Wicklow Dementia Support

The Community Foundation for Ireland

HEARING THE VOICE OF CITIZENS WITH DEMENTIA IN COMMUNITIES

A TOOLKIT FOR LOCAL GOVERNMENT AND SERVICE PROVIDERS

HEARING THE VOICE OF CITIZENS WITH DEMENTIA IN COMMUNITIES: A TOOLKIT FOR LOCAL GOVERNMENT AND SERVICE PROVIDERS

Created by Dr. Marita O'Brien in collaboration with Jackie O'Toole, Gillian McCarthy, Jade Butler and members of Wicklow Dementia Support Monday Club

The publication has been produced with the support of the Community Foundation of Ireland

CONTENTS

SECTION 1: INTRODUCTION

SECTION 2: FINDING OUT WHAT MATTERS TO PEOPLE WITH DEMENTIA AND CARERS

SECTION 3: KEY ELEMENTS AND RESOURCES

SECTION 1

INTRODUCTION

1.1 BACKGROUND

Wicklow Dementia Support (WDS) is a voluntary organisation, which supports people with dementia through befriending services, social clubs and carer support groups in Co. Wicklow. WDS is also a member of local government decision-making fora including Co. Wicklow Public Participatory Network (PPN) and Co. Wicklow Dementia Working Group. Co. Wicklow Dementia Working Group includes representatives from HSE Older Persons' Services, Public Health Nursing, Old Age Psychiatry, Age Friendly Wicklow County Council, Alzheimer Society of Ireland, Carer's Association and Wicklow Partnership. This toolkit arose out of the need for people with dementia and family carers to have their voice heard at these fora to ensure local services such as housing, transport, health and social care supports enable people with dementia to live independently and stay included in their communities.

1.2 PURPOSE OF THE TOOLKIT

This toolkit is to assist local government and public bodies to support people with dementia and their carers to have their say where it matters at local government and in the development of local health and social care services. Ireland's ratification of the United Nation Convention on the Rights of People with Disabilities (CRPD) means that pubic bodies must promote, protect and ensure the full and equal enjoyment of all human rights of people with disabilities including those with dementia. For people with dementia, these rights include:

- an accessible environment;
- to live independently and participate fully and equally in society;
- to freely participate in enjoyable activities and leisure of choice;
- to privacy;
- to access the same standards of health and rehabilitation as anyone else, and to live with the highest quality of life possible;
- to enjoy all of the above without facing judgement, assumption and stigma.

These rights underpin the Irish National Dementia Strategy now being implemented. For example under Principle 2, people with dementia are to be supported, encouraged and enabled to live well as valued citizens, entitled to the same from life and their community as everyone else. Their voice and experiences should inform the development of supports, services and amenities in local communities[1].

This toolkit provides practical guidance and links to resources to support engagement and consultation based on the experiences of people with dementia, carers and facilitators involved in the 'Our Voice' project. This project, funded by the Community Foundation of Ireland, developed eight experiential workshops using different creative mediums, to enable people living with dementia to express their views as to what is important to their wellbeing. The project was guided by the principle that each person is an individual with different strengths and abilities.

1.3 WHAT WILL YOU FIND IN THE TOOLKIT?

The toolkit includes:

- Information on dementia and the barriers to engagement.
- Outline of engagement processes to support people with dementia and carers to have a voice.
- Learning from the methods used by the 'Our Voice' project.
- Key elements to support the engagement of people with dementia and family carers.
- Resources to enhance accessibility.

1.4 DEMENTIA AND BARRIERS TO ENGAGEMENT

Dementia is a term which describes a range of conditions which cause damage to the brain, the most common being Alzheimer's disease. This damage affects memory, thinking, language and the ability to perform everyday tasks. Currently there are 55,000 people living with dementia in Ireland. The majority, 30,000, live in the community. The number of people living with dementia is set to double by 2031. Approximately, half a million people live in families that have been affected by dementia[2].

