



DAI SUPPORT GROUP GUIDELINES 2020



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WHAT IS A PEER-TO-PEER SUPPORT GROUP?

A Dementia Alliance International (DAI) peer-to-peer support group consists of a small group of people with a diagnosis of a dementia, who meet regularly to discuss their experiences, problems and strategies for coping and living more positively with dementia. There are a number of different types of support groups, but the types DAI provides are weekly online peer-to-peer support groups, and one to one buddying and mentoring.

HOW CAN SOMEONE JOIN A DAI SUPPORT GROUP?

- Contact us at info@infodai.org
- One of our members will then contact you to assist you find an appropriate 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?

- The DAI support groups meet online, and the weekly group is restricted to 12 people with dementia and who attend regularly;
- Peer-to-peer support groups help to beat the isolation of dementia;
- Learn how supportive it is being part of a support group- with others also 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 can assist you to attend, but participation is for people with dementia; and
- Learn how rewarding it also is to support and empower people newly diagnosed with dementia.

THE ADVANTAGES OF JOINING A SUPPORT GROUP

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.

The importance of meeting with peers facing the same things as you cannot be underestimated, whether it is a life experience, a terminal or chronic illness, or a pandemic. No matter who you are, what you do, we can all use more people in our lives who “get” it. Whilst our family and friends, and professionals working in the field of dementia try hard to be supportive of us, they often don’t really know how we feel, or even why it can be so hard for us sometimes.

An example of a long-standing and very successful organisation that runs peer-to-peer support groups is Alcoholics Anonymous, which has been in operation since 1935.

George Rook, a person in the UK living with a diagnosis of dementia wrote the following on his blog (2017) about peer-to-peer support groups:

Wikipedia: “Peer support occurs when people provide knowledge, experience, emotional, social or practical help to each other... I like that. Note the “or” You don’t have to be a trained expert for peer support to work. Just need to have lived experience and a degree of emotional intelligence and self-awareness.”

Peer-to-peer support has a wide range of both practical and emotional benefits, as listed although this list is not exhaustive;

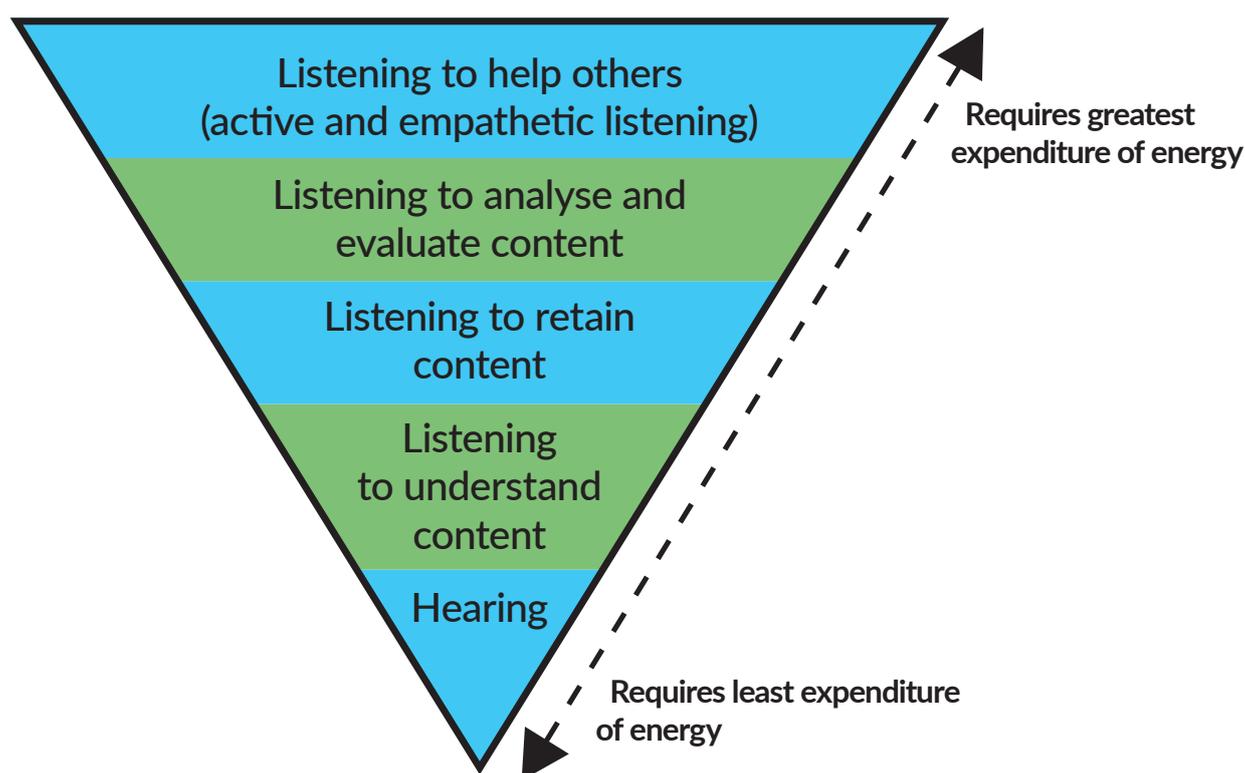
- Many people with a chronic illness (especially those recently diagnosed) benefit from receiving practical tips about adjustments they can make to their day-to-day living to better manage their condition;
- The emotional benefit of realizing that one is not alone cannot be overstated and this often 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.

