Support group guidelines 2016

These guidelines have been written in consultation with clinical psychologists and professional counsellors and remain the property of Dementia Alliance International.

What is a support group?

A Dementia Alliance International (DAI) support group is a small group of people with a diagnosis of a dementia, who meet regularly to discuss their experiences, their problems and their strategies for coping and living with dementia.

How can someone join a DAI Support Group?

• Contact us at info@dai.org
• The host will then contact you to find a group with a vacancy
• Please note, you must be a member of DAI to join, which is free - www.joindai.org

What does a DAI support group provide and how do they work?

• DAI support groups meet online, and the group is restricted to 12 people with dementia, and who attend regularly for support
• Beat the isolation of dementia
• Learn what fun it is being part of a supportive group of friends — all living with a diagnosis of dementia
• There is no need to leave your home, if you have a way to connect to the Internet;
• Your family support person, or even a paid carer is able to assist you to attend, but participation is for people with dementia
• Learn how rewarding it also is to support and empower people newly diagnosed with a dementia
What are the benefits?

Research shows that hearing from and sharing with others with similar experiences can be very helpful. A peer support program provides a structured environment in which people who share the same long-term illness or condition can safely share their experiences.

Peer support has a wide range of both practical and emotional benefits.

Many people with a chronic illness (especially those recently diagnosed) benefit from receiving practical tips about adjustments they can make to their day-to-day lives to live better with their condition. The emotional benefit of realizing that one is not alone cannot be overstated and this often inspires peers to become more independent; More experienced peers may also be empowered by being able to pass on their skills and experience, and in the process they remind themselves of all they have learned about dealing with their condition.

A support group can provide the following benefits:

- Offer a safe place to discuss frustrations and joys of living with dementia
- Reduce isolation
- Reduce apathy and depression
- Strengthen motivation
- Show you that you are not alone
- Help develop new skills in relating to others
- Permit you to ‘open up’ and discuss your situation and feelings
- Give practical skills and advice — such as how to draw up and stick to a treatment plan, or manage living with the symptoms of dementia and memory loss
- Provide new coping strategies — share your solutions and learn from each others’ experience
- Supply strategies for managing any stigma associated with dementia
- Offer practical tips for living with the disabilities caused from the symptoms of dementia
Guidelines for participants

- Confidentiality is imperative

- Discussions on the lived experience

- Support groups run for 90 minutes, but it’s OK to leave earlier

- It is not appropriate to send the meeting link to others as all participants need to join DAI and contact the host first

- Focus on how to live well with dementia

- Topics such as death, suicide and euthanasia are not always suitable topics for support groups
  - Some members find these topics too distressing to discuss or listen to, and may not be comfortable openly discussing them
  - If most members of a group prefer not to discuss these topics, and you still feel the need to, please ask your host to find you another support group or forum, or someone to talk to about them
  - Therefore we ask each support group decide for itself and then members abide by the majority
  - We would also recommend you seek professional advice for these feelings.
Guidelines for the host/facilitator

This best practice framework aims to set out some of the guiding principles behind development and operation of peer support programs. Whilst the overall goals of support groups or programs are generally similar, they can vary significantly in design.

- Remind all members of the guidelines for participants; read out in full if new members are present
- Reminder the group runs for 1.5 hours; people may leave earlier, or may wish to stay longer which is possible if the host is available
- Remind members who have been attending for a longer time, to allow newer members and people more recently diagnosed the freedom and space to speak
- Avoid topics that some members find upsetting; each support group may decide on it’s own list of topics to avoid, depending on members

In some of these peer support arrangements, there is no clear division between those receiving support and those facilitating it – the focus is one of informal mutual support by sharing knowledge and experience.

DAI in most cases, considers members who have been recently diagnosed, or only recently joined the support group, as the ‘peers’, who may require more support than those who have been receiving support for longer.

The members who host DAI support groups have not been formally and professionally trained to do so; they are doing it as volunteers and cannot be responsible for someone’s experience in the group. However, support group host/facilitation training is provided to the person hosting them.
Support and Advocacy: 
Of, by and for People with Dementia

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<tr>
<th>Advantages</th>
<th>Potential Pitfalls</th>
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<tr>
<td>Gives any individual group member access to a range of peer views on any specific topic or issue.</td>
<td>Can require a regular time commitment at a specific location and hence busy people may be reluctant to get involved.</td>
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<td>Allows longer-term exploration of issues over a series of meetings.</td>
<td>Requires a “critical mass” of participants (maximum of 12).</td>
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<td>Provides a positive role model. Informal social events can provide a non-threatening way for new people to become involved.</td>
<td>Members may upset others by discussing topics that the group agreed to avoid. It can be difficult to find peer facilitators, and to support or manage some members.</td>
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Nobody gets dementia like we get dementia.