



The Dementia Engagement
and Empowerment Project



Women with dementia – our voices

In June 2015, a group of seven women with dementia along with some supporters got together to talk about the JRF-funded project on Women and Dementia.

We are not against men, and recognise that men with dementia and men who care for people with dementia have many of the same issues as women. We do not want to create a divide between men and women.

However, we know that a ‘sisterhood’ of women working together can empower women and support them and we hope that this approach might help women with dementia.

In addition, we support the idea of men sometimes needing separate support.

Key messages

- **Women-only groups could be very useful for many women with dementia**
- **Women with dementia themselves can play a big part in supporting other women with dementia**
- **Women’s voices should be heard and women should be encouraged to get involved**

Women's groups and how women with dementia can support each other

We don't want to exclude men from our lives but we do think there is a place for groups and activities that are reserved for just women.

Women's groups offer a safe place where women can talk to each other in a relaxed atmosphere, where they do not feel have to worry about what they say.

In particular, there are women who have chosen not to have men in their lives and should have the choice of women-only groups

There are specific women's issues that we need to talk about together – for example the menopause or continence.

There are issues that only women really understand - like what it means to you to be feminine.

We think that men also need time without women.

Following a diagnosis of dementia, women can lose confidence and talking with other women can help to give women their confidence back.

We as women with dementia can support women who are newly diagnosed to come to terms with what is happening to them by offering friendship and support.

How we as women with dementia can help more women to have a voice

We want more women with dementia to influence their own care and dementia policy and practice more widely.

We need more women who are role models to inspire other women to get involved.

Women like us can help other women to get more involved if they wish to by mentoring women and passing on our knowledge. One specific way would be to give joint presentations to support women new to public-speaking, and to offer to let women practice their presentations in front of us.

We also need to acknowledge the role that women do locally – it's not all about big conferences. Women talking in smaller groups can be just as influential.

We need to use our networks – for example other women’s groups and social groups – to raise awareness about dementia.

In group situations, men tend to dominate the conversation. We can support women to have their say by being a friendly face and supporter. Women are often used to having close friendships and doing things in pairs with another woman throughout their lives.

We can encourage women to join groups.

We can encourage both women and men to share their experiences and not to be afraid of their emotions.

We can challenge people who might (sometime unintentionally) dismiss or put us down through humour or actions.

Our carers

We know that our husbands and other men in our lives support us really well. But we know that many family carers are wives and often daughters and daughters-in-law. And that there is an assumption that women will take on the role of ‘carer’.

We don’t want our relationships with our families to be ruined by them being carers.

We especially want our daughters to be our daughters – not our carers.

We think that men who care for family members can sometimes get more recognition because society doesn’t expect them to be the ‘carer’.

The services provided for us

We have noticed that the attitude of some staff is different towards men and women. For example it’s assumed that women will make tea whereas men will have tea made for them.

The feeling is that women can manage by themselves – they will chat and make friends.

This leads to special services being developed for men – eg men in sheds and reminiscence about sport - with no equivalent for women.

What we want for the future

We want people to hear what we are saying today.

We want women with dementia to have more support in the future.

We want the experiences of women with dementia to be followed over time to see if what we are saying has an impact on women's lives in the future.

We hope that this project has a legacy for future generations of women with dementia.

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