

Virtual groupwork sessions for dementia post-diagnostic support in East Edinburgh GP cluster

March 2022

As part of their post-diagnostic support (PDS) services, East Edinburgh GP cluster delivered face-to-face groupwork sessions for people with dementia and their carers. The feedback received was very positive.

Due to the COVID-19 pandemic, the team could no longer host face-to-face sessions. In this case study, we share East Edinburgh GP cluster's experience of delivering their groupwork sessions virtually.

“

“It has been a great experience for me and I have hopefully made some new friends that I can meet up with. The virtual group are doing great work in these difficult times and it makes you feel better that there [are] people trying to help us. Long may it continue.”

Carer



Background

Since September 2017, East Edinburgh GP cluster have been testing delivering PDS in primary care. This pilot is part of national innovation improvement work funded by Scottish Government and supported by Focus on Dementia, of Healthcare Improvement Scotland's improvement hub (ihub). Groupwork was tested as part of this improvement programme. The groupwork aimed **to support people affected by dementia and to enable them to meet others in an informal but informative setting**. Five face-to-face groupwork sessions were held, and feedback from them was very positive. However, the arrival of COVID-19 and subsequent lockdowns halted this work.

A team, consisting of the project manager, the dementia support facilitator (DSF) and a third-sector representative, were keen to explore alternatives especially given the isolating impact of the pandemic and the need for peer support. They agreed to test virtual groups as an alternative to **face-to-face** groupwork for people newly diagnosed with dementia and their carers.

To date, the team have held two cohorts of groupwork sessions. This report shares the experiences and learning from both cohorts.

Attendees

The DSF identified which people with dementia and carers to invite to the sessions. Considerations included:

- who would be **willing to participate** in virtual sessions
- who had the **appropriate technology** to participate, and
- the **optimum group size** for an online session.

Attendees

The majority of attendees to the first cohort sessions were carers. Ahead of the second cohort, the team took steps to further encourage people with dementia to attend. They reviewed the invitation and introductory materials to emphasise that the sessions were intended for both the person with dementia and their carers. For cohort two of the group sessions an equal number of carers and people with dementia participated, a great improvement from the first cohort.

Facilitators

The team also agreed the optimum number of staff to attend so as not to outnumber participants. The project manager took responsibility for facilitating the session, with the DSF helping with specific questions about local services, adding some personal details as she knew the participants, and leading a session on memory boxes. The third sector worker focused on providing technical support but also talked about the services they provided and added to the discussion generally.

Overview

By holding virtual groups, the team planned to:



facilitate the coming together of service users so they could **benefit from information sharing and peer support**, and



learn more about **how technology could support the service**.

The session was attended by people with dementia, their carers and a small team of staff.



Across both cohorts **fifteen participants** regularly joined the sessions:

- Eight carers
- Five people with dementia, and
- Two people with dementia participated off camera.



Three members of staff attended each session for the purposes of:

- Facilitation
- Input, and
- Technical support.

Planning

The team identified and addressed a number of practical considerations when planning the online group sessions.

Identifying a suitable platform

They had difficulties identifying a platform that would meet their internal security requirements and accommodate a group conversation.

They decided to work with a third sector organisation and utilise their platforms. The third sector organisation would set up the meeting and create the link. The team would send it out to people inviting them to join.

The team approached [Pilmeny Development Project \(PDP\)](#), a key partner in the face-to-face groups, and they agreed to support the first cohort.

PDP were not able to support the second cohort due to other commitments. The team approached [Care for Carers](#) who agreed to provide support. The team found working with both third sector organisations to be a collaborative and positive experience.

Ensuring safety online

Great care was taken to keep participants as safe as possible online. The team ensured:

- careful monitoring of who joined any session
- names were changed to first names on screens
- the meeting was always locked, and
- participants were asked not to share the meeting link with anyone.

Providing technical support for attendees

Attendees were invited to join sessions early so that any technical difficulties could be rectified before the session started. Contact was made with participants outwith the session when it was felt that they required some additional support.

During the sessions, the team provided technical support as needed.

Before the second cohort group sessions began, the team offered an additional “try your tech” session for group members who felt they would benefit from some additional technical support.



Session format

Six sessions of the group were held, each with a different focus. The first session followed the structure set out in the table.

There was less facilitation and structure needed for the second group as participants were more confident about talking to each other.

"I've really appreciated meeting up like this"

Person with dementia

"We listened to the fact that they didn't want professionals involved and gave them a semi-formal structure for the first 3-4 sessions then withdrew our input gradually enabling them to take ownership of the group".