People with dementia are one of the most marginalised, socially excluded and highly stigmatised groups in society. Low levels of understanding and awareness of dementia leads to misconceptions resulting in perpetuation of stigma. There is a focus on impairment, rather than on strengths and abilities, resulting in the stereotyping of all people with dementia as one undifferentiated group. For example the belief that people with dementia are unable to contribute their viewpoints.

Negative perceptions and misunderstandings of dementia act as barriers to engaging with and hearing the 'voice' of people with dementia. Opportunities for people with dementia to input into public consultation processes may also be limited by low expectation about what user involvement can mean for people with dementia and a lack of confidence and training among stakeholders to facilitate engagement. In addition people with dementia may not know their diagnosis, making it difficult to engage openly in discussions about dementia and instead having to talk in terms of 'memory problems'.

UNDERSTAND TOGETHER

Research undertaken for the Understand Together campaign, a public support, awareness and information campaign led by HSE, showed that fear and stigma surround dementia, resulting in unnecessary loneliness and isolation for people living with dementia and for their families.

http://www.understandtogether.ie

---

[1] https://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf

[2] https://www.alzheimer.ie/About-Us/News-and-Media.aspx

SECTION 2

FINDING OUT WHAT MATTERS TO PEOPLE WITH DEMENTIA AND CARERS

2.1 ENGAGEMENT PROCESSES

Engaging with people with dementia and their carers to get their views on a topic can take many forms. It can be one-to one conversations, group discussions, questionnaire or a purposeful activity like “walking the patch” or “experiential workshop” or a combination of some of these. The approach adopted will depend on what works for the person with dementia, the information required and the resources available.

ONE TO ONE CONVERSATIONS

One to one interviews can give people the space in which to think and construct a response. Communication can be adapted to the individual’s needs. Questions can also be adjusted for understanding and there is an opportunity to explore in more depth individual experiences. This method may be particularly suited where a person has more advanced dementia.

GROUP DISCUSSIONS

Taking part in a group discussion can be helpful to people with dementia in articulating their viewpoint on a particular issue. Hearing the views of others stimulates discussion, maintains focus and gives confidence, especially in established groups where people know each other.

QUESTIONNAIRE

A survey could be used to collect the views of people with dementia on a particular issue. This method might work well for people who prefer not to engage face to face, but are happy to complete a questionnaire. The questionnaire should include clear instructions on filling in and where to return completed questionnaires. A more in-depth understanding of an issue may be achieved by providing respondents with an opportunity to add comments.

WALKING THE PATCH

This is a way of finding out from people, how they experience their environment, or a service; for example, going to the shop, taking public transport or attending an appointment in a primary care centre. All the time the person is carrying out their task, they are explaining what their thought processes are. This process not alone reveals the significant role environments play in disabling and constraining people living with dementia, but also offers insights into values, beliefs, and sense of belonging associated with spaces important to the person with dementia[3].

EXPERIENTIAL WORKSHOPS

The 'Our Voice' project provides examples of experiential workshops that used the creative arts to support people with dementia to express their views and opinions on different issues.

2.2 LEARNING FROM THE METHODS USED BY THE 'OUR VOICE' PROJECT

The Wicklow Dementia Support, 'Our Voice' project aimed to identify ways of supporting and enabling people with dementia to express what is important to their wellbeing. Over a 6 month period, people living with dementia, family carers and volunteers attending Wicklow Dementia Support (WDS) Social Clubs participated in eight experiential learning workshops. The workshops used the creative arts to support the participants to explore a wide range of topics including self - identity, strengths, hopes and wishes, place and the supports needed (see Appendix One for details of workshops).

To support people with dementia to express their views on an issue, learning from the 'Our Voice' project suggests consideration be given to the following questions:

2.3. WHAT IS THE PHILOSOPHY OR PRINCIPLES UNDERPINNING YOUR ENGAGEMENT PROCESS?

To empower and engage in a meaningful way, think about how the process can create a "failure free" environment, by focusing on strengths, with no right and wrong answers but enabling everyone to give their opinion.

