

Guidance for setting up groups for people affected by young onset dementia



We often receive enquiries from people who are interested in setting up a group for people affected by young onset dementia. Age-appropriate support is lacking in many parts of the country and so we are very keen to encourage people to set up groups that are specifically intended for the under 65 age group.

Based on our experience, we have put together the following guidance which shares some suggestions to help others who are considering starting up groups, either face to face or online. We hope it will help you to plan and run a successful group where you live.

What are the advantages of young onset dementia specific groups?

- People often feel isolated and know no one else with young onset dementia
- Socialising, exercising and keeping your brain active is beneficial for us all, but has particular benefits for people living with dementia
- A group meeting enables people to share information, ideas and their experiences with others as well as build up a supportive network
- Groups can enable people to socialise in a supportive environment and make new friends who understand their situation
- Most dementia groups are for older people whose interests are often very different. They may be physically frailer than younger people. Young onset dementia specific groups can tailor conversation and activities to the needs, interests and physical abilities of a younger age-group
- A support worker (or similar) can meet several people at once and find out how things are going for each and identify issues an individual may need help with

What are the challenges?

- The mix of people can create some difficulties. If partners want to talk about issues they are facing, having the person with dementia present may be awkward or stop that happening
- Dementia symptoms may result in a person dominating the group, whilst others may be very quiet. Ensuring that all have an opportunity to speak is important
- People may be at different stages - some may wish to talk about a new diagnosis, others about care home issues
- It can be daunting for people to mix with others who are at a much later stage
- Having a group that is predominantly one race, gender or class - it is important to ensure equality for all
- The numbers of people with young onset dementia are relatively low – group membership may be small but can still be very valuable
- Due to work, family and other commitments, there can be issues around the best time of day to meet. It is also important to consider travel and access requirements
- Groups can be difficult to get off the ground or may flourish for a while and then fade
- As a member's condition progresses, attending or participating in the group may become more difficult. This is a challenge for the host and member and needs to be handled with sensitivity
- If the group is online, people may lack the confidence or knowledge to use the necessary apps or technology and may find following conversations on a screen draining, especially if there are a large number of people taking part

Things to consider before setting up a group

- Has a young onset dementia group been requested?
- Do you think people would benefit and attend?
- Consider whether the group would work best meeting face to face, or if it could be run online, or as a mix of the two
- Do you have one or two potential members of the group who can work with you on setting things up? Their ideas may be immensely helpful
- Consider who the group is for - be as clear as you can
- What will happen in the group? Is it:
 - a peer support group – where people can share and discuss their challenges and experiences
 - an activity group eg active (walking, cycling, dancing, swimming, gym etc), creative (singing, art / craft, music etc) or visiting places
 - a campaigning group that hopes to increase understanding of the issues of young onset dementia
 - a self-education or training course
 - a social gathering for people affected by young onset dementia
- **Regularity** - how regularly will you meet? Meeting regularly can help people remember each other and build strong relationships. But people may have other commitments and getting out often, particularly if they need support to attend, may be challenging
- **Commitment** - It is helpful to have attendance at groups as open as possible but for some education / training groups you may want people to make a commitment to attend a certain number of sessions
- **Venue** - where will you meet? You need to find somewhere that is easily accessible. Choosing a venue that has parking, is on a bus route and fairly central can boost attendance. Using somewhere with a quiet space, or where you can meet at less busy times and that offers refreshments is ideal. Meeting in an everyday place such as a café or pub, rather than in a medical setting, can make the group feel more

appealing and 'normal'. Initially, you might want to choose somewhere small, and then move on if the group grows