Staff

"Putting people into breakout groups seemed to come at just the right time and enabled them to have more in-depth conversations at a one-to-one level".

Staff

Session	Focus	Content
1	Forming the group and getting to know each other	<ul style="list-style-type: none"> • Introductions. • Ground rules. • Getting to know each other. • How are people managing in lockdown? • Discussion on group content and function.
2	Getting to know each other / discussing any specific concerns	<ul style="list-style-type: none"> • Focus on objects of importance for each person as way of learning more about each other. • Conversation about how things are for people.
3	Getting to know each other / share issues	<ul style="list-style-type: none"> • An activity where participants give true and false statements about themselves. Other attendees guessed whether statements are true or false. • Conversation about how people are. • Plan for next three sessions.
4	Discussion on how people are/ coping strategies/ getting to know each other more in-depth	<ul style="list-style-type: none"> • Breakout groups for people to have opportunity to have one-to-one discussions.
5	Discussion on how people are/ coping strategies/ getting to know each other / ways to engage	<ul style="list-style-type: none"> • Breakout groups for people to have opportunity to have one-to-one discussions. • Value of keeping a memory box. • The role of music in triggering cherished memories.
6	Sharing contact details so they can continue engaging with each other / celebrating the conclusion of the group programme and what has been achieved	<ul style="list-style-type: none"> • Breakout groups for everyone with each participant/couple so that contact details can be shared if wanted. • Film of highlights using music of significance and reference to stories shared through the use of photos.

Feedback

The team collected feedback from both staff and service users involved in the first groupwork cohort. Although all participants were invited to provide feedback, all feedback received was from the carers involved.

Despite some scepticism from staff initially on whether participants would benefit from a virtual programme, there was an overwhelming feeling that the sessions had been a positive experience for people. The third sector organisation was particularly pleased to be involved in delivering a piece of work that fitted their own service priorities.

Feedback from carers has demonstrated that the participants found the group a helpful way to make and develop connections. After the formal sessions ended, **the group members have continued to meet each other.**

"It was good to talk and listen regarding the ups and downs and various problems and sometimes solve them!!"

Carer

"...By the third session they really seemed to want to be in this group. They were committed as indicated by the high attendance. They wanted to be there and looked forward to it."

Staff



Feedback from carers

Most useful to carers

- The support they felt from each other and the **sense that they were not alone.**
- Participants appreciated how **friendly and welcoming** people were on the group and this gave them confidence to participate.
- They also **valued the additional IT skills they learnt** from the information they received and the practise they gained.

Least useful to carers

- Some found the **time of the session** less convenient (this was changed in the 2nd group)
- One felt the **support offered was rather limited.**
- The **lack of face-to-face contact** due to lockdown was something they continued to miss.



Feedback from staff

Most useful to staff

- Staff felt that the way **the group format adapted to the needs of the group** worked particularly well.

Least useful to staff

- It was disappointing to staff that not **more people with dementia** appeared on the screen alongside their family carer as this made involving and communicating with them harder. This was fully rectified in the second group
- When there were **technical difficulties**, staff (more than participants) found this quite frustrating.

Conclusion

The team found:

- the virtual groupwork was much appreciated by participants and **helped to reduce isolation, and**
- although no substitute for face-to-face meetings, they **have a place in helping to support carers** in particular, and when given the opportunity, people with dementia too.

The team highlighted seven learning points, which are shown here.

More information

The Dementia and Memory Support Service participated in a pilot project as part of Focus on Dementia's work to test the relocation of diagnosis and PDS services into primary care. Visit the [Focus on Dementia webpages](#) to find out more about this work.

Read about the service's experience using the Quality Improvement Framework for Dementia Post-Diagnostic Support in their [case study](#).

1. Timing of session

An afternoon session was preferable to members.

2. Break-out groups

The use of breakout groups is recommended to help people get to know each other in more depth.

3. For people with dementia and carers

Emphasising in communications that these sessions are for **both** the person with dementia and the carer.

4. Practice technical skills

Offer the opportunity to practice with participants some of the technical skills in advance of the first session, including use of the 'mute' button.

5. Facilitation is key

Good facilitation is key, especially in initial sessions.

6. Face-to-face celebration

If possible, have a face-to-face 'celebration' after the final session to cement friendships.

7. Be flexible

Ensure a flexible approach to facilitation. Some groups will require more support than others.