A guiding principle of the 'Our Voice' project was that each person is an individual with different strengths and abilities. The workshops therefore were designed to draw on these, to give people their voice. To do this, the workshops incorporated elements of cognitive stimulation therapy framework including focusing on opinions rather than facts, new ideas, thoughts and associations, maximizing potential, inclusion, involvement, building and strengthening relationships. This approach creates a 'failure free' environment, increasing confidence to speak out and encouraging the sharing of opinions creating connections between people.

---

[3] See http://www3.hants.gov.uk/2012-dementia-friendly-communities-toolkit-engagement.pdf).

2.4 HAVE YOU SHARED INFOR MATION ABOUT THE PROJECT/ ACTIVITY WITH PEOPLE WITH DEMENTIA?

Has this information been provided in a meaningful way so that participants now understand:

- Why, they are being asked to engage /participate.
- How they will engage/ participate.
- When and where the engagement will take place.
- What the outcomes are of engaging/participating (for the person with dementia as an individual/ group/ wider stakeholders/ society).

People with dementia and family carer/supporter attending the social group were invited to participate in the 'Our Voice' project with the goal of identifying activities or processes that supported them to contribute their views on what is important for the wellbeing of people with dementia living in Co. Wicklow. A number of formats were used to provide information about the 'Our Voice' project to members of the Wicklow Dementia Support Social group. These included a Powerpoint presentation which outlined what the 'Our Voice' project was about, how it was connected to national policy, the National Dementia Strategy, the recently ratified United Nation Convention on the Rights of People with Disability (CRPD) and local decision-making fora in Co. Wicklow such as Co. Wicklow Public Participatory Network and the Wicklow Dementia Working Group. The slides used pictures with text kept to a minimum.

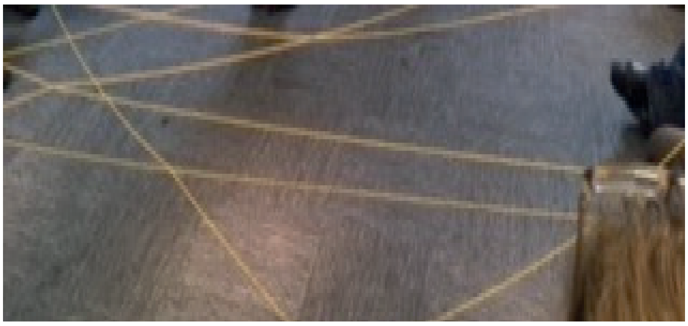
A printed copy of the slides, an information sheet on taking part in the project and a consent form were provided to each person. After the presentation, the project facilitators asked each person if they had any questions; they explained the consent form and outlined again what their participation would entail. The attendees took the information home to read. At the follow up meeting, the Powerpoint presentation was made again, where people had not brought/ signed the consent form, new information and consent forms were provided to each individual and any questions addressed.

2.5 HOW WILL YOU CREATE A SAFE SPACE SO THAT PARTICIPANTS WITH DEMENTIA WILL FEEL CONFIDENT TO SPEAK AND KNOW THEY WILL BE LISTENED TO?

Think about how you will start the conversation and ensure everyone can contribute to the best of their ability. Starting the conversation in a positive way by asking a question that enables everyone to speak and share something about themselves, builds confidence and enables links or commonalities to be established between participants, making it more likely that the engagement process will include the views of all participants.

In the first workshop, a ball of wool was used to start the conversation and create connections between participants. The ball of wool was passed between participants. The person holding the ball of wool had the floor, and was invited to tell the group something about themselves. Where a person found it difficult to think of something, the facilitators asked specific questions such as tell me about the things you like to do? The wool created a visual of stories shared (e.g. where people grew up) identifying commonalities. By breaking the task down into smaller parts, the facilitators ensured that each participant, regardless of their stage of dementia, took the opportunity to share something about them and their lives with the group. This approach worked well to make people feel at ease as people can be apprehensive about taking part in new things.

It was also important that facilitators used short questions and repeated each response back to the whole group to accommodate people with hearing loss and people with more advance dementia and keep their attention, thus ensuring the discussions involved all participants.



