Top tips for running online support sessions for people with dementia and family carers

These top tips are aimed at community groups and those providing, or thinking of providing, support sessions using an online platform.

There are many different platforms available for running online support sessions, such as Zoom, Microsoft Teams, StarLeaf and Go To Meeting, and this guide cannot cover every single one. Instead, it aims to provide some top tips and advice that should be applicable regardless of the platform, and poses some questions to get you thinking about your sessions.

Practical considerations before you start

- If possible, choose a platform that you are familiar with and comfortable using. This should make it easier to help people if they have problems with their set-up, rather than being something you're new to as well. You might also find it helpful to try accessing your chosen platform yourself using different devices such as a laptop, tablet and mobile phone, so that you can experience the process in each case. Again, this should make it easier to support people if they are having problems.

- Choose a platform that you know or think the people you support will already be using. Some might be connecting with family already and it would be preferable if they had a consistent experience, just as though they were in a familiar building or room.

- Consider whether any staff/volunteers need training to help facilitate the sessions. This might be in terms of learning about the platform/technology and having some test sessions with them, or in terms of data protection and safeguarding in case things arise during the sessions.

- Consider who is going to be attending your sessions. Is it an established group you know, or will new people be coming along? If you were running a face-to-face session you would have a chance to chat to new people on their own and get to know them, assuming you hadn't been in touch already. There isn't usually the opportunity to do this in an online session, so it might be a good idea to contact new people individually in advance to find out a bit about them and why the session might be of benefit to them. This also gives you the chance to see whether they may fit better with people in one session rather than another based on interests and personality. In addition, it provides an opportunity to avoid potential safeguarding issues and confusion or disruption by having more confidence and control over who is part of your sessions.

Helping participants before a session

- You may find it useful to produce your own short set of instructions to help people understand the platform you've chosen to use, including images or screenshots to illustrate what you mean when talking about different things. Hopefully you will know some of the things to look out for or can remember what it was like when you first used it.

  - What helped you?

- What problems did you have and how did you resolve them?

- Do you need to use a particular web browser?

- Is it better to use a PC, laptop, tablet, mobile phone and do you see the same thing on each type of device? For example, you might not see everyone at the same time if you are using a mobile phone, so it may be confusing if you hear someone speaking but you can't see them, or disorientating if it flicks to show who is talking at the time rather than having the same image on the screen all the time. If this is the case, it may be better to recommend a device with a larger screen, or try using 'gallery' rather than 'speaker' view depending on the platform.

- If you can, help people to know how to check that their camera and microphone are on, or if they will be prompted to allow these to be set up when they join the session.

- Encourage people to just use first names when prompted, as this keeps the screen simpler and makes the session less formal.

- The guide by the DEEP 'Zoomettes' useful for getting some ideas, such as including screen shots to show people what they can expect to see during a session. As the name suggests, this is specific to Zoom but again the principles may apply across different platforms. https://www.dementiavoices.org.uk/the-zoomettes-guide-to-setting-up-a-virtual-peer-support-meeting-using-zoom/

- Consider offering individual test sessions with people who are particularly anxious or less tech-savvy. This could help to sort out issues in advance of a group session where there is less pressure, and boost their confidence in being able to join the actual session.

General considerations for sessions

- It may be better to keep sessions relatively short as it can be tiring (for anyone!) to be in a long session. Between 30 minutes and 90 minutes appears to work well depending on the purpose of the session and activity taking place. The duration may also depend on the frequency of the sessions; if they are once a week longer sessions may be better, but daily or more regular sessions could be shorter.

- Holding regular sessions, e.g. at a fixed time or on a particular day, can help with planning and routines.

- Factor in additional time at the start of a session to give people time to join and resolve any potential tech issues.

- Make sure that you leave yourself plenty of time for the session in case someone needs to speak to you at the end.

- You may have to run multiple sessions to reach everyone (who wants to be involved) while keeping group sizes relatively small. However, it's important to remember that:

  - Not everyone will want/be able to join a session.

  - Some people may prefer morning sessions while for others afternoon sessions might work better.

- Think about group size. How many people do you need for an activity to work? When might a group become too big/confusing, especially if people start talking over each other? This could differ depending on who you are expecting to be in the session. From experience up to 8 members/carers plus staff/volunteers appears be a good guide, but see what works for you and your participants as everyone is different. Some people may prefer smaller groups while others could like seeing more people at the same time.

- Inviting people to a session may work better than having an open session as it gives you better control over the group size and composition. For this reason, you should require potential new members to contact you to obtain details, rather than publicly advertising a link to a session. This is important from a number of perspectives:

   o You have a better idea of who will be in the session and can plan activities accordingly.

   o You will be able to get to know new people in advance and introduce them to the rest of the group in an appropriate manner, which can help to avoid confusion or disruption.

   o It gives you protection from a safeguarding point of view, as you will not have unknown people attending.

- If there is sufficient interest, you may find it useful to run separate sessions for new people and groups who already know each other from attending face-to-face sessions.

- If possible, have more than one member of staff and/or volunteer in each session, especially group sessions, as it is easier to monitor/keep an eye on everyone and check they are ok than if it is just you.

Planning before individual sessions

- Think about what you are planning to do during the session. Will it work online/with a group? Is it worth having a trial run with a member of staff to check that things work, especially if you are planning to play music, show pictures etc.? Don't be afraid to try new ideas, but again a trial run could be beneficial.

