

Benefits of being a group member in our involvement network for people living with dementia

Summer 2017 Topic

Words in colour font are themes identified from responses

Group	What's the most important things for you about taking part in your group?	How important is it to you to feel part of your group – rather than are just meeting people once or twice for a focus group discussion?	How do you feel you use your skills, knowledge and talents in your group – for example do you feel you can be creative and influence change?	If you could change one thing about these groups what would it be?
Bishop Auckland	Belonging, Helping others: I enjoy being part of the group, being able to have my say and hopefully the people who read these things take notice and make changes or the better	Acceptance: I trust everyone in the room. I know I am listened to and respected for who I am.	Confidence: I push my daughter away now so that I can still do things for myself for as long as possible – this group has given me the confidence to do that.	Doctors are awful to get in touch with and I feel like I am passed from pillar to post. I would be interested in shaping change in areas like this as I'm sure it is not just something I experience when trying to organise appointments.
Bishop Auckland	Peers, Helping others: You can talk to other people with dementia and you know that what is said is fed up the line and taken notice of to help others.	Belonging: "I feel like I belong - we are friends with lots in common."	Helping others: We're trying to shape change and I feel we are being successful in this	Inclusion, Acceptance: Change nothing. The people who come here appreciate everyone. You are all kind and respectful. In some other organisation's meetings they see you but don't include you. Not here!
Bishop Auckland	Acceptance: "I enjoy the fact that I can say exactly what I want, and nobody minds if I can't find my words easily"	Acceptance: "Any idea whether good or bad you can just say it. You don't have to hide your feelings here."	Learning, Helping others: "When you're diagnosed it's as though you're not needed any more, but with this group you know you are needed and you can learn new things while helping others - and that feels good."	Feedback: Getting the feedback sooner from the person sending the request would be helpful
Cardiff	Acceptance, Respect, Peers: I feel the same as others here. I like hearing people's views. We are very open, you can say anything.	Peers: Sometimes there are things that I can't tell my own partner – I can discuss them here.	Confidence: "My willpower has returned since I got involved in this group. Getting to have my say without being rushed. I didn't used to say anything when I'm with my wife and she'd talk for me. But here I've got my confidence up, so now I say what I need."	Doctors: I wish GPs would ask us to help them improve. It's great when people ask and we can provide the answers. It really helps to motivate us.
Leicester	Belonging, Peers: "Ours is a group of jolly nice people who have a lot in common with one another thanks to dementia. This gives confidence in an otherwise difficult situation."	Confidence: "Since joining the group, I've found my voice again. I am less reserved and do not feel alone."	Learning, Confidence: It's all doom and gloom when you're diagnosed – you get so much of it. Nobody tells you what you can still do, or that you can still learn new things – so you just feel put aside and a burden, like 'I might as well be dead now'. In this group I've found my confidence and self-esteem.	Care settings, Environment Audit: I liked it when we helped the hospital make sure the frailty unit is dementia-friendly. It might be nice to have more of this when possible.
Haywards Heath	Peers: One advantage of this group is that we are all people with similar afflictions.	Confidence, Peers: "I feel better about the situation as others have similar difficulties."	Confidence: "This group helps you feel able to challenge things, especially when people are insisting on doing things for you without letting you do them for yourself. You get stagnant otherwise."	Care Settings, Environment Audit: I would like us to go to see the local hospice and care homes. We could help them to make sure they work well for people with dementia.
Ilkeston	Purpose: You sit at home with this and gradually get worse, with a wife and children who know what it is, but you need more than that.	Acceptance, Belonging: It's a lovely feeling to be cared for in the sense of enjoying the friendship of like-minded people rather than cared for because of being ill.	Learning, Confidence: This group has opened a lot of different opportunities up to me – things I'd not have thought of volunteering for – except for the fact that I come here.	Local Services: I would like us to invite councillors – local councils have an agreement about paying for services, such as different prices. We all live quite locally, but depending where exactly we live, we have to pay different prices for the same services. I don't think that's fair.