2.6 WHAT TECHNIQUES CAN I USE TO SUPPORT PEOPLE WITH THE DEMENTIA TO EXPRESS THEIR VIEWS?

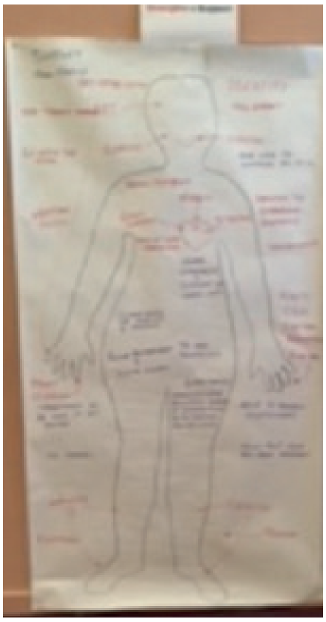
It is important to recognise that each person with dementia is an individual with different strengths and abilities, so different techniques will need to be considered for appropriateness.

In the 'Our Voice' project a number of techniques were used to support the person with dementia to express their views

SOCIODRAMA is a technique used to explore an issue experienced by a group by enacting the scenario and looking at how the issue can be resolved using an improvised play. Sociodrama was found to a useful medium for portraying barriers people with dementia encounter in their day to day life. The sociodrama successful explored with participants barriers people with dementia can face such as attitudes and aspects of the physical environment for example difficulty in locating toilets in public places due to poor signage. These barriers can be a deterrent to people with dementia continuing to participate in activities. The sociodrama format also enabled participants to identify and express their opinion as to how these barriers could be addressed, for example by staff being more respectful and better signage for public toilets. .

Whilst sociodrama techniques are helpful in highlighting, naming and addressing attitudes and behaviours, for people with dementia it is important to keep the improvised play short and simple and confine to one scenario. This technique may not be appropriate for people with more advanced dementia as they can interpret the drama as 'real' life, and find it more difficult to participate in the process used to resolve the issue.

A BODY MAP, a drawing of a full size outline of a person's body provides a visual focus which can be an effective tool in supporting both the person with dementia and carers to speak about experiences and express views. The 'Our Voice' project used body maps to facilitate group discussions on strengths, hopes and support needed. Facilitating discussions in two groups concurrently, one for participants with dementia and one for carers worked well as participants could speak honestly for themselves. Once again the questions were kept short (see Appendix One) and the visual aid of the body map enabled participants to think holistically. For example where different strengths came from within their body such as having strong legs allowed a participant with dementia to walk from their home to the town. It moved the focus away from what the person can't do because of dementia.



For participants supporting a person with dementia, the Body Map created a focus outside of the individual, which enabled the acknowledgement of the impact of dementia on their lives. For example the disappointment and hurt they felt when friends faded away once they became aware of their spouse's dementia diagnosis and symptoms became more obvious and the difficulty of being there for the person 24 hours a day.

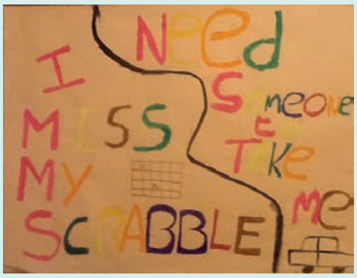
REMINISCENCE is another technique that can be effective in gaining insight into things that are important to the person with dementia. Using objects related to the topic for discussion can help stimulate discussion and provides an opportunity for everyone to engage at some level in the discussion. It can highlight every day activities/ occupation that are meaningful and important to the person with dementia.

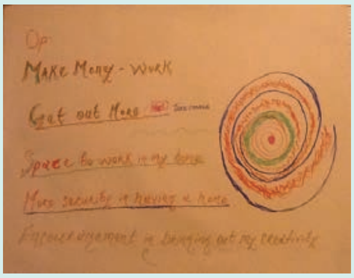
VISUAL ARTS, such as painting, collage and clay, offer a powerful medium for expressing inner thoughts and feelings. The 'Our Voice' project used collage, clay and painting to explore answers to questions such as "Who I Am", "What I Hold Close to my Heart" and "What I Want".

