

In-person Dementia Support Group Meeting Guidance Document

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Contents

The purpose of this document:	1
Aims of a support group meeting:.....	1
Decisions related to support group meetings.....	2
The Coordinator's role:	3
Essential personal traits and knowledge of coordinators.....	5
Desirable advisors/ experts for the coordinator	6
Desirable resource base for the coordinator	6
More on the actual conducting of the meeting	6
Orienting to the caregiver's perspective: things a coordinator may need to consider while coordinating a caregiver support group:	6
Understanding why people attend SGMs	7
Some do's and don'ts while speaking	8
Some tricky situations and possible ways to handle them	8

The purpose of this document:

To describe the skills and activities of a coordinator of a face-to-face support group meeting of dementia caregivers.

Aims of a support group meeting:

To provide dementia caregivers a meeting place that:

- Provides them a sense of community so that they understand that caregiving problems are faced by others also, and that they are not alone
- Allows exchange of useful experiences and practical tips and resources, so that they have information and ideas on how to tackle their individual problems better

- Allows them a time to relax and feel free of caregiver stress
- Respects their privacy so that they can speak without hesitation about their problems and are not scared that what they say will be used outside and embarrass them
- Does not judge them or criticize them or make them feel small or inadequate in any way
- Makes the caregivers feel heard, respected, and valued
- Does not mislead them in any way with respect to miracle cures or by implying that their problems are simpler and will go away easily; the meeting provides a balanced picture of what to expect and what the benefits of various shared tips may be
- The specific focus of a particular meeting may be informational support or emotional support, or a mix of the two (see *Focus of support* below)

Decisions related to support group meetings

Focus of support (could be a mix, with one hour reserved for one type, and another for another type, but the decision on the time division needs to be taken before the meeting so that participants have realistic expectations and the coordinators can also manage appropriately)

- Without any agenda--mainly any type of experience sharing--typically a drop-in meeting often held at the same time every month--focus is on emotional support around a specific aspect of caregiving
- With a specific topic around which the experience sharing revolves; the coordinator and/or an invited expert keeps the discussion on track and also provides overall tips at various places--focus is on emotional and informational support around a specific aspect of caregiving
- An expert gives a presentation on a specific topic, and caregivers can share experiences/ask questions related to that topic-- focus is on informational support around a specific aspect of caregiving

Types of forums:

Some decisions need to be taken in advance:

Should the group be open or closed:

- Closed group: a continuing forum, where only the same set of caregivers attend (this allows covering a range of topics for both emotional and informational support, with bonding between participants, but excludes new caregivers from joining in till the next forum starts)
- Open group: a walk-in forum, where some caregivers may continue, and new ones may join (this sometimes requires repeated introductions and content may get repetitive for old-timers, but the forum allows mixing old participants and new, and can lead to a lot of experience and tip sharing)

Number of participants:

The coordinators may choose to stop publicity/ invitations if the group size seems too large, or they may split the group into two or more to keep each group manageable. The group size chosen depends on the comfort of the coordinator--a very small group may not provide enough width of experience, but a large group may not allow everyone a chance to speak and share, and can be intimidating. Tentative recommendation is a size of 8 to 15.

Other logistics:

Location:

The location may be a fixed one, or rotated with every meeting. It could be a hired place, or part of a hospital, or someone's house. There are pros and cons for all decisions, and the evaluation needs to be done based on the convenience of the expected participants, and how comfortable they will find the venue. Not everyone may want to meet in the house of someone, for example, and finding out the comfort levels can be done by giving multiple choices and asking them which they would prefer.

Duration of the meeting:

Typical duration is 1.5 to 2 hours, but the chosen duration should take into account the scope of the meeting (for example, if the meeting combines a presentation and an experience sharing session, it may need to be longer) and the convenience of the participants.

Date and time:

Usually meetings are arranged during the daytime (afternoon or early evening), so that commuting is not a problem, and often they are on weekends, so that participants don't need to take leave from work, and homebound participants can leave the patient under the care of other family members. A quick, informal survey will help the coordinator decide. Sometimes, the date and time is determined by the availability of an invited expert

Frequency of meeting:

Again, it depends on the participants, but less frequent than one month is unlikely to help, and more often than once a fortnight may be impractical for people to come.

Announcement of the meeting:

This needs to be done well in advance, as well as reinforced by a reminder closer to the actual date. E-mails and phone calls, and announcements on websites and blogs are usually used, but these assume that the targeted participants are already aware of the organizers and are in touch. More persons can be informed through social media, and through newspaper announcements (city event pages); these may attract caregivers who want support and were not aware that such a caregiver community exists.