- **Confidentiality** - how will you protect the confidentiality of the members? If you are in a public space, you may need to consider how to separate yourselves from others who are using the same space
- **Transport** - depending on people's circumstances, it may be necessary to offer / arrange / pay for transport. This can be challenging!
- **Costs** - some venues will have a hire charge; others will be happy for you to use their space if members of the group buy food or drinks – especially if it is a quiet time for them. The main costs will be any paid members of staff who attend the group. You may need to fundraise or find a source of funding to cover the costs of running the group (for example for room hire, refreshments, materials and activities), or charge people a fee for attending
- **Timing** – mornings / afternoons / evenings / weekdays / weekends and for how long – all needs to be considered. Some groups fail because they are run on a day of the week or time of day that are inconvenient for people. Canvas opinion on when is most suitable. A two-hour duration is usually enough to make it worthwhile but not too long
- **Publicity** – we suggest you send out personal invitations, to be followed up with written information and encouragement. The number of people with young onset dementia is small, so publicity / advertising needs to be very targeted. Informing local key workers ie GPs, clinics, social worker teams and local dementia charities will help raise awareness but the more direct and personal the contact the better. The Young Dementia Network can also share information about young onset specific groups on their website, newsletters and social media
- **Reminders** - people can forget dates and times. It is good to have a system for reminding members a few days ahead – for example via an email, text message or telephone call. Make it as personal as you can.

If you are the host, let people know that you will be there. It can make a huge difference to a person attending a group, if they already know someone who will be going along

- Remember that many people will be nervous about attending, especially for the first time. Offer the extra support and encouragement to attend to try and reduce any fear or anxiety
- If the group is online, you will need to decide which online meeting / webinar software to use – Zoom and Teams are both very popular. Ask members what would work best for them

Things to consider at the meeting

- Make sure the venue is comfortable, easily accessible and welcoming
- Having two hosts can really help – one to lead and one to ensure that everyone is included and enabled to participate or to manage drinks or other activities
- Welcome everyone and ensure that introductions are done each time. This is especially important if people have dementia as they may not remember from session to session
- At the first meeting - have a shared discussion about the group and what the participants would like to achieve / get from the group. Agree how you will decide if the group is successful so that you can review six months / one year down the line
- Give time to discussing how the group will run ie confidentiality / equal opportunities for each participant / respect and agreeing the purpose of the group. It may be helpful to have these written down and brought to each meeting or given to new members
- Remember some people may be nervous or may be experiencing a challenging time so always make the group friendly and welcoming
- As the host, you will need to manage discussions to keep them flowing, keep everyone included, quieten dominant people and encourage those quieter members to contribute

- For many reasons, people with dementia and their family members may find it difficult to arrive on time and may need to leave early. This may be a challenge but needs to be accommodated
- Careful planning is essential, particularly for activity groups. A risk assessment may be required for the venue and for activities such as visits to local attractions. For walking groups, make sure the route has been tried in advance, has easy parking, toilets nearby and is appropriate for the physical abilities of all members – fairly flat, not too far, no stiles or uneven paths. If it is a creative group, make sure that the activity is possible for all or that you have support for each person who needs it
- And finally, relax, enjoy it and remember to have fun. The key thing is to provide a space where people can be themselves with understanding and no judgement

Follow up

- Keep a record each time of who attends
- Send notes of the meeting if appropriate to participants afterwards
- Follow up issues that have been raised individually
- If someone shares information about for example a service, activity or piece of equipment that has been helpful to them, it may help to then share the details with all members post-meeting
- Establish a time for reviewing the group on a regular basis – say six monthly - and ask for members feedback regularly
- Going back to the original aims, is the group achieving what it set out to do? Have these aims changed?
- Consider if the numbers attending / feedback from the group members is proving the need is sufficient for the group to continue
- If members stop attending, try to find out why and whether there are barriers to them attending that you can help with

Useful reference documents

Young Dementia Network

We are very happy to share details of new young onset dementia groups on our website, newsletter and social media.

Please do let us know if you start up a new group so we can share the details via our communications channels
youngdementianetwork.org

Dementia UK

Database of young onset groups and services across the UK
dementiauk.org/find-support

Dementia Voices - DEEP

Resource information around setting up groups and involving people with dementia
dementiavoices.org.uk/deep-resources

The Young Dementia Network is hosted by Dementia UK and is a collaboration between people affected by and working in the field of young onset dementia. It campaigns to bring about improvements for people living with young onset dementia now and in the future.

Anyone with a question or concern about dementia can call the Admiral Nurse Dementia Helpline on 0800 888 6678 or book a video appointment in a virtual clinic: dementiauk.org/get-support

To find out more about the Network and to join, visit: youngdementianetwork.org or email youngdementianetwork@dementiauk.org

This guidance was originally created by a young onset dementia groups coordinator from Oxfordshire in 2019 and was updated in 2022.