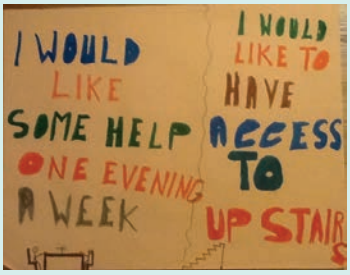
Using collage to explore self-identity, provided participants with an opportunity to speak about who they are, their good and bad qualities and how these shape their lives, in the past and now as they live with dementia. The process was effective in highlighting how dementia is not the defining aspect of the individual and it allowed the person with dementia to identify as a unique individual with many qualities, abilities and strengths. The process also enabled the facilitators to gain insight into the person's life, the things they had achieved and their strengths and abilities.

It can be difficult to acknowledge to others that we need support and ask for help. Putting our thoughts on paper can be an effective way of communicating emotional and hard to acknowledge aspects of our life. Using paint and words to communicate things important to the person with dementia and the support they need to continue doing things they enjoy was very effective in highlighting needs and practical actions that public bodies and others can take to meet their needs.

For example, participants were asked to imagine going on a protest march, what would be on their banners or placards.







In many instances, the person with dementia and their carer worked together to design their placards. The process uncovered simple things like "missing going to scrabble" due to needing support from a companion to be there with the person. It also highlighted gaps in the system where a person with dementia had to depend on her son-in-law to carry her downstairs every morning and back up in the evening as the family were unaware of how to access a stair-lift.

In another workshop, participants were asked about places and amenities important for their wellbeing . Painting pictures of amenities that are important to people with dementia, such as the DART, walking Bray seafront highlighted how the social inclusion of people with dementia is dependent on amenities being made accessible to people with dementia.

A key learning from the 'Our Voice' project was how engagement with the creative arts generated information in an organic way (i.e. naturally occurring data), in that the conversations around the activity revealed valuable information about what people with dementia think and feel which can contribute significantly to public policy and service development, if noted and acted on.

SECTION 3

KEY ELEMENTS AND RESOURCES

3.1 KEY ELEMENTS TO THE ENGAGEMENT OF PEOPLE WITH DEMENTIA

People with dementia, as citizens, have an equal right to participate in public life and influence the decisions that affect their lives and communities. Their will, preferences and priorities (and their families as appropriate) should inform the supports and services that are provided to them. Key elements in supporting people with dementia to have a 'voice' in local government decision-making processes and influence policy and service development are:

- An environment in which everyone expects, promotes and supports participation of people with dementia as central to responsive policy and practice ;
- Public bodies allocate time to plan and build trusting relationships with people with dementia and family carers and support them to contribute to the process in ways that are helpful to them.
- A variety of opportunities for people with dementia to get involved are provided and different methods are used to enable them contribute their viewpoints based on the strengths and abilities of the individuals.
- People with dementia and carers have the information needed in order to be involved.
- Organisational processes are made accessible to people with dementia. For example by ensuring written material uses straightforward language (avoid use of acronyms), meetings include visual materials (e.g. powerpoint, handouts) to back up discussions; agendas are restricted and there are frequent breaks.

Ground rules are established to enable all participants to gain maximum benefits from any engagement, learning event or meeting, for example people speak slowly and don't interrupt.

Resources are allocated to support the engagement of people with dementia in discussions. For example a staff member within an organisation acts as 'connector': providing information; helping people with dementia to prepare for meetings; offering practical support such arranging transport; responding to queries, organising meetings; maintaining the relationship between people with dementia and decision-makers.

Ethical principles are applied including getting full, informed consent.

Communication is the key to engagement so must be appropriate and effective. For example facilitators of face to face engagement process are dementia aware communicators and have some understanding of the lived experiences of people with dementia.

The engagement process creates an environment where people with dementia feel free to express views and wishes; feel confident to do this without fear of adverse consequences; they are listened to and have their views respected and heard.

The engagement process is not tokenistic or a one off event, but seeks the views of people with dementia on an on-going basis and their viewpoints influence decisions and what happens.