If you are not currently attending a peer to peer support group, and would like to, please contact us at info@infodai.org.

¹ Rook, G, (2017). Blog: Living with dementia as well as I can, We need to talk about...Peer Support, , <https://georgerook51.wordpress.com/2017/10/19/we-need-to-talk-about-peer-support/>

SUPPORT GROUPS CAN PROVIDE MANY BENEFITS:

- Offer a safe place to discuss frustrations and joys of living with dementia;
- Reduce isolation;
- Reduce apathy and depression;
- Strengthen motivation;
- Show peers they are not alone;
- Help group members develop new skills in relating to others;
- Modify and establish exiting self management behaviours;
- Help and support members to overcome blocks and barriers or if not, seek alternatives
- Allow people to 'open up' and discuss their situation and feelings;
- Discussions on practical skills and guidance – such as how to draw up and stick to a treatment plan, or manage living with the symptoms of dementia and memory and other cognitive changes;
- Provide new coping strategies – share solutions and learn from each other's experience; and
- Supply strategies for managing any stigma associated with dementia.



GUIDELINES AND RULES FOR PARTICIPANTS:

- Confidentiality is imperative;
- Discussions focus on the lived experience;
- Speak in the first person;
- Focus on how to live more positively with dementia;
- Don't speak over others;
- Use your mute button when not speaking
- Don't interrupt;
- Give others time to speak;
- Listen to what is being said by others;
- Treat each other with dignity and respect;
- No verbal, emotional or other form of abuse or bullying
- We do not challenge anyone's diagnosis
- No medical advice is given at these meetings;
- Being personally transparent and avoid hidden agendas;
- Be visible on the screen, when possible;
- Members are free to leave at any time; As a courtesy to others, we ask you not to eat during the groups unless absolutely necessary.
- We do not discuss politics or religion in support groups, due to the diversity of personal beliefs; and
- Topics such as death, suicide and euthanasia are also not generally suitable topics for support groups, because:
 - Some members find these topics too distressing to discuss or listen to members who may be comfortable openly discussing these topics;
 - If most members of a group prefer not to, ask your host to find you another support group, forum or person to talk to about them;
 - We ask each support group to decide for itself whether this topic is acceptable and members must abide by the group decision; and
 - We also recommend you seek professional advice for these feelings.

Our group members must agree to abide by these guidelines; attendance at a DAI peer-to-peer support group indicates your consent.

Respect, confidentiality, allowing every person in attendance time to speak, staying focused on living with dementia, and not talking over others are the tenets of a support group. We are not a counseling group; if you need professional counseling, we recommend you seek support from a health care or other professional. People with dementia host our peer-to-peer support groups. Please, do not place unreasonable demands on them or other members, during or outside of the group times.

Structure of the group: Each member will be given 5-10 minutes to share (depending on numbers attending), and we are all expected to abide by the guidelines. Failure to comply with group guidelines may lead to you being muted by the host, or removal from the current meeting. Continued non-compliance with our guidelines can result in you being asked to leave the group permanently.

Members and hosts are not permitted to record these meetings in any way, including taking photographs or screen shots, nor take notes about individuals

All members of these groups assume responsibility for the guidelines, and by attending a DAI peer to support group this is expected. If the guidelines are not adhered to, a member may be asked to leave a group for the benefit of the group. If this happens, we offer one to one mentoring and support as possible, with the goal of supporting a member to return to a support group

“Most people don’t listen with the intent to understand;
they listen with the intent to reply.” *Stephen Covey*



Talk Less
Listen More

GUIDELINES AND RULES FOR HOSTS/FACILITATORS:

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.

