Our Voice Matters

Dementia Enquirers Report

We have dementia!
Our research is your future

2019-2021

Dementia Enquirers

COMMUNITY FUND

iD Innovations in Dementia

Key messages from Dementia Enquirers projects

1. People with dementia can lead their own research projects – both drawing on previous life skills and learning new ones to explore the questions that most interest them.

2. The research questions that people with dementia generate can be different from existing research questions. They are based on lived experience – on topics that will make a real difference in people's lives.

3. "Being in the driving seat of research" doesn't mean that you have to do everything yourself. Team work and support can really help. But controlling the research and leading the way gives people with dementia a huge boost in confidence.

4. Making the language and processes of research more accessible helps everyone!

5. Research between people with dementia makes communication and engagement more possible, because having something in common increases trust.

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You can download this report here:
https://dementiaenquirers.org.uk/individual-projects/our-voice-matters-in-hartlepool/

You can read other Dementia Enquirers reports here:
https://dementiaenquirers.org.uk/individual-projects/

To find out more about Dementia Enquirers visit:
https://dementiaenquirers.org.uk

Watch the group's video here https://bit.ly/3h1VuQR

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Our Story

We are Our Voice Matters and we have put together a piece of research around how community based activities can have an impact on people living with dementia.

From our own personal experiences, we have thrived by being involved in different groups and activities throughout Hartlepool and think a lot of it is down to the encouragement at the start of our diagnosis to attend sessions to give us the confidence to start or join groups of our own.

Before groups and activities

"I felt anxious before going to any groups, I wouldn't mix or speak to anyone. I had to stop driving which was the worst thing for me. I felt like I didn't know what to say, so I didn't say anything."

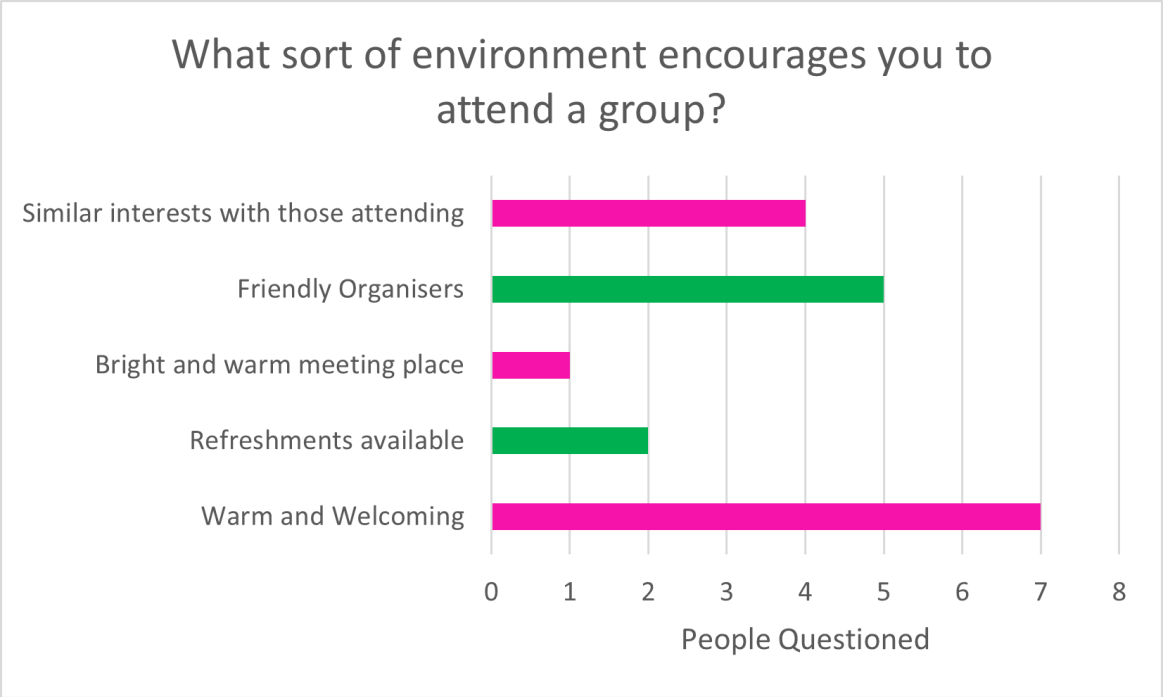
During the research we gained feedback from group members, professionals and had many group discussions to find out and piece together impacts on individuals living with dementia that have engaged in activities or not.

