

Setting up and maintaining an online caregiver forum to support dementia caregivers

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The purpose of this document:

This document shares my thoughts on the broad areas to address for creating and maintaining an online forum for dementia caregivers.

Introduction

If you are a concerned person trying to support dementia caregivers, one option you consider could be establishing an online support group that is stable and can act as a continuing resource for caregivers, and which will remain a safe, effective, and reliable forum for a diverse range of caregivers. This type of group can provide 24x7 support to overwhelmed and isolated caregivers, but setting up and running such a group requires time, effort, and funds, and the effective use of resources. This document shares thoughts on various aspects involved.

Clarity about the objectives of the online forum

This includes clarity on aspects such as the target audience, the areas in which caregivers should be able to interact and get support, and the extent of support being aimed at. For example, is the group only for dementia caregivers or all types of caregivers, and can volunteers, health professionals, interested students, and others concerned about dementia also join and participate? Will it be open for (and friendly enough for) persons with dementia? Will the group provide medical information and advice, or only provide support for living with dementia?

These objectives and target may change over time, but an initial clarity is required to launch the group and get it functional.

Clarity about the investment and resources for this support group project:

Includes clarity on who will handle the project, how many persons may be involved, and whether they will be compensated (or at least have expenses reimbursed). The skills required in group administrators and other involved persons should be identified based on the group objectives and scope. The time, effort, and funds that will be used to establish the forum and to sustain it should be identified.

One important aspect is the technical skills and resources available, because there is need to select a platform for the forum, and then to do the setup and whatever technical work is required to keep the forum functioning on that platform.

Again, the understanding of the required investment and resources will get refined over time, but an initial estimate is needed to define the scope and begin the project.

Set up and Launch Efforts

The scope needs to be translated into an appropriate choice of platform and a clear set of rules and guidelines. This may include creating various documents, such as welcome documents, guidelines, rules, etc., for members and also for moderators.

The choice of the technical platform is an important part of the set-up. The selection depends on multiple factors, such as the technical expertise available to the group managers, the costs involved in setting up, hosting, and maintaining, and how well the features of the available platforms meet the criteria of privacy, user-friendliness, ease of search, and other important things. Potential group members may be more used to some types of technology (even if that does not provide as much technical flexibility). They may prefer a mode where they don't have to specifically go to a site to log in and can, instead, use their usual social media settings or email to stay connected. All these factors need to be evaluated while making a choice.

Typical modes used are email groups, bulletin boards, and Facebook groups, but there could be others, and trends change over time, so ability to migrate may be important, too.

The actual group set up requires time, especially if opting for a structured forum such as a bulletin board with forums, sub-forums, queries, multiple privacy levels, etc. Decisions may be required regarding aspects like user profile settings, types of users, etc., and on procedures to be used to receive and process requests for membership. For example, are pseudonyms allowed? What sort of vetting is done (if at all) before approving a new member?

Set up and launch includes inducting moderators and experts who will provide the backbone for the group to be effective. And some initial drive to get caregiver members.

Some groups opt for soft launches where they make the group operational and let the initial glitches get ironed out before they announce the group and start membership drives; others prefer a big-bang announcement approach. Each of these has its pros and cons.

Managing the ongoing interactions in the group:

This is often underestimated, as people think that once they set up a group and get in some members, the group will function by itself and members will support each other. But the truth is that ongoing effort is needed to ensure that the group remains active and useful. This means active moderation and backend administration.

Let's look at moderation.

One role of moderation is to keep the interactions clean and useful, and to stop offensive or misleading posts. Some examples of these are inappropriate humor, judgmental or critical comments, offensive language, etc. These can make the group an unsafe and stressful experience for some caregivers and therefore these posts need to be handled before they spin out of control and hurt some members and maybe even make them opt out. Some interactions can get very ugly if not caught in time.

Some members may use groups to spam them with messages promoting their own products, videos, facilities, etc., and keep on announcing discount schemes and other promotions. Depending on the group policy, moderators may need to add disclaimers or even remove such posts and warn the spammers.

The group moderators should also handle posts that give medical advice or advice on alternate therapies; many serious groups do not allow promoting "miracle" cures of any sort, and discourage any direct medical recommendations (though they allow sharing of experiences of side effects or personal experiences with the medical systems).

One related aspect is deciding whether comments can include links, and if so, what sort of links. This is particularly important because some persons may post inappropriate/ misleading links, or may try to use the forum to promote their own work and products which are not relevant or useful to the group members.

Moderators may also need to check that members follow participation guidelines if the group has some rules on the headers and formats of posts, or on which forums can be used for which types of posts (usually in email groups or bulletin boards).

Moderators can also use positive interventions to ensure the group remains vibrant and has a flow of useful interactions.