- Send out the link to the session and any instructions well in advance of the session to give people time to prepare, but follow this up with a reminder (including the link) closer to the time. Clearly state the date, start time and end time of the session in each communication.

- Do you need to send out anything specific in advance to help a session run smoothly? E.g. circulating song lyrics, an activity for people to do beforehand so that they can share the outputs (baking a cake, drawing a picture etc.), if a particular prop/item is required.

- If you are planning to have external people joining a session, for example someone who is going to lead an exercise session, tell everyone about it in advance. While they will obviously be introduced properly during the session itself, some people can find it helpful to know beforehand.

- Once people are familiar with the technology and the format of the sessions, consider asking them what they would like to do during sessions. At the start they may not know what is possible online, but with a bit of experience they may have suggestions that you haven't thought of.

At the start of a session

- Join the session early to make sure it is all set up and you have got everything you need/everything works. It can also be useful in case participants try to join early. If people have to wait to be admitted to the session rather than automatically joining, you will need to consider how early you will admit people; if you start admitting people too early, there is a risk that each session will get earlier and earlier. A maximum of five minutes before the 'official' start of the session could be a reasonable compromise, but if you have a rule like this make sure everyone is aware of it.

- Have a proper 'start' to the session once everyone has joined and you are ready to get going, just to make it clear that the session is different from the set-up period. This also helps to give the session some structure.

- The start may involve reiterating any ground rules such as:

  - Making everyone aware that they may be asked to mute themselves for some bits to avoid potential issues/make the sound better for others, e.g. if watching a video clip, singing along to a song.

  - Making sure everyone knows it is ok for them to get up, move around, answer the telephone, go to the toilet during the session as some people could feel anxious about thinking they have to stay still for the whole thing. Maybe just encourage people to mute themselves while they are away for privacy reasons.

  - Making sure everyone knows they can bring along drinks and snacks – unless there is a particular reason not to – as again this can help to reduce anxiety and relax people.

  - You can obviously ignore these suggestions and use any other rules or guidance that you wish to implement instead. Once you've got a group up and running, you could ask people if they have any suggestions for ground rules to make the sessions work better for them.

- While it is useful to know who is in the session, it can potentially take a long time if you get everyone to say hello or introduce themselves each time. One option could be for you to say everyone's name in turn and get people to wave when it's their turn, as this should be fairly quick but still help people to find out who everyone is. If you have an external person in the session, make sure they are properly introduced to the group, explaining why they have joined in and what they are going to be doing.

During a session

- To minimise disorientation and confusion, reduce how often what people see on the screen changes, i.e. don't keep flicking between slides, photos, video clips, music. If you do want to show/share something, prepare people for the fact that the screen will change and make sure whatever you're showing is on screen long enough for people to see it properly.

- Remember that you don't have to do a lot during a session. People are likely to be attending for the social aspect, so make sure there is plenty of time for chatting. While it's nice to have a theme or focus for the session to give it a purpose, don't try and cram too much in. You don't have to do music, exercises, photos and a cake competition all in the same session!

- These sessions can be a good distraction for everyone involved, so try not to focus on the current situation too much. Instead, keep conversations, activities and language positive and appropriate. However, if people ask questions about what is going on you need to acknowledge them and respond accordingly. Try not to show your anxiety though as this can transfer to others. You need to be aware that what you say and how you act can have an impact on the other people in the session.

- If you want to take any photos of the group, ensure that everyone gives permission and knows what you intend to do with the photos, e.g. put them on social media, send to everyone in the group.

- As with face-to-face sessions, it's important to ensure that everyone gets a chance to join in and try to prevent one or two people from dominating conversation too much. You should encourage people to join in with any activities but also accept that some people might not want to, or might prefer to just watch everyone else, just as they might in a face-to-face session.

- It's also important to be aware that it can be more difficult to pick up on body language and generally see what is going on during an online session. As a result, you've got to pay closer attention to how individuals are reacting and behaving, but also be clearer with any actions or instructions during activities as people's ability to read visual cues may be affected.

Ending a session

- Try not to run over the advertised end time of the session if possible.

- When you are ready to end a session, rather than just waving and saying goodbye, lead up to it with prompts such as 'we've only got five minutes left' or 'it's nearly time to go so is there anything else anyone wants to say?' so that people are prepared. Also make sure everyone knows how to leave the session or close it down.

- Make sure that you or another member of staff/volunteer is the last person to leave a session, and everyone else has left before you; don't end the session until you are sure everyone has left as there may be occasions where a family carer has set up the session and left the person with dementia to join in while they do something else, but not come back in time for the end of the session.

- You may find it useful to have time following the advertised end of the session in case anyone wants to stay on and have a one-to-one chat about an urgent issue they've got, or to debrief with fellow staff/volunteers to see if anything needs following up as a result of what happened during the session.

  - If you and your staff have the capacity, you may want to offer one-to-one sessions as well as group sessions. These could be bookable sessions at specific times, where individuals can contact you to request a particular session. These could be used to address issues that have arisen during a group session, but may also help to prevent issues being raised in an inappropriate forum in the first place. For example, if a carer knows one-to-one sessions are available they may not feel their only option is to raise a personal issue in a public setting.