During the research we also took part in questionnaires and created questionnaires to give out to professionals to gain their feedback on organising activities in the community and even came up with some top tips.

After attending groups and activities

"It brought me back to life".

Qustionnaire Results



Above are the main feedback areas we gathered from the questionnaire which had the most answers. However there where some other suggestions such as:

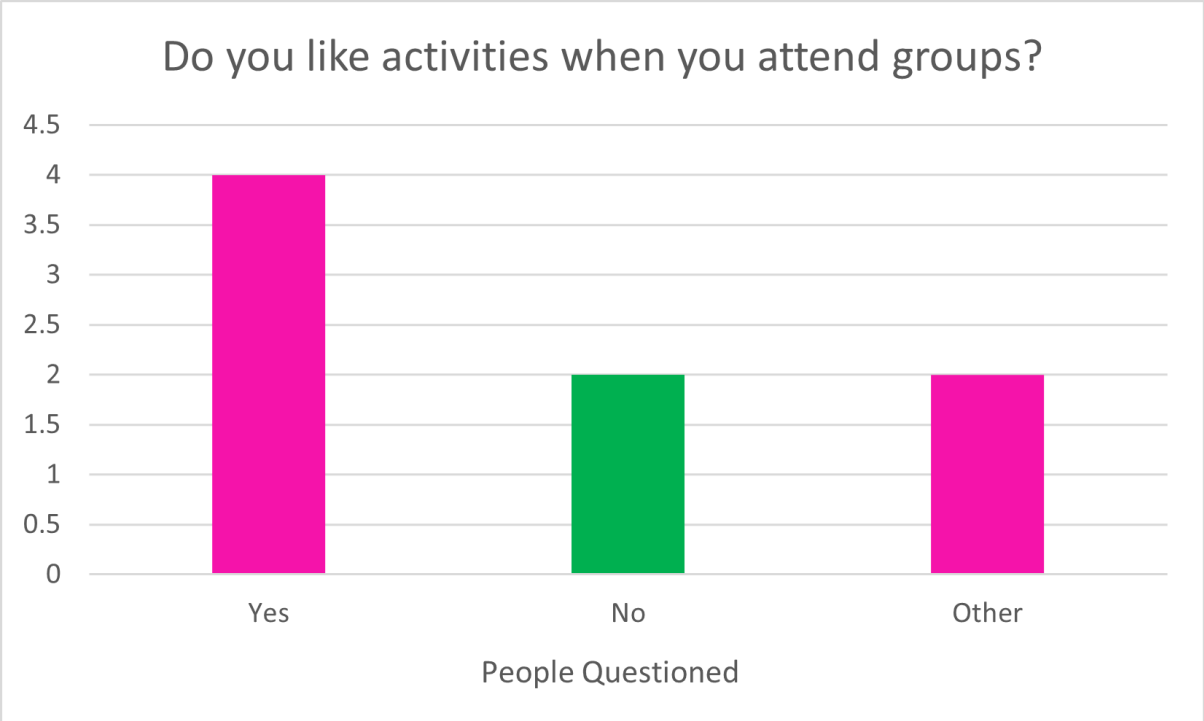
· Attended due to advice from a professional

· If there is someone there who you are already comfortable with

We think the main theme gathered from this question is people want to go somewhere they know they are going to feel comfortable, not only with the environment but the people running and attending the group as well.

The feedback for this question was mixed but when we asked people to explain their responses a lot of it depended on whether they had their own transport or not. For those that said it didn't make a difference still had a car or a partner with a car, however for those who drove said parking charges were something to consider.

For those that didn't have their own transport they said that location was important, for example, it needed to be on a bus route or not too far if you need to get a taxi or walk.



As a whole activities within groups seemed to be more popular. However the two that said no, went on to explain that they prefer to have discussions within groups than activities.

Within the other category they stated that they liked both, they liked to have the option to do activities but also liked to have the opportunity for discussion as well.