Sometimes queries are posted but no one responds. Moderators can notice this and either answer the queries or ask an expert to answer them, or highlight the unanswered query to the group so that other caregivers notice it and perhaps give their own comments and suggestions. Basically, they need to remain alert about possible ways to intervene if the queries are not getting good quality responses.

Sometimes some days may pass and no one posts anything. Moderators can liven up the group by sharing something relevant, such as a comment that can kick off a discussion or some sharing or a link to a resource or a video.

Unanswered queries are a downer in any group, not just for the person whose query was ignored, but also for others who see an unanswered query and therefore decide not to post their own query. Similarly, long lulls in the group interactions discourage members from posting, because they assume the group is dying and it would be pointless to participate. Caregivers are more likely to participate--posting queries and comments, and well as responding to them--if the group has regular posts and seems alive and active.

Moderators can, by being watchful and proactive, make sure the group remains friendly, active, and useful.

Consistent and ongoing moderation is key for group effectiveness because it keeps away what is unhelpful or offensive and encourages useful interactions. To achieve this, moderators need guidelines, too, so that moderation is consistent in its type and degree and members know what to expect and how to interact in acceptable ways. They may even have a private forum of their own where they discuss how to handle some especially tricky situation, or whether a certain member needs to be removed for spamming or offensive content, etc.

The number of moderators required would depend on the group size and level of interaction, and some groups may need moderators working in different time zones so that discussions don't swing out of control before getting detected.

Some groups opt for pre-approval of posts (posts will go live only if a moderator approves), but this can get restrictive and slow down discussions, and also increase the workload of moderators, and so groups may decide to depend only on moderation, or may use pre-approval only for newcomers.

A related point is the tendency of inducting patrons and experts who are reputed, but unlikely to have the time to actually participate. This gives the group some reputation and may attract some members, but the group managers should remember that just because someone has agreed to be listed as an expert associated with a group does not ensure that the person will take on an active role; it may even happen that the person contradicts some of the group philosophy, or has joined to promote their own book or service or other agenda. When pulling in resource persons for the group, this needs to be factored in.

Maintaining an inflow of members

As members will typically reduce participation or stop it after some time, new members need to be inducted all the time. This will make sure that there are enough actively participating members in the group at any time, and that there is enough diversity of perspectives represented in the group.

Various approaches are possible to attract new members, and can be combined as suitable. The group may be linked to its own resource website which is visible in searches. It may be linked from various blogs or sites of relevant organizations and experts. Social media may be used. Paid (sponsored) advertisements may be used in social media or on search engines, etc. Existing members may be asked to direct other caregivers to the group. Other word-of-mouth publicity may be encouraged. Videos can be put up introducing the group on channels like Youtube. The group may arrange events or training, or connect with other organizations, thus broadening its base. The methods chosen would depend on the membership numbers being aimed for, and the effort and funds available, but the point is, without some inflow of new members, the group will stagnate over time.

Old members often continue indefinitely as they don't bother to leave the group even if they are not active or interested anymore. And sometimes members never even start participation, and it is unclear whether they are benefitting from the group or uninterested. Most support groups allow lurkers (members who never post), but again, some groups may prefer to periodically weed out lurkers/ ask for reconfirmation of subscription to remove dead/ unused email addresses, etc. Such cleanups keep the membership count more reflective of the actual status rather than bloated by uninterested members.

Ongoing administration and technical support

Another ongoing activity is ensuring that the technical platform of the support group remains usable and free of problems like viruses. Many groups use free software products and free platforms, and these sometimes change their rules and settings, and sometimes they require migration or even close down. To ensure the group keeps running smoothly, some technically skilled persons need to remain alert and take actions as and when necessary. Regular backups, if applicable, may also be needed.

Similar technical effort is required if the support group is on a self-hosted platform.

There may also be funding associated with running the group, such as paying for a domain name or hosting or some other service, and ensuring that funds

Funds may also be required for paying expenses to volunteers, paying for sponsored ads and other activities. These have to be managed, too.

Closing the group/ Transferring to another management

It is possible that you will run out of resources and will need to close the group or opt out and let someone else take over.

As the exchanges on the forum can be private and confidential, you need to ensure that the trust shown by the members is not violated. Maintaining/ archiving an old forum has its merits because it is a database that can be useful to persons living with dementia and others concerned about dementia. However, the members may not want a new management to have access to their posts. You will also not be able to reach many of the caregivers who participated. Passing on all that data to another group may not be an acceptable solution.

Sometimes persons who set up resources later sell off or transfer the resource to someone along with the membership list, but this may violate the privacy expectations of the existing members and if that is so, this should not be done.

In conclusion

In this document, I have shared my thoughts on multiple aspects of setting up and maintaining an online caregiver forum. I consider such groups very useful and necessary, but also a responsibility towards the members because they come here in hope and desperation and bare their personal lives.

This is a draft document, a preliminary exploration.

I hope you find the document useful and would appreciate if you share your thoughts, observations, and concerns with me, so that I can use your input to refine the document.