- All hosts need to have a high level of self-awareness, which means knowing what you are thinking, feeling and saying, and be mindful of what group members might be feeling;
- It is imperative that hosts allow support group members to have the time to speak; this is their time to receive support;
- Hosts and support group facilitator's main role is to be there for the benefit of members. ;
- Best practice for hosts is to enable support for members by speaking less and listening more;
- Remind all members of the guidelines and rules for participants; read out in full if new members are present, and add to chat box to refer to as necessary;
- The group runs for 1 hour, but if people wish to stay longer and the host is available, discuss whether the meeting can be extended;
- Members may leave at any time;
- Hosts are to avoid giving direct medical, religious or political advice; they can however, facilitate discussion by participants, but still to avoid these topics;
- DAI Hosts / Leaders are here for participants; the participants are not there for them;
- In most cases, DAI considers members who have been more 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 and we ask long-term members to be mindful of this;
- Being too upbeat can be distressing for people who are still in deep grief; therefore new members may need individual support before they join a larger support group;
- Hosts don't need to elaborate on their own diagnosis but can offer to talk with an individual participant after the group time is over, if requested;
- Remind members who have been attending for a longer time, to allow newer members and people recently diagnosed the freedom and time to speak;
- Avoid topics that some members find upsetting where possible; each support group may decide on its own list of topics to avoid, depending on members;
- If facilitators/hosts need support, this role is not suitable for that, and joining another support group as a member is appropriate;
- Hosts should seek debriefing sessions, with other hosts or a professional, as required.

In some peer-to-peer support groups, 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, although to be a host, it is imperative you listen more than you talk.

There are times when members of peer to peer support groups may become difficult to manage, or that others find hard to be with. Whilst this may be due to the pathology of some types of dementia, e.g. the behavioural variant of Frontotemporal Dementia, it is also often due to other factors such as dominant personalities.

Here are a few tips to support facilitators, and some effective ways to deal with difficult people:

- Realize that rudeness such as interrupting is not new.
- Attempt to stop it, by reminding members of the guidelines.
- Don't take it personally.
- React to rudeness with kindness.
- Use humor to defuse a difficult person or situation.
- Call the person out on his or her behavior.
- Don't allow it to escalate.
- Show empathy and sympathy.
- Be a good role model.

If these strategies fail, then refer the member to a senior co-host to set up a one-to-one meeting to discuss.

The members who host DAI support groups have not been formally and professionally trained; they are doing this as volunteers and cannot be responsible for everyone's experience. They will do their best at all times.

Host/facilitator training is provided annually, when possible.

If you are, or wish to become a support group host, this is what our members will expect of you. Hosts also have an expectation support group members will respect these guidelines.

Reminder:

- These groups may not be considered as professional legal, medical or psychological advice.
- Support group members and hosts are not permitted to give out medical or legal advice, even if that was their previous career.
- It is not always possible for some people to continue in the DAI support groups, if they are unable or unwilling to manage their own responses.

ADVANTAGES AND PITFALLS OF DAI PEER TO PEER SUPPORT GROUPS

Advantages

Potential Pitfalls

- Gives group members access to a range of peer views on any specific topic or issue.
- Allows longer-term exploration of issues over a series of meetings.
- Provides positive role models.
- Provides access to tips from peers on living more positively with dementia
- Informal online events can provide a non-threatening way for new people to become involved.
- Rewarding for hosts and participants
- Attending virtually is cost effective, allows more people to attend, and does not require transport
- Attendance offers care partners some time out!

- Can require a regular time commitment at a specific time and hence busy people may be reluctant to get involved.
- Requires a “critical mass” of participants (maximum of 12).
- 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.
- Zoom meetings are less personal, and can contribute to ‘computer fatigue’
- Ability to access the internet or Zoom

BURNOUT

As the focus of the DAI peer to peer support group co-hosts are primarily to support the needs of group members, the potential to consistently fail to attend to their own needs is quite high. Co-hosts can experience many things, such as feeling emotionally depleted or drained, isolated, unmet needs, grief and worrying excessively about those they support, which is commonly referred to as burnout.

Burnout will often manifest initially as emotional exhaustion, and sometimes, as depersonalization of others or oneself. It has also been referred to as “emotional fatigue” or “emotional overload,” when the person feels drained, empty, all used up, and as if they have nothing left to give.

Potentially, co-hosts can also experience criticism from those they are volunteering to support, as the leaders of their groups. This is especially difficult as a volunteer, as people usually only volunteer because they want to help others, or to a particular cause that is close to their heart. Having a diagnosis of dementia themselves, also makes this more challenging.

Here, we provide some basic tips for preventing and managing co-host burnout:

- Reach out to other co-hosts for one to one support
- Attend the support group co-host training sessions
- Attend regular group co-host support sessions
- Talk to a professional counsellor
- Switch off between your support groups
- Attend a peer to peer support group, as a member (not as a co-host)
- Take time out for you
- Try relaxations techniques such as meditation, mindfulness, and yoga
- Mind your physical health, including your exercise and diet
- Take a short break

If as a facilitator, you sometimes feel burnt out by your role, please do not hesitate to discuss it with another co host, and to ask for support.

