

Bristol Dementia Action Alliance recently ran two workshops for projects within the BAB programme and other organisations working with older people in the city. The aim of these workshops was to learn more about how organisations and individuals **can reach, engage and include older people with dementia within their community activities.**

This Learning Digest presents the key learning and ideas from these two workshops.



Understanding the context

It is estimated that 850,000 people in the UK have dementia¹, **4,500 of whom live in Bristol**².

Dementia is not a single disease, it is an umbrella term to describe different conditions affecting the brain. Alzheimer's disease is the most common form of dementia, but other types include vascular dementia, Lewy body dementia and frontotemporal lobe dementia. It is caused by diseases of the brain and involves some of the brain cells to decline in function and die prematurely.

Dementia is progressive; the condition will get worse over time and there is not currently a cure.

Dementia is not just about memory loss, it also affects spatial awareness, perceptions, speech, understanding, concentration, energy levels and sometimes hallucinations. In addition to there being multiple conditions under the category of dementia, even **the same type of dementia will affect individuals in different ways.** Although you may be familiar with one person with dementia, somebody else with the same type of dementia may have very different symptoms and experiences.

Dementia can make everyday tasks such as preparing food or a hot drink very difficult and time-consuming. Friends, family and carers of people with dementia sometimes report finding it difficult not to step in and do these tasks on their behalf. However by doing so it may prematurely deskil the individual before the dementia progresses to that stage. There are **a variety of ways you can make your home dementia friendly** in order to support the person with dementia, for example having clear pictures showing what is inside a cupboard.

There is **more to the person than the dementia**, and they are able to **live an active, full life.** During the two workshops, attendees brainstormed the possible barriers to community engagement which might be faced by someone with dementia and/or their carer. The following pages present these ideas, with the aim that increased awareness of these barriers can help organisations working with older people in Bristol to be more inclusive of those with dementia and to feel more confident in actively reaching out and engaging with these individuals.

Further information and resources can be found in the section on page 4.

¹ Alzheimer's Society: Facts for the Media

² Projecting Older People Population Information System: 2018



What might be some of the main barriers to community engagement faced by older people with dementia?

Frustration about not being able to do things in the same way as before – having to find new ways of taking part in community activities.

Anxiety about being **treated differently**, that other people will only focus on the dementia instead of other parts of their personality.

Feeling unwelcome by community groups who see someone with dementia as **difficult or inconvenient**.

Uncertainty about the future, the changes that will happen and the decisions that will need to be made at some point, but not knowing when.

Tiredness, particularly in the afternoons and evenings or when the dementia is affecting sleep patterns.

Lack of information - not knowing what activities or support are available.

Feeling **embarrassed** about having dementia - not wanting to admit it to others.

Feeling more **vulnerable** than before - unsure who can be trusted when meeting new people.

May need to fit community activities around a **carer's availability**. Some groups require a carer to attend, even if the individual does not need this.

Sense of loss – not wanting to do the same activities or see the same friends that they used to when they did not have dementia.

May no longer be able to drive or navigate public transport **independently or as confidently** as before.

Other people assuming that they know best, making decisions on behalf of the person with dementia.

Taboo and lack of understanding surrounding dementia in some cultures.

Some groups or activities are only for those with a **diagnosis of dementia**, despite cognitive impairment occurring before this.

Not feeling in the mood to socialise and meet new people due to **stress and anxiety**.

May **lose** existing **social networks** but then **gain** the chance to be part of others.

Filling in the **forms** required by some activities and services can be difficult without support.

Fitting community activities around **other appointments**.

Other people's **misconceptions about dementia** and how someone should (or should not) be behaving.

Other people's disbelief if the person with dementia is **younger than expected**.



What might be some of the main barriers to community engagement faced by the carers of people with dementia?

Carers may have their **own health conditions** to manage alongside the caring role.

Impact of long-term **stress and exhaustion**, for example may feel less motivated to meet new people.

Lack of time to take part in community activities for themselves, as may need to fit these around the person with dementia.

Finding community groups or activities that both the carer and the person with dementia are **interested in doing together**.

Not knowing where to find help or support for themselves as a carer – difficulty navigating the system.

Lack of **finances**, particularly if the caring role affects their ability to work.

May **lose contact** with previous social networks as a result of becoming a carer.

Some activities only allow someone with dementia to attend if the carer is present – which means the **carer needs to give up this time too**.

May feel **guilty** about having time away from the person with dementia, or having fun without them there.

Fear of being labelled as a carer and seen this way by others instead of an individual with their own interests and personality.

Always being 'on call' even when not with the person with dementia, therefore finding it **difficult to relax** and focus on other things.

May not feel confident to take part in community activities if they rarely do so.

Future uncertainty – may not want to start something and **then have to stop again** when the dementia progresses and the caring role changes.

Difficulty of **breaking habits and routines** if things have been a certain way for a long time, even when they feel lonely and isolated.

There may be a **family expectation** that they focus on the caring, without spending too much time on themselves.

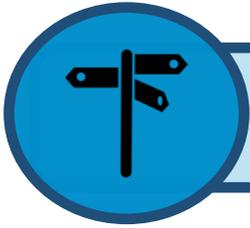
Loss and bereavement when they are no longer a carer – finding their own identity after things change.

Changes in the relationship with the person with dementia – activities that used to be done together might be different now.

Vulnerability to low mood, depression and feelings of loneliness. May find it difficult to ask for help and support for **their own mental wellbeing**.

May feel like they **lack control** over their own life, and therefore may need additional encouragement to take part.

May feel anxious about the possibility of **needing to cancel at short notice** if something comes up with the person with dementia.



Further information and resources



Bristol Dementia Action Alliance

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Alzheimer's Society

- <https://www.alzheimers.org.uk/>
- National dementia helpline: 0300 222 11 22
- Talking Point online community: <https://www.alzheimers.org.uk/get-support/dementia-talking-point-our-online-community>
- Make your home dementia friendly: <https://www.alzheimers.org.uk/get-support/making-your-home-dementia-friendly>
- Resources for organisations to become dementia-friendly: <https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/organisations/resources-organisations>

Dementia Wellbeing Service

- <http://www.bristoldementiawellbeing.org/>
- 0117 904 5151

Dementia UK

- <https://www.dementiauk.org/>
- Dementia helpline: 0800 888 6678

National Dementia Action Alliance

- <https://nationaldementiaaction.org.uk/>

First Bus Safe Journey Card

- <https://www.firstgroup.com/help-and-support/safe-journey-card>

Carers Support Centre

- <https://www.carerssupportcentre.org.uk/>
- 0117 965 2200