For those that did like activities some of the ideas are as follows:

- Crafts
- Gardening
- Bowling
- Walking
- Singing, dancing and entertainment
- Guest speakers
- Board games
- Chair exercises

For this question the majority said that they had not attended a group that they didn't like before. However, for the few responses that we got for yes, the reasons were as follows;

“One group insisted I had a carer come with me if I wanted to attend. I wasn't made to feel welcome”.

“Clash of personalities”

Another said that one activity in the community that they attended was above their understanding, so this didn't make it enjoyable.

An idea to try and prevent this is to have different activities available to cater for all abilities.

Questionnaire Results

We put together a set of questions to ask professionals who run groups to get some ideas around organising and advice for starting groups.

1. How much do you think location influences attendees of groups?

This is very key; you need it to be central on bus routes or with free parking. I have also found that a separate area for the opportunities for people to have time out is also beneficial.

2. General group or specific theme?

I have found both work well but more people come back to groups with activities they have enjoyed. I think a mixture is always the best option to have the social element but also have activities people can take part in.

3. How to introduce something new to an established group?

First ensure that it is going to be suitable for that particular group. Have a shorter taster session and get peoples feedback to see if they liked it. Make sure it is user led.

4. Would you recommend different activities to different members of the group?

This depends on the resources and staffing. I would normally say no more than 2 different activities at a time as people may be overwhelmed by the choice and you don't want too much going on at one time.

5. How to structure a group with different responsibilities?

User led committee rotation. Have a chairperson and active members of the committee and encourage the group to vote people in ensuring rotation on a 6 monthly or yearly basis so everyone who wants to have a chance to be a member.

6. Any fundraising advice?

Charge attendees for teas and coffee etc, suggested donations for attending, sell forget me not flowers, tombola, bake off cake sale and sell crafts.

7. How, when and where to publicise a group?

Drip feed people the information, tell people about the group and its potential. Then closer to the time tell them of the dates and times. Then remind them a few weeks before and then the day before. This can be done by email, newsletters and displays.

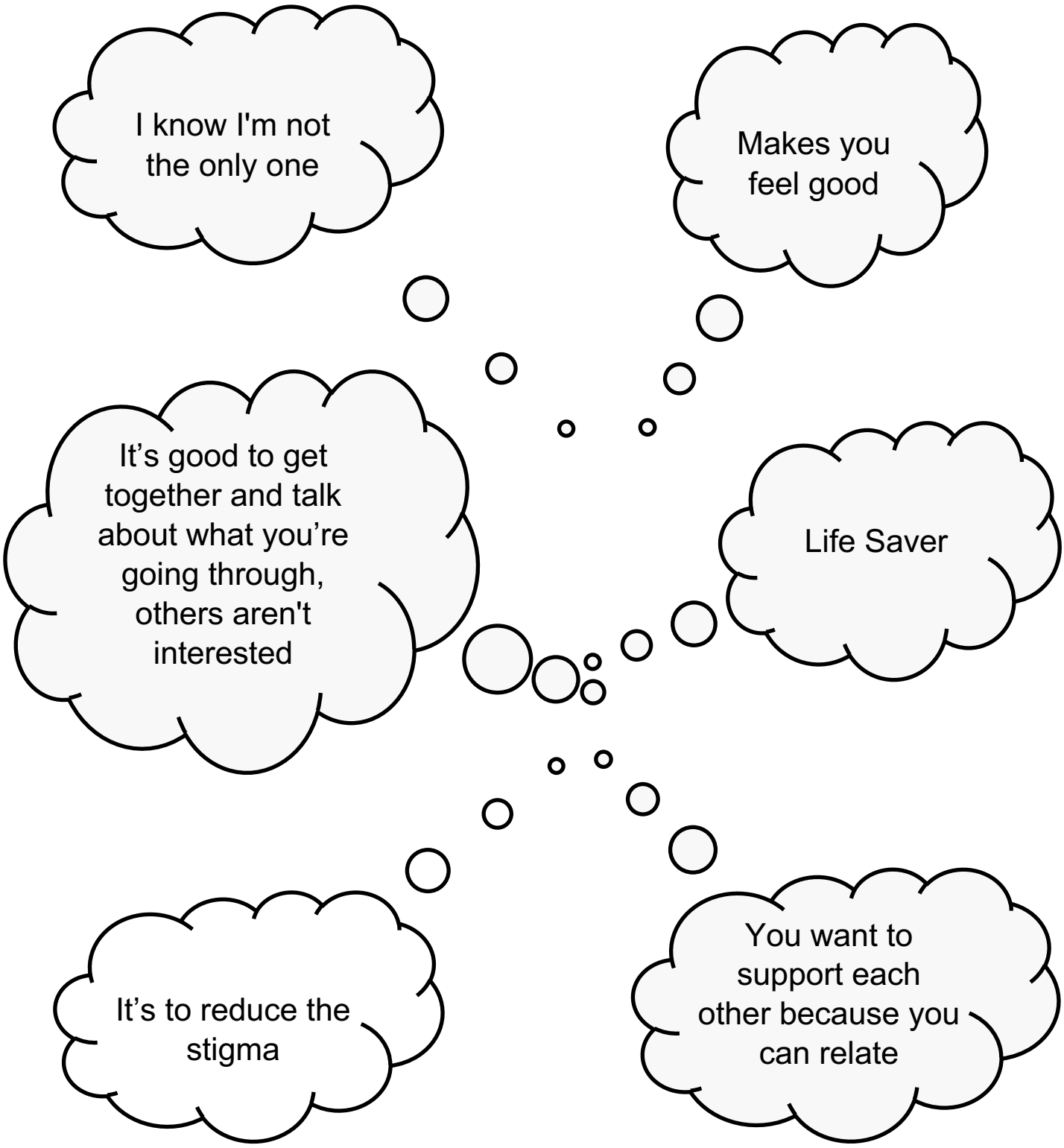
8. Do you steer groups in a general direction or let them develop in their own way?

