



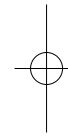
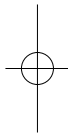
**Alzheimer's Disease
International**

Starting a self-help group

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Self-help groups

This booklet offers help in starting a self-help group for people who care for persons with dementia.

It presents useful ideas on how to start and maintain such groups.

It was produced with the co-operation of members of Alzheimer's Disease International.

Key words:

Alzheimer's disease, dementia, self-help groups, support groups.

Foreword

This booklet has been produced by caregivers with experience of self-help groups from around the world. It has been put together by Alzheimer's Disease International, a non-profit-making, non-governmental organisation in official relations with the World Health Organization (WHO), to whom we are most grateful. It brings together the simple and practical views of those who live through the experiences of having a family member with dementia.

The preparation of this text benefited from contributions from many members of ADI.

Introduction

The aim of this booklet is to help you start and run a self-help group for caregivers of people with dementia. Such a group can offer support to caregivers as well as to other members of the family or friends who are also affected.

One of the ways in which those who provide care find help and relief is when they meet with others in the same situation as themselves. A self-help group provides an opportunity for such meetings to occur.

There are many different kinds of self-help groups. No one kind is necessarily better than another. What matters is that they are helpful to those who take part.

When you start a group, you will want to find an approach that is most appropriate for you and the other members of your group. You may use the ideas in this booklet as a starting point, or you may have your own ideas.

The term caregiver will be used throughout the booklet. It is used to describe a person who cares for a family member or friend with dementia.

What is a self-help group and what can it do for you?

A self-help group, which is sometimes called a support group, is a gathering of people who are caring for family members or friends with dementia. The purpose of this group is to provide support to the members and thus allow them to cope better by:

- Sharing their feelings and experiences
- Learning more about the disease and giving care
- Giving caregivers an opportunity to talk through problems they are facing or choices they have to make
- Listening to others who share similar feelings and experiences
- Helping others through the sharing of ideas and information and providing support
- Offering caregivers a break and a chance to get out of the house
- Encouraging caregivers to take care of themselves in order to safeguard their health and well being
- Knowing they are not alone

A support group provides an opportunity for caregivers to share their feelings, problems, ideas and information with others who are undergoing similar experiences. It helps caregivers pay some attention to their