The Coordinator's role:

- Decisions related to meeting scope and focus
- Manage the logistics before the meeting

- Coordinate participation during the meeting:
 - Facilitate: Help the group meet its purpose by using various ways to provide relevant information to the participants, to encourage participants, guide them along, help them, manage challenging group situations, etc.
 - Moderate: Make sure that the discussions remain respectful and productive, and do not get offensive/ judgmental/ personal in a way that hurts any caregiver or shuts a person up
- Consolidate lessons and do required follow-up after the meeting

Logistics before the meeting

- Do the background administration to announce the meeting, and to ensure that all participants are informed of the time, place, and directions, and have some idea of what to expect
- Make the location ready for the meeting (typically, arrange chairs in a circle for emotional support focus, and in a lecture room format for an informational presentation focus), arrange for tea, water, biscuits, writing pads and pens, whiteboards, etc. Keep any required material (books, pamphlets) handy for circulation
- In case an expert is invited, coordinate for receiving the expert, and also providing any required projector/ whiteboard, etc., photocopying any handouts

During the meeting:

- Ask participants to give their names, contact information, etc. , on a meeting log sheet
- Kick off the meeting by welcoming participants, explaining the scope and purpose, and reinforcing the privacy aspect and the *it is not medical advice or personalized counseling* aspect
- For experience sharing sessions, begin coordinating the introductions and then manage the discussion as required
- For expert presentation sessions, introduce the expert
- During experience sharing/ question-answer sessions, ensure that the aims of the support group meeting are met and that any deviation from them is corrected immediately
- Track and bring closure to any queries raised during the meeting, either by answering questions, or declaring that they will be tackled as part of follow-up activities
- At the end, wrap up the discussion, thank people, and let them know about any material you will be emailing to them later
- If possible, gather feedback on what the participants felt about the meeting, and how the meeting can be made more useful to them
- If relevant, gather suggestions on subsequent meetings

Consolidate lessons and do required follow-up after the meeting

- Provide participants with any material(or answers to queries) that was promised during the meeting
- Analyze what happened to learn how to handle meetings better in future
- Analyze what happened to gather overall tips for caregivers that can be collected to create material and resources that could help other caregivers

Essential personal traits and knowledge of coordinators

- Genuine involvement and interest in caregiver welfare
- A positive and empathetic attitude towards caregivers:
 - Compassion and empathy for caregivers
 - Patience (even if a caregiver keeps repeating the same problem again and again, in unrelated discussions, or acts insistent for attention or keeps saying "nothing works" and seems closed to suggestions)
 - Respect for the caregivers, regardless of the gender, financial status, social skills, ability to speak well, way of dressing, religion and region and race, even the caregiver's apparent lack of love or care for the patient (or downright hatred for the patient)
 - Some basic knowledge of caregiver skills and stress avoidance
 - Some basic understanding of what the typical home care challenges are, and how caregivers feel
- An open, non-judgmental, and honest attitude while listening and discussing
 - Non-judgmental about the care being given (even if it seems neglect, lacking creativity, full of impatience, etc.)
 - Ability to observe the caregivers' body language and expressions and stay attentive. A good listener.
 - Honesty in stating things, and sensitivity while talking
 - A good communicator, who is reasonably articulate while explaining things
 - Considerate and diplomatic (ability to phrase suggestions and comments in ways that are positive and constructive and yet do not make the caregiver feel guilty or blamed for past "mistakes")
- Knowledge of dementia, related behavior, and of care approaches, skills and issues
 - Good grounding of dementia fundamentals (should know enough to conduct a dementia awareness program independently)
 - Good grounding of essential dementia caregiving skills, such as communication, helping in daily activities, handling challenging behavior, use of activities,

reminiscence therapy, pros and cons of tools like distraction, filets, validation, aspects like family coordination and conflicts, adapting home, social environment impact on care, seeking help, etc.

- Enough base of interactions with caregivers and experts to be able to fit in caregiver stories in the overall dementia care framework and thus moderate the discussion to keep it useful and productive, while emphasizing that there is no "one size fits all"
- Conflict management skills
 - Ability to handle conflict in the group with gentleness. Ability to direct the conversation or take control of the conversation when needed
- Ability to clearly state the goals and limitations of the meeting, along with a good understanding of what a support group meeting can help with, and what it should not attempt to do. A good understanding of the limitations of the coordinator's own ability to help, and of the limitations of the support group meeting as a forum to help others

Desirable advisors/ experts for the coordinator

The support group coordinator should ideally have access to

- Some medical experts who can help the coordinator understand at least some basics if the coordinator wants to understand hem/ or someone the coordinator can refer the caregivers to
- Some expert caregiver-counselors or other trained counselors who can help the coordinator review what happened in a meeting and discuss how a tricky situation could have been handled, or to give the coordinator a realistic understanding of the caregiver perspectives and problems

Desirable resource base for the coordinator

The support group coordinator should ideally have access to

- Material and pamphlets that can be circulated to inform caregivers about dementia and relevant care skills and tips
- Videos to demonstrate possible behavior challenges, and also to show application of various skills (such as in taped role plays or instructional videos).
- Videos to demonstrate essential home nursing skills (applicable for advanced stage patients)

More on the actual conducting of the meeting

Orienting to the caregiver's perspective: things a coordinator may need to consider while coordinating a caregiver support group:

- The caregivers did not study for, or plan to become caregivers. They had their own ambitions, education, skills, etc., and this is an unexpected role they are doing

- Caregiving is not theoretical for them; they are seeing a family member suffer and are emotionally involved and affected
- The caregiver may not have had a loving relationship with the patient (like an autocratic mother/ mother-in-law, abusive or negligent father, etc.) This makes caregiving even more difficult
- Caregiving takes up a lot of time, energy, and money
- Caregivers may not be sharing their personal situation fully in a meeting, so it is wrong to assume that they are not trying hard enough based on what they say publicly. For example, they may not share some embarrassing behaviors of the patients (sexual misbehavior, playing with fecal matter, severe incontinence) or some of their own limitations (family conflicts, economic hardship, abuse by family members, etc.) out of shame or a sense of privacy.
- Caregiving is, even now, not the only role the caregiver plays. There are other responsibilities towards elders, spouse, kids, and also other roles, like career, social roles, etc. There may be health problems and the effects of long-term stress.
- Caregivers are skilled and creative in their own spheres, even if they seem overwhelmed by caregiving (which was an unexpected role for them and they are not trained for it)

Understanding why people attend SGMs

Different people come with different needs and expectations to an SGM. Understanding the sorts of needs they have will help the coordinator be more effective in facilitation and moderations. Note that some expectations that people have cannot be met by the meeting, and some may even be disruptive to the group, and the coordinator may need to decide how to handle these expectations given the scope and focus of the meeting.

Some reasons that caregivers may be attending a meeting for are:

- They want information about the disease (what it is, the symptoms, what to expect, why the patient behaves in a particular way, what the patient feels, treatments, whether the condition is infectious, who are the good doctors, how to improve the quality of life of the patient)
- They want to share their practical problems and are looking for solutions and resources
- They want company of others like them, just so that they don't feel they are alone in doing such work
- They are facing stigma/ social problems (or financial problems, or other problems in their own life balance) because of the patient and wonder how others are coping.
- They are tired and frustrated and full of resentment because of the problems they are facing while coping with the patient, the system, the family, the doctors, the medical companies, the attendants, etc. They may just want to express their frustration and anger and may not be expecting solutions. They may even pick holes in any solution or tip

offered, because their main need is to be heard unconditionally; they want everyone to understand that they are facing a tough deal which has no answers

- They are stressed and want magical solutions, but are also sure nothing can help them.
- They don't really believe the diagnosis and suspect the doctor has misled them and that the patient is pretending, or that the doctor has misled them and that the patient is therefore not getting the right treatment and suffering, and they want confirmation of this

Some do's and don'ts while speaking

Do	Don't
<ul style="list-style-type: none"> • Acknowledge problems caregivers state • Show appreciation for their sharing/ problem. Look for something positive to appreciate even if they are sharing a major mistake. For example, you can appreciate the caregiver's effort, the caregiver's love and concern about the patient, or the caregiver's opening up about the problem and looking for suggestions • When giving a suggestion, always state that every person's situation is different, and that your suggestion may or may not help, and that it is for the caregiver to decide whether to follow the suggestion • Place any suggestion in context rather than making it sound like the best/ only solution • Emphasize that the caregiver had no way of knowing in advance that her approach would not work/ that there is another approach • Talk to caregivers with respect, like they are competent and hardworking persons with the right intention and with commitment to caregiving 	<ul style="list-style-type: none"> • Don't criticize mistakes made • Don't use "you" for critical sentences which may seem like fault-finding • Don't speak as if you know what is best and your solutions are obvious and will solve all problems • Don't use phrases like "it is your duty" and "you must love" and "they looked after you, now it is your turn" • Don't act over-sympathetic or pitying. • Don't, in any way, show any doubt about the motives or intention or commitment of the caregivers • Don't assume that all the caregiver's time and energy is available for implementing better caregiving solutions

Some tricky situations and possible ways to handle them

What happens	Options to try out
Caregiver, when asked to introduce herself,	To reduce the probability of this:

<p>keeps talking for a long time</p>	<p>When asking people to introduce themselves, clearly say that this is just to get some basic facts: For example,</p> <p><i>Please tell us about whom you are caregiving for, what the patient's state is, and mention a couple of your major problems. We will discuss the problems in more detail later; this is just an introduction so that we all get to know each other</i></p> <p>If the problem happens:</p> <ul style="list-style-type: none"> • Ask her to stick to bare facts to begin with • Summarize her situation • Assure her more detailed discussions will follow
<p>Caregiver starts describing a problem very far removed from the topic being discussed</p>	<ul style="list-style-type: none"> • Thank her for sharing • Say this will be very useful a discussion when the other topic is being discussed • If the caregiver is overwhelmed, suggest that you will talk to her later about this, or that this problem can be discussed after the current topic discussion is over
<p>Caregiver monopolizes the discussion (for example, she just keeps interrupting everyone to "share" her story/ problem/ suggestion, often in a long-winded way, unconnected to the current discussion)</p>	<p>To reduce the probability of this, state in the beginning that we want everyone to participate, and that every participant is important.</p> <p>If a participant monopolizes, acknowledge the overwhelm of the participant, and thank them for sharing, and then do one or more of the following, as appropriate:</p> <ul style="list-style-type: none"> • If the monopolizing participant is talking of some very emotionally overwhelming problem, assure her that you will discuss the problem later • Remind the person that you are discussing a different topic • Quickly summarize the main point of what the monopolizing person is saying, and look around at other participants and ask them for comments • If the monopolize continues to talk, interrupt, point out that you are sure others want to talk, too, and again ask others for comments • Switch to a speak-by-turn mode, where the monopolizing participant is towards the end of the circle

	<ul style="list-style-type: none"> • Do not make eye contact with the monopolizing person, Instead, look around and talk to others. That makes it difficult for the person to continue talking • You may need to act firmly if the person just doesn't stop trying to monopolize
A participant starts insisting that her suggestion is the right one (use of a particular herb/ medicine/ technique). OR the participant starts prescribing a medicine to another or claiming that a medicine is wrong	<p>Gently say that this is not the forum for medical advice (unless an expert is present), and:</p> <ul style="list-style-type: none"> • that most situations are too complex for us laypersons to know what works and what doesn't • while a solution may have worked for the participant giving the advice, it may or may not be advisable for others. • For any advice of this sort, the specific situation needs to be known, and that only experts can comment, but that this data about a treatment/ technique could be used by others to find out more details and check suitability for their own cases later.
A participant starts lecturing another on "love" and "duty" and "patience" for the patient	<p>Tell them that this is good, but you are sure everyone is trying their best under their circumstances. Let us, instead, look for ways to make caregiving easier and less stressful so that we can all do it better. Do not let such preachy talk continue.</p>
Someone makes a funny comment that is inappropriate/ hurtful	<p>Depending on how the others respond, you can:</p> <ul style="list-style-type: none"> • Ignore it and continue • Say gently that others may be concerned about the topic and serious about it, so maybe we can focus on the discussion right now
A participant does not open her mouth	<p>Check the participant's body language. If the participant is reluctant, do not put any pressure. But if you feel she is being shy, then you can prompt for a comment. Do not directly name the participant or point at her, but look in her direction and ask questions, such as:</p> <ul style="list-style-type: none"> • Do you have anything to share about this discussion • Do you have any comments or suggestions about this problem • Add a "It is okay if you don't have any comments right now," to make sure there is no pressure

	<p>If the person remains silent, but you feel she wanted to ask something (and hesitated), approach her during a break, or after the meeting, and check whether she has any concerns she wanted to discuss. Again, do not put pressure. Some people speak less than others, and also take more time to feel comfortable about speaking, but may still be benefitting from the meeting by hearing people discuss.</p>
No one is speaking	<p>Some silence happens when people are trying to grasp something, or after a member has become emotional.</p> <p>But if the silence stretches out too long, you can break it by the following:</p> <ul style="list-style-type: none"> • Ask people whether they have any comments of what was just discussed • Switch the topic to another one, and ask open-ended questions, or present a new concept or situation and ask for responses • Give everyone a paper slip and ask them to write down one or two questions or concerns they have
A participant is very agitated or angry about something	<p>Some amount of expression of anger and frustration is natural in a support group, but beyond a point, it makes others uncomfortable. If you feel the anger is distracting the others and making the meeting unproductive for everyone, you can:</p> <ul style="list-style-type: none"> • Acknowledge the situation that provoked anger, and ask others in the group what they feel about it, and what solutions they have • Give the person a few minutes to feel better before continuing the discussion, and reassure the person that everyone is trying to help • Acknowledge the upset that the person is feeling, say you will discuss this later, and move on to another topic
A participant starts crying	<p>Some amount of sobbing is natural in most emotional support forums. Usually, people allow for such crying and accept it, but after a point, they are uncomfortable. Give the person time and privacy, assuring her this is normal. Move over to discussing the topic with others. After a while, ask the person who was crying whether she is feeling better, and</p>

	whether she wants to talk more right now.
Some participants start a side-talk	Side talking creates pockets within a group, and makes people feel excluded. Ask the persons who have formed this side-talk group whether they'd like to share what they are discussing, or could they please join the main discussion instead. Be polite but firm about this.
