



FACT



# GUIDELINES FOR MEANINGFUL PARTICIPATION OF PEOPLE WITH LIVED EXPERIENCE OF DEMENTIA:

## THE CO-PRODUCTION OF CREATIVE AND CULTURAL OPPORTUNITIES.

The words and comments in this guide are taken from consultation with people with lived experience of dementia who attended the FACT workshop in Liverpool in November 2017 and shared their narratives. Many people who have a diagnosis of one of a dementia engage in creative activities, and are productive as artists, writers, musicians, song writers, bloggers and social and cultural activists in their own right.

Human Rights entitle us all to a community life, equity of respect and the highest attainable standard of clinical and social health. Creative opportunities are one of the means that can fulfill those rights, and can empower us to live well with a dementia. If people living with experience of dementia are involved as co-producers from the start and throughout the creative process, those rights are fulfilled with responsibility, and community and individual well-being are mutually enhanced.

### Key Messages:

- People living with dementia are creative individuals and have significant expertise to contribute.
- The keys to meaningful participation are support, enablement and accessibility.
- Meaningful involvement is fundamental to well-being and social health.
- Creative opportunities do not have to be dementia focused but should be dementia inclusive.
- Creative opportunities should be built on people's needs, interests and passions.
- Diversity enriches us all, and creative opportunities help to preserve and develop our cultural and individual identities.

## Core Values and Principles:

### 1. Planning and co-production is the key to success.

“We can be enabled by the environment and not limited by our diagnosis.”

- Creative and Cultural opportunities may be designed to include people with lived experience of dementia; may be led and initiated by people with lived experience or be a combination of these initiatives.
- Involve us as co-producers, researchers, and facilitators from start to finish.
- Ask us about what our access needs are, perhaps on an accessible proforma. Treat each of us as an individual, because everyone’s experience of dementia is unique. Ask about sensory issues (noise/audio, light/vision, mobility/safety.)

“Poor access is a big hindrance. Can be bad signage, too many steps etc. If you can’t get in the front door you won’t want to come back.”

- Where necessary, make adjustments, and provide appropriate, personalized, support. Maps, directions, signage, noise reduction, an attentive welcome – all these help us to feel welcome. Often, a bad experience regarding parking or transport can discourage attendance.
- Invite us to lead a dementia friendly audit of the venue and the activity, and be keen to repeat and update that audit as your “project” develops.
- Provide us with clear information about the best way to get to the venue, where the lifts are, what we need to bring, and give us any warnings we may need to take heed of (e.g. cobblestones or one-way systems).
- Help us to make sure we can have confidence in the transport system.

- Make sure timings are appropriate, for example, bus passes are not always usable. Be aware that we may need to opt in and out of activities. We have a right to make our own choices.

“I have lived with Alzheimer’s for eight years. Let me snooze if I need to. My catnaps are very important to me, they refresh my mind.”

“It was really appreciated that mummy was helped to walk to the building from the car. It made her feel included and respected.”

- Find out about and plan for the needs of our care partners. Many of us cannot be socially active at all without their help.
- Find out and plan for cultural differences. Try to allow for language, food, local and cultural differences. Celebrate those differences.
- Not all of us can get to community venues. Consider taking cultural and creative opportunities to where we live. This can help us to remain safe.
- Consistent and reliable times are appreciated. Reminders and updates help. Some of us use text, some email, voice-mail, or the post. If you find out what we prefer we can stay involved.

“Creative activities enhance life, they can enrich life for people who live in care homes.”

“Knowing there will be a legacy from the opportunity is very important.”

- Let us know what outcomes result, and ask us how it was for us.

## **2. Be Hopeful, be positive and be respectful to each other.**

- Creative and Cultural opportunities should be about the person not the diagnosis.

“It is very important to recognise that my definition of a creative opportunity may be different to everybody else’s. It is a very personal matter.”

“I am a mother of three, and a grandmother. That is who I am.”

“Song Writing. I have always been creative, needed to express myself. I have written more songs since my diagnosis. My aim is to win the Cannes Festival, and I’m not joking.

- If the Opportunity is based on our individual, community and cultural needs, interests, and passions it is likely to be very productive and enriching for facilitators and participants.

“Living with dementia is not the end of the world.”

“I live with Lewy-Body disease. I have a vendetta against my dementia. It is possible to live successfully with dementia. I am still me.”

- Creative opportunities help us to preserve cultural and individual identities, and to share with and learn from others.

### **3. Work with Love and Compassion**

- Meaningful participation can help to address and challenge Stigma.
- Collaboration in Creative opportunities can be an effective way of enhancing cultural equality and diversity. All age groups and communities can share the opportunities.

“Living with dementia I find that I can read very well, but I am less able to write. Creative opportunities help me to express myself in new ways.”

“I use photography. I did the modelling and my husband did the photography. The photography and the images helped me to express what I wanted to say, to “catch the words.” – I know it, I can see it, but I can’t say it, so the photograph interprets with me.”

- Empowering us to meaningfully participate and co-produce can make sure that we can access mainstream art and cultural activities.
- It is very important to recognise that it is an achievement to be independent, and to build that into opportunities.
- Those of us who live with dementia are still part of the community. Listening to each other's narratives helps us all.

“A ninety-one-year-old artist came to give our community a talk. It was very inspiring.”

“Creative opportunities create social opportunities and social health. They help people to avoid a dead-end.”

“I was diagnosed 4 years ago, my family support me, we are all doing ok. It was not really a surprise, there is a family history, Nana had dementia. The hospital she was in was like a prison. I was horrified by her treatment. Thinking of the past makes me cringe.”

#### **4. Difference and Diversity enrich us all.**

- People who live with the experience of dementia have expertise and creativity to offer the community. We write books poetry and plays, exhibit our art-works, and compose and perform music and song.
- This is true of people in every community of interest or cultural community.
- Creative opportunities can help us all to understand each other and enrich our personal and social lives.
- If opportunities are co-produced then we can remain part of our community by accessing community events, and our community can share our experience through our expression.
- Meaningful participation and co-produced creative and cultural opportunities can enable everyone to speak, to learn new skills and to understand.

- Creative opportunities can help us to live well, and celebrate our lives and relationships.

“I like to be independent.”

“Creative opportunities can address loneliness issues by being inclusive and building from the ground up, not from the top down.”

## **5. Keeping an open mind**

- During co-production processes a flexible approach can be very helpful. An accessible structure allows for choice, and breaks as they are needed.
- An accessible structure or agenda gives us the room to express ourselves.
- Too much structure can be stressful.
- Not enough structure can be distressing.
- Networks are essential. If participation and co-production are integral to creative and cultural work, we will get to know what is going on and get involved.
- We have the right to have the support that we choose at events and meetings.

“Medication is important, but it is not as important as being involved.”

“Using and giving support and helping other people is really important to me.”

**PMT Innovations in Dementia Nov 27 2017**