and how to live well with your diagnosis. It is for people living with dementia, their carers family and friends, people working with a person with dementia and organisations. It will also include links to the newsletter produced by dementia voices and have information to encourage people to become involved in their community, building on their capacity.

Anticipated Outcomes are that people living with dementia, their families and those that provide support to them are connected, informed, empowered and live as well as possible with dementia and prepare for the future.



# What we are doing.

## Newsletter

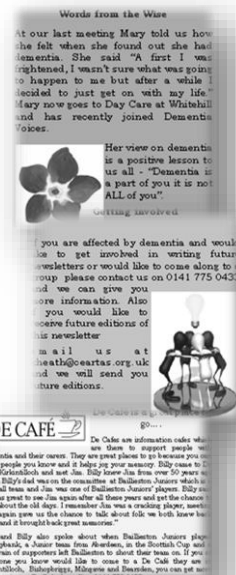
People living with dementia are experts in their own lives. Life is not all about dementia and people in East Dunbartonshire wanted to get that message out there. Dementia Network has had a newsletter for the past few years however it was felt that a change was needed; a newsletter written and produced by people with dementia with the support of the Dementia Network.

The outcomes to be achieved were: that people living with dementia are recognised as “the voice of experience” concerning dementia; that people with dementia get the opportunity to have their voice heard in the local community and that people living with dementia are aware of support

## Supported Walks

From the Co-Production workshops an action plan was co-created on what needs to change. One of the key themes to emerge was connecting to the community. The development of Supported walks was suggested and using the skills and resources of the walk development officer in East Dunbartonshire, Ceartas advocacy, who run the De Café (Dementia Café) and the willingness of people who attend the de café the plan was devised to try supported walks.

Supported walks are about facilitating those that live with dementia, their carers and families to take part in physical activity within and being part of the local community. It is anticipated that through taking part in this activity, participants would experience improved confidence, health, wellbeing and self-esteem, a reduction in feelings of isolation through staying connected to other people and their community. It also serves as an information and signposting service to increase awareness of support services and activities that they can access.



Dr Harry Seth talks about making a difference to the community he lives in.

## Music Network

The East Dunbartonshire Care Home Music Network is an email community with members of all 11 care homes and supporters in the broader community including Ceartas, Carer's Link, three faith groups, Care Inspectorate, Health Asset mapper, Glenkirk and Woodlands Memory Clinic, Art Beat, Alzheimer Scotland, PlayList for Life and local musicians. This is an organic group with the membership growing week on week due to the overwhelming interest in this area. 'Mind That Song' is a monthly music group whose participants come from local care homes and residents who still live independently within the community. The activities take place within local churches and present an opportunity for care home residents to connect with their community, meet, socialise and have fun taking part in a stimulating and enjoyable activity. The activities are facilitated by staff from Alzheimer's Scotland who lead the group in a range of musical activities where participants sing, laugh, discuss and share their lives, experiences and memories. Outcomes for participants include, reducing feelings of isolation, provision of support, having fun and improved health and wellbeing.



## Sharing Stories and experiences

A constant theme which runs through all the activities within the PRESENT project is the opportunity and desire for those that live with dementia, their families, carers and friends to be able to share their thoughts, feelings, experiences and hopes with each other and with the communities that they are part of. This allows individuals to feel that they have a voice and what they have to say has some value both for themselves and for others.

Sharing brings people together and builds relationships, confidence and trust.

This collective process can then assist in shaping services, activities and influence decisions that affect people living with dementia to help them to help themselves to improve how they live with the condition.



# .... and the difference we make.

Outcomes are about the change or difference our activities or services make for those that are involved or take part. Outcomes can be both positive and negative and can often be subtle and very personal to the individual.

The PRESENT project aims to make a difference for those that are living with dementia, their carers, families and friends by *"giving people affected with dementia a stronger presence in local communities and public services enabling them to make a contribution to other people's lives"*

**Some of the differences we are making for those living with dementia.**

Increasing fun and enjoyment in their lives

Increasing Awareness of Support Services and Activities

Helping people to stay positive and in control – better placed to take part and make informed choices

Making a contribution to their community and feeling valued

People living with dementia feeling they have a voice and can shape services

Keeping people more socially connected – Making and maintaining friends and connections

Maintaining/increasing sense of self-worth – recognising what they can do not what they can't

Increasing Physical Activity.

