

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



Age–appropriate support for people with young onset dementia is lacking in many parts of the country and the Young Dementia Network is very keen to encourage people to set up groups that are specifically intended for the under 65 age group.

Based on our experience and recommendations from groups that are already established, we have put together the following guidance which shares 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.

Reasons to start a young onset dementia group

- People often feel isolated and know no one else with young onset dementia
- A group meeting enables people to socialise, share information, ideas and their experiences in a safe space with others as well as build up a supportive network of friends
- Most dementia groups are for older people whose interests are often very different, and 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.
- People with young onset dementia are more likely to have a rarer type of dementia so finding others in a similar situation can be difficult
- Socialising, exercising and keeping your brain active is beneficial for us all, but has particular benefits for people living with dementia



Things to consider before setting up a group

- Do groups already exist in your area for people with young onset dementia?
- Consider who the group will be for, for example people with young onset dementia, family members or both
- Talk to people who are affected by young onset dementia about the type of group they would like:
 - a peer support group – where people can share and discuss their challenges and experiences
 - an activity group for example active (walking, cycling, dancing, swimming, gym etc), creative (singing, art / craft, music etc) or visiting places
 - a campaigning or activism group that aims 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
- 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
- Group leaders – who will run the group? Will it be run by, volunteers or paid staff?
- Regularity – meeting regularly can help people remember each other and build strong relationships, but they may have other commitments and getting out regularly, particularly if they need support to attend, may be challenging
- Commitment – attendance at groups should be as open as possible but for some education or training courses you may want people to make a commitment to attend a certain number of sessions
- Venue – find somewhere that is easily accessible. A venue with parking, that is on a bus route and fairly central can boost attendance. A place that offers a quiet space, or where you can meet at less busy times and that provides refreshments is ideal. Everyday places such as a café or

pub, rather than in a medical setting, can make the group feel more appealing and ‘normal’

- Transport – this can be a barrier, all avenues to help someone attend should be explored
- Confidentiality and safeguarding – if you are meeting in a public place, you may need to consider how to protect the confidentiality and safety of members
- Costs – 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 – canvas opinion from the group members on what time of day is most suitable to meet. Some groups fail because they are run on at a time that is inconvenient for people. A two-hour duration is usually enough to make it worthwhile but not too long
- Publicity – publicity or advertising needs to be targeted. Make direct contact with potential members if possible, and inform local key workers ie GPs, clinics, social worker teams and local dementia charities. The Young Dementia Network can share information about young onset specific groups in its newsletter and social media
- Reminders – it is good to have a system for reminding members a few days ahead. 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
- Collaborate – it may be possible to collaborate with other local organisations in your area to provide advice and activities
- Online groups – ask members which online meeting / webinar software they prefer to use – Zoom and Teams are both popular
- Sustainability – closing a group can have negative impact on the people that have come to rely on it, so be clear with members if the group is only going to run for a certain length of time at the outset

Things to consider when running the group

- At the first meeting:
 - have a shared discussion about what the members would like to get from the group. Review this in six months to a year
 - allow time to discuss and agree the purpose of the group and how it will run including confidentiality, equal opportunities for each member and respect
- Some people will be nervous or experiencing a challenging time so always make the group friendly and welcoming. It could be the first time the person has joined a support group and they may need reassurance
- The host may need to manage discussions to keep them flowing, keep everyone included, quieten dominant people and encourage quieter members to contribute
- It may only be possible for some people with dementia to attend if they are brought to the meeting or accompanied. If the group is for both people with dementia and family members, it may be possible to split the group for part of the session to give each their own space to talk
- 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 needs to be accommodated
- Careful planning is essential, particularly for activity groups.
 - for activities such as visits to local attractions, a risk assessment may be required
 - for walking groups, make sure the route has been tried in advance, has parking, toilets nearby and is appropriate for the physical abilities of all members – fairly flat, not too far, no stiles or uneven paths
 - for creative groups, make sure that the activity is possible for all or that you are able to support each person who needs it
- Attendance at the group may change each week. Check in with members regularly to encourage them to attend

- Ensure that any activities, information provided and things like the type of music playing are age-appropriate
- Providing name badges to all members can ease the pressure to recall everyone's name
- 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 actions

- Keep a record each time of who attends
- Send notes of the meeting if appropriate to participants afterwards
- Follow up any 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 share the details with other members post-meeting
- Ask members for feedback at regular intervals. Is the group achieving what it set out to do? Have these aims changed?
- Are the numbers attending sufficient for the group to continue? You may need to find new ways to promote the group locally
- If members stop attending, try to find out why and whether there are barriers to their attendance that you can help with

What are the potential challenges?

- Paid staff and volunteers may move on
- Securing sufficient funding to keep the group running long-term
- The mix of people can create difficulties. Some individuals may dominate the group, whilst others may be very quiet. Ensuring that all have an opportunity to participate is important
- If family members want to talk about issues they are facing, having the person with dementia present may be awkward or stop that happening

- 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
- The numbers of people with young onset dementia are relatively low, group membership may be small but can still be very valuable
- Younger people may have to juggle work, family and other commitments which can create difficulties around attendance
- Groups can be hard to get off the ground or they may flourish at the start, and then attendance drops off as members circumstances change. It is important to encourage new members to join to keep the group active
- As a member's condition progresses, attending or participating in the group's activities may become more difficult. This is a challenge for the host and member and needs to be handled sensitively
- If the group is online, people may lack the confidence or knowledge to use the technology and may find following conversations on a screen draining, especially if there are a large number of people taking part



Useful reference documents

Young Dementia Network

The Network shares young onset dementia groups on its website, newsletter and social media. If you set up or run a group, please email the details to us via the email address below

Dementia UK

Information around young onset dementia and a database of groups and services across the UK

dementiauk.org/young-onset-dementia

dementiauk.org/find-support

Dementia Voices – DEEP

A network of around 80 groups connecting people with dementia

dementiavoices.org.uk

Resources including how to set up groups and involve people with dementia

dementiavoices.org.uk/deep-resources

The Young Dementia Network is hosted by Dementia UK and is the online community for everyone living with, working with or interested in young onset dementia. It campaigns to bring about improvements for younger people living with 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. It was updated in 2022 and 2025.