There is transparency – people with dementia know how the feedback collected will be used and will be informed of the outcomes.

3.2 RESOURCES TO SUPPORT ENGAGEMENT

People with dementia have developed a number of resources outlining how to support their involvement and make it count. For example the Involving People Living with Dementia Reference group in the UK, which included people with dementia and family carers, developed 'what works' resource cards to help organisations to engage and consult with people with dementia. Card 17 offers tips from people with dementia which include

Take the time to find out about my interests, what I have done in my life and how I like to be involved.

Find out the best way to communicate with me.

When is the best time to talk to me? This has to take into consideration my daily routine and 'good' times of day for me.

The Dementia Engagement and Empowerment Project (DEEP) in the UK brings together and supports groups of people with dementia to try to change services and policies that affect the lives of people with dementia. DEEP have developed guides to support the involvement of people with dementia in policy and service development[4]. Guidance is provided on

How to make written material accessible in the Guide to Writing Dementia-Friendly Information, available at **http://dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf**

Choosing accessible meeting rooms or venues in the Guide to Choosing a Dementia-Friendly Meeting Space available at **http://dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Choosing-a-meeting-space.pdf**

---

[4] DEEP Guides http://dementiavoices.org.uk/resources/deep-guides/

Ways organizations can engage with people with dementia includes facilitation tips for one to one conversations and discussion groups in the Guide to Collecting the View of People with Dementia, available at **http://dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Collecting-views.pdf**

Adjusting organizational process such as meetings to support people with dementia to take an active role in steering/advisory groups in the Guide to Involving people with Dementia in Advisory Groups, available at **http://dementiavoices.org.uk/wp-content/uploads/2016/03/DEEPGuidance_involvingpeoplewithdementiainadvisorygroups.pdf**

Another resource on engaging people with dementia is the Dementia 2020 Citizens' Engagement Programme: Toolkit for engaging people with dementia and carers, available at **https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/564973/Dementia_toolkit.pdf**, contains examples of guiding principles, facilitation hints and tips, a consent form and a survey.

3.3 COMMUNICATION RESOURCES

Resources are available that provide guidance and support around effective communication with people with dementia. These range from basic tips on communication to online communication skills training in dementia to tools such as Table Mats:

Communication Tips for example those outlined by Surry Dementia Friendly, available at

http://housetheatre.org.uk/wp-content/uploads/2014/03/Top-Ten-tips-for-communicating-with-a-person-with-dementia.pdf

The By Us For Us Guides are a series of guides created by persons with dementia and/or partners in care, available at **https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/products-education-tools/by-us-for-us-guides**. The guides are designed to equip persons with dementia with the necessary tools to enhance their well being and manage daily challenges. The guide, Enhancing Communications outlines the main challenges associated with communication as experienced by persons with dementia and provides practical solutions using a wide range of communication strategies in order to make opinions, feelings and experiences known.

The UK Social Care Institute for Excellence (SCIE) online communication training. Available at

www.scie.org.uk/dementia/open-dementia-e-learning-programme/7-positive-communication.asp

Talking Mats, an interactive resource that uses three sets of picture communication symbols - topics, options and a visual scale, to help people with dementia express their views. Available at **https://www.talkingmats.com**

APPENDIX ONE: DETAILS OF WORKSHOPS

PERFORMING ARTS

The first four workshops used elements of the performing arts as a medium for self-expression and were co-facilitated by a drama professional. Table 1 outlines the aim, approach taken and learning from each workshop (each workshop took approximately 75 minutes).

TABLE 1: WORKSHOPS USING ELEMENTS OF THE PERFORMING ARTS

WORKSHOP 1 GETTING TO KNOW YOU

Aim: To build confidence and make people feel at ease

Approach: The focus of the activity was to give each person an opportunity to speak and share something that is important to them. A ball of wool was passed or thrown between participants, each participant kept hold of a piece of wool. The participant holding the wool shared what matters to them in their day to day life. The responses were recorded on flip chart (a spider web approach was used as visual representation to record responses).