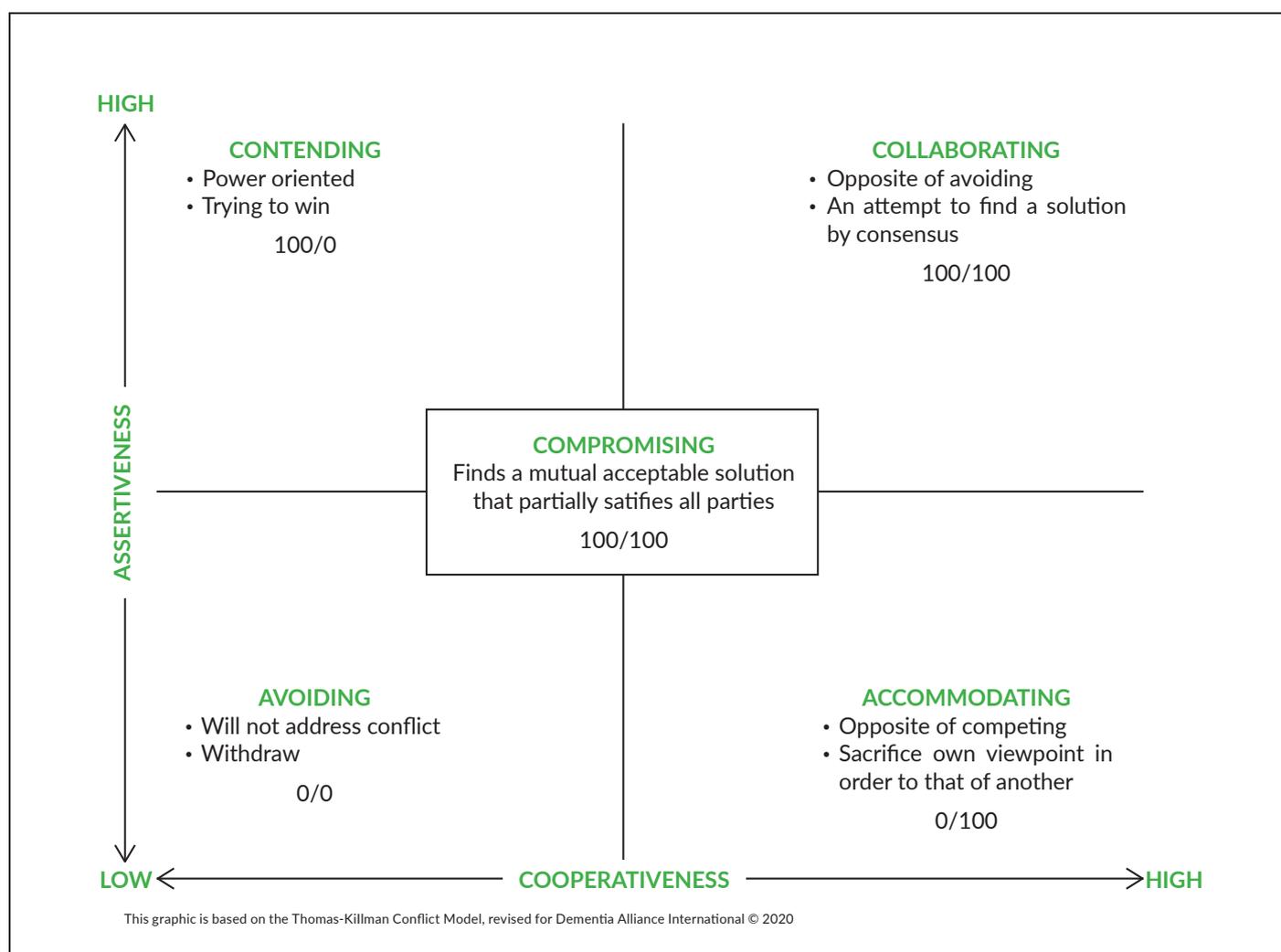
**Take a bow: everything you do,
is appreciated by DAI and by our members.**

Principles of Effective Communication

Keys to Effective Listening

The Poor Listener	The Key	The Effective Listener
Continually interrupts.	Stop Talking.	Gives speakers time to say what they have to say.
Tunes out if delivery is poor.	Judge Content not Delivery.	Judges content, skips over delivery errors.
Tends to enter into arguments.	Hold Your Fire.	Holds temper, doesn't jump to conclusions.
Listens only for facts.	Listen for Ideas.	Listens for important themes.
Influenced by who speaker is.	React to Ideas, not speaker.	Pays attention to what speaker says, not who they are.
Shows little attention, or fakes it.	Show interest.	Actively listens to understand rather than only to reply.
Is easily distracted.	Resist distractions.	Avoids distraction, knows how to concentrate.
Gives no feedback.	Ask Questions.	Encourages speaker to develop points further.
Reacts to emotional words.	Keep an open mind.	Knows loaded words and phrases but does not get hung up on them.

“Remember: You can’t listen if you’re talking.”



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