Reducing anxiety



*It's good to get out and have a chat and sing"*  
-Norma-

*It's lovely having the young ones here to chat to, they're full of fun"*  
-Janice-



*"I enjoy chatting", "Don't feel on my own"*  
-Helen-



*"Billy and I used to play football, we had a great chat about the old days"*  
-Jim-



*"I love to sing but will never remember all the words"*  
-Sally-

- Sally remembered the words to all the old songs!!!



*"I don't feel alone when I'm here"*  
-Margaret-



*"this is the first time we've Come along to anything like this, we've both enjoyed it and met some lovely people"*  
-Bill & Bernadette-



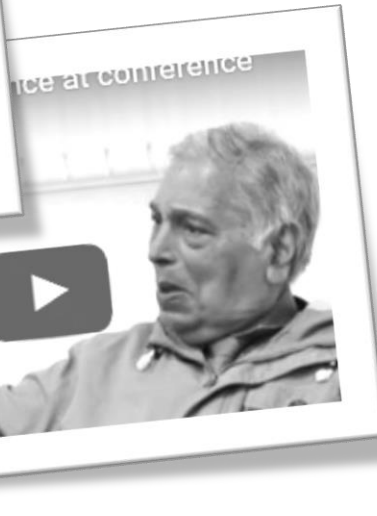
*"This is new for me, I won't be singing"*  
-Jim-

- Jim never stopped singing!!

*"Oh yes I like to come along, gets me out of the house"*  
-Bill-



.... and the difference we make.



Since his diagnosis a number of years ago, life has been challenging for Billy, his wife and carer Julie and their family.

Like many couples in this situation, they have good days and bad days but what keeps them going is their desire not to give into the condition and their willingness and motivation to get involved in activities and services that keep them active within their community and provide opportunities to be supported and listened to when they need it.

Billy says, "He's fighting it all the way"

Mary is an MBE and was a ballerina and an accountant in days gone by. She has lived with dementia for some time now but continues to have a strong voice and a valid contribution to make to her community when given the opportunity.

The "Walk my neighbourhood" consultation event gave Mary an opportunity to be heard.

# .... and the difference we make.



Karen Heath, Dementia Development Worker from Ceartas talks about the importance of being heard.

The PRESENT project is about reaching out not only those individuals that live with dementia but also to their families and those that provide care and support. It gives a voice to people that can help to shape and influence the planning of services and activities but it also provides an opportunity in the “here and now” to allow individuals to share their feelings and experiences, feel a sense of being valued and having some fun.

**Some of the differences we are making for families and those caring for people with dementia:**

Improving the understanding of the needs of people that live with Dementia

Providing Peer Support

Reducing the Stigma associated with Dementia

Families and carers are more willing and able to access services and opportunities

Improved Planning and Decision Making

Stronger support networks within the community

Reduction in anxiety



*"It's something we both enjoy and can do together"*  
-Willie-



*"We have good days and some bad days but don't we but when you're part of a group you can have a laugh and talk about things, makes you feel a bit better"*  
-Doreen-



*"You can relax in the group and not be self-conscious"*  
-George-

*"My wife loved it, we both had a great time and will be coming back next time"*  
-Bill-



*"We enjoy social occasions and learn and feel it's important for people with dementia to have a voice"*  
-Tom-



*"Grace and I had a great time and are looking forward to our next visit"*  
-Lindsey-



*"Makes you feel you're not alone"*  
-Hugh-

*"It's very difficult at the moment but it's good to be here and feel there are people you can speak to and get information"*  
-John-



# .... and the difference we make.

Some of the differences we are making for practitioners and those that work with people living with dementia.

Improved Collaboration and integration between Partners

Improving the understanding of the needs of people that live with Dementia

More effective services

Better utilisation of resources

Organisations are better able to meet local and individual needs

More effective and meaningful community engagement

Reduce Stigma and break down barriers that serve to isolate those living with dementia

Earlier Diagnosis and earlier intervention to improve outcomes

Building Capacity in the community - Increased Recruitment of volunteers



*"The group provides an opportunity to gather intelligence about other things they want to do"*  
Alex, Alzheimer's Scotland.



*"they stay engaged and in the moment", "it's a good thing to be involved in"*  
Alastair, Bearsden Cross Church of Scotland.

*"For young people volunteering on the Community café, it is a great way of improving understanding and overcoming stereotypes"*  
Scott Lafferty, East Dunbartonshire Voluntary Action



*"they love it when the young ones are here", "it brings back a lot of memories for them" "they like to tell their stories and this allows them to express themselves"*  
Pauline, Mavis Bank Care Home.



*"It takes people back to moments, places and people and important events in their lives, which they can then share, it's lovely."*  
Susan, Nurse at Westerton Care Home

*"Principle is that the groups are not done to but part of the event and bringing their personality to the activities"*  
-Sylvia Rossi, Dementia Champion, Eats Dunbartonshire Council talking about "Mind That Song"-

*"It was great for me to be there, it felt more than a standard consultation, and they felt valued and listened to, their views are important"*  
Richard Todd, Land Planning, East Dunbartonshire Council



*"Supported walks have so many health and wellbeing benefits but also act as a signposting service to other forms of support and activities that people living with dementia can access"*  
Andrew Lynch, Walking Development Officer, East Dunbartonshire Leisure and Culture Trust



Andy Lynch, Walking Development Officer from East Dunbartonshire Leisure and Culture Trust talks about supported walks for people living with dementia

# Learning for the Future.....



Some inspiring words from Harry to end.

One of the outcomes from this project is highlighting what can be learned from what has been done and the hard earned experience gained from this. This can help to inform how services are developed and delivered in the future and allow further improvements be made in terms of using Co-Production as an effective means of stakeholder engagement. Some of the key learning points to emerge include;

People are keen to remain part of their community

Music seems to stimulate people emotionally and physically

People with dementia have good insight into what they need in their Community

People want to talk and express themselves

There is a willingness from people to be involved and it is a better way to work with people, as it ensures effective communication and better outcomes for everyone

Co-production and an infrastructure for co-production will lessen some of the duplication that happens in localities.

Co-production enables people to stay active in their communities. The impact social isolation on people's mental health and physical wellbeing and encouraging socialisation and staying active may help combat some of the current challenges associated with older age

PRESENT is part of a culture change for all, including people living with dementia, carers, family and friends, third sector, health and social services.

Community Café is an approach that could be developed further and rolled out to other Care homes and schools.

A number of the songs engaged the participants in actions which are great for physical movement and co-ordination

Use person centred planning for people to look at their own solutions

Some people need extra support to keep involved but still accrue the benefits that come from participation

For this Culture change to be sustained there needs to be a real infrastructure to enhance and encourage the capability approach that PRESENT and co-production encourages

People want opportunities to get together

Involve people with dementia and their carers when planning services Asking people what they think will work

By working with people in communities this way, we will be able to enhance their wants and wishes and create better communities that better reflect the needs of the people

# Learning for the Future.....



Bishopbriggs Academy  
Pupils have some ideas for the future

Changing culture. Young people are valuable citizens and are important. They want to engage and have a voice, holding decision makers to account.

The trick is to engage people in activities not about dementia

We learn that older people haven't had their day and have something to give. They are a community asset but we need to be open and imaginative about how they are engaged.

A significant number of participants would talk and express themselves during the songs and discussions

They just want to live life normally. Control is taken away from them, independence is being stripped away from them. We need to help them restore some of this

Community engagement and consultation.  
Include other groups within this process other groups that suffer inequalities because it provides a means of integration, improves understanding, between groups. People with dementia feel more valued, what is normal and an equal member of the community

Barriers need to be removed to allow them to contribute and set the agenda. They should help shape the agenda. Dealing with some of the underlying assumptions about vulnerable people. They can still contribute.

Community resources are needed that have an overview of what's available  
Sustainability is the key issue

The group provides an opportunity to gather intelligence about other things they want to do

Future work- schools are very rigid as are care homes, don't offer flexibility to do things, structural barriers, old and young need to be at the table setting agenda. They need to be involved in evaluation of change. They need to be engaged on every stage of change,

A rethink is required on how to engage and consult with people and communities where they drive the agenda. To achieve this required a different mind-set and new skills

People who were inanimate during coffee saying very little all of a sudden became engaged and came to life when the music and activities began. It was like someone had put on the lights. Many participants could recall the words of the songs that were sung



people with dementia  
NHS  
social services  
communities  
leisure  
carers  
housing  
Community Health Partnership

**PRESENT**



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