A little bit of steering but also let them grow and give them options. Encourage them to try different things and see which one they like the best by presenting with pictures of each activity for example and get them to vote so then in the next group they have chosen for themselves what they would like to do.

9. How would you solve any problems or conflicts within a group?

If it is personality conflicts, ensure each person is heard and they get equal attention. Speak to them individually to find out what the issue is. Don’t sit the people opposite each other or in really close contact.

General Feedback about what groups mean to you



Top Tips

From the findings of the research that was carried out we came up with some top tips for people starting a group and those that are going to attend a group for the first time.

Starting a group

- Ensure the venue is suitable for purpose
- Ensure the room is comfortable and well arranged for attendees with room to hold the amount of people attending
- Offer refreshments as this is a good way to socialise and break the ice
- Consider the time duration of the group as people may have limited concentration
- Ensure venues have disability access
- Welcome people when they arrive
- Provide name tags
- Include everyone and look out for the quiet ones to ensure they have a voice as well.
- Establish a core to organise and coordinate the group
- Just start small, you will learn as you go

Attending a group

- Go with a friend or family member or carer as this will give you confidence
- You may meet old friends you haven't seen in years
- Get involved in the activities provided or contribute to the group in some way as this will give you a lot of personal satisfaction
- The more you get involved the more you get back
- One group leads to another
- Relax and be yourself
- It won’t be as scary as you think
- Most importantly enjoy
- You will find the fog will lift and that you can live well with dementia

Conclusion

Attending group activities provides you with lots of benefits such as:

- Making new friends
- Socialising
- Having fun
- Relaxing
- Enjoyment
- Find out other things that are available in your area

Our research would suggest that groups and activities are good for your mental health and wellbeing. So, we would encourage you to give them a go and enjoy the experience for yourself.

Thank you to everyone who took part in the research and helped make this happen. We wouldn't have been able to do it without you!

Methodology

This research was conducted by the DEEP Group which is made up of around 12 individuals of people living with dementia and their loved ones. In total we had around 20 people take part in the research. We had 10 people complete the questionnaire and 6 take part in the group discussions. One professional took part in the questionnaire created by the DEEP group.

As a group we decided to complete questionnaires and do some group discussions to gather peoples feedback who are living with dementia, but thought it would be also beneficial to hear from professionals who run groups and organise them.

Lessons Learnt

From conducting this research one of the main things we have learnt is that you have to be very careful when involving other organisations. When we started off, one of the areas we wanted to research was a group run through the NHS. For us to be able to do this we would have been required to go through their ethics board and have all of the research signed off and approved.

Once learning this information, we decided to rethink the direction of the research, to something that was more generalised and that didn't need to go through another company's ethics board.

Our Voice Matters