LEARNING

- Importance of creating a safe space to speak and be listened to.
- The visual representation (the wool and the drawing of spider's web) of being linked together at a time and place, sharing similar experiences and needs encouraged the sharing of stories
- A facilitator with knowledge of dementia can ensure all can contribute their views by breaking down into small parts the questions and tasks
- To keep people's attention, it is important that facilitators use limited short questions and repeat each response back to the whole group. This accommodates people with hearing loss and people with more advance dementia.
- The activity was overall effective as the discussions provided information about things that are important for people with dementia in their day to day lives but also the acknowledgment of how it was harder to do some of these things now. For example a participant with dementia spoke of loving to look around the shops but needed someone to go with her now; a carer shared how they like to go for hill walks, but couldn't as "under house arrest".

WORKSHOP 2 THE TEA DANCE

Aim: To explore barriers in attending a social event.

Approach: This activity used socio-drama (a play centred on attending a tea dance) to support participants identify barriers they can encounter when attending an event. The focus was on dealing with situations such as ordering a coffee, way finding and signage.

LEARNING

- Socio-drama is a useful medium for portraying barriers people with dementia can encounter in day to day life and for exploring ways of resolving these. However, the drama needs to be kept short and simple. The inclusion of a number of scenarios in the workshop made it difficult for some participants, particularly those with more advanced dementia to engage with the drama and contribute to the discussions.
- Some of the volunteers and carers found the scenarios hard to relate to in relation to the person with dementia being in such circumstances, i.e. going to an event unaccompanied.
- This activity did facilitate participants to explore barriers such as attitude that could deter people with dementia from continuing to do things they enjoyed; the physical environment such as difficulty with way-finding highlighting the importance of signage for facilities like public toilets. It also initiated discussion on how to resolve the issues identified.

WORKSHOP 3 MY STRENGTHS AND HOPES

Aim: To explore strengths, hopes, wishes and supports needed.

Approach: Using the two outlines of a body, people with dementia and family carers, separately, considered these questions:
What do you feel are your strengths? Or 'Are there particular things you are good at?
What are your hopes?
What are your wishes?
What would help you make your wishes come true?
Are there things that you may need help with?

LEARNING

- The visual body map was a very effective tool. It assisted people with dementia to think about where different strengths came from within their body e.g. strong feet and legs allowed them walk down town. So whilst there was an issue with their brain, their bodies were strong in other ways which allowed them to sing, read, walk, dance. They also related their hopes to different parts of the body map e.g. peace and contentment at the core (the heart). It was very positive for some of the participants with dementia to name and think about their strengths instead of deficits. It was equally interesting to hear their hopes for the future regarding the importance of retaining their sense of identity, who they are, feeling respected.
- The activity provided carers with an opportunity to express how they felt as a carer in relation to the different questions. They did not have to retain the façade of 'all is well'. For example they spoke of feelings of disappointment and hurt where friends had faded away once they became aware of their spouse's dementia diagnosis and symptoms became more obvious. They could speak openly about the difficulty of providing round the clock care and shared tips on how to get a break.
- The Body Map activity was very effective in supporting both people with dementia and carers to also speak about what they needed help with. People with dementia identified support from family and group support as being vital to their well-being; help to remain independent such as transport to events and shops are also important. Carers identified information and person-centred support for the person with dementia as crucial for their well-being.
- All of the participants were able to engage in this activity, although a few did require support from a facilitator with knowledge of dementia, to contribute.

WORKSHOP 4 CONNECTING THROUGH REMINISCENCE

Aim: To share memories of Christmas and by doing so give some insight into things that are important to people with dementia

Approach: Items associated with Christmas were set out on a table and participants gathered around the table in a circle. Each person chose an item and related why the chosen item was meaningful to them.

LEARNING

- The activity provided an opportunity for all of the participants to engage at some level in the discussion. For example participants told stories about what the object chosen meant to them, those with more advanced dementia nodded their agreement with a memory shared by their care partner or in reply to questions asked by the facilitator.
- The activity was effective in highlighting the importance of family now and in the past and being able to participate in traditional events like decorating the Christmas tree.

VISUAL ARTS

The second four workshops used elements of the visual arts as a medium for self-expression and were co facilitated by an artist. Table 2 outlines the aim, approach taken and learning from each workshop (each workshop took approximately 70 minutes).

TABLE 2: WORKSHOP USING ELEMENTS OF THE VISUAL ARTS

WORKSHOP 5 WHO I AM

Aim: To explore self-identity.

Approach: In this workshop, participants considered the question ‘Who I am’. The focus was on giving participants an opportunity to express who they are, their strengths and attributes, using collage. Participants used fabric and other materials to build a picture of themselves and then added individual words that described who they are, e.g. warm, strong, generous, loving. The focus was on identifying strength and abilities

LEARNING

- People with dementia can become defined by dementia, their other attributes and talents ignored
- Initially participants were asked to draw an outline of themselves. This was a barrier to some, so in the pilot workshop, the facilitators provided a photocopied outline of a person to each participant.
- This activity provided participants with an opportunity to speak about who they are, their good and bad qualities and how these shaped their lives in the past and now as they live with dementia. Where participants had support in engaging in the activity, volunteers/facilitators got new insight into the person’s life, the things they had achieved and their strengths and abilities.
- The activity overall enabled participants to speak about themselves and it was effective, as participants identified the many attributes and talents that define them.
- The works produced challenged stigma, as they constructed the person with dementia as unique with many qualities, abilities and strengths.

WORKSHOP 6 MY TOWN, MY PLACE

Aim: To explore place and amenities important to the wellbeing of the person with dementia.

Approach: This activity focused on giving expression to place and what is important about place to the person with dementia and carers. Participants were asked to paint a picture of places and/or amenities in their town that they enjoyed or other places that gave them joy.

LEARNING

- Despite many of the participants never having painted before, all were enthusiastic about the activity.
- This workshop fostered conversation on where people were from, activities they enjoyed and also the sharing of stories about different places.
- It highlighted amenities that are important to people with dementia, such as being able to walk on Bray seafront. It also highlighted services such as public transport e.g. the DART, which make places accessible to people with dementia.
- The information gathered identified places and amenities that contribute to the wellbeing and independence of people with dementia. This information informed a submission on wellbeing to the Co. Wicklow Public Participation Network. Information like this can be used to lobby and advocate for these places and amenities to be made dementia friendly/ accessible.

WORKSHOP 7 THINGS I HOLD DEAR TO MY HEART

Aim: To explore things that participants keep close to their hearts.

Approach: Feelings come from the heart, so the idea for this activity was to facilitate people with dementia to express what is in their heat. They used clay to make a model of a heart, and added words to describe things they hold dear. They identified things like grandchildren, joy, hope, friends, flowers.

LEARNING

- The activity highlighted how regardless of the impact of dementia on the brain, people with dementia will always hold things that are dear to then in their hearts.
- Once again the focus was on the person with dementia's abilities, things people feel within their hearts.
- The information generated counters stigma and stereotyping of dementia highlighting how a person with dementia is still a person with feelings.

WORKSHOP 8 WHAT WE WANT

Aim: To provide participants with an opportunity to identify and speak about things they no longer do, but want to do and with the 'right' support can do.

Approach: In this workshop, participants were asked to imagine going on a protest march, what would be on their placards or banners. In many instances, the person with dementia and their carer worked together to design their placard.

LEARNING

- This workshop was very effective at uncovering the barriers carers and people with dementia encounter to living well.
- In sharing stories, participants got advice and support from each other. For instance, one dyad wrote 'to be able to use the upstairs' explaining to the group how her mother's bedroom was upstairs as was the bathroom, so her husband had to carry her mother downstairs every morning and back up every night. The group discussion then focused on access to information about resources like stair-lifts, incontinence wear, carer's benefits etc.
- It worked as a platform for conversation, about things people find difficult – asking for help, emotional things like having to depend on partner.
- The activity was very effective in giving voice to the participants and the stories that emerged provide strong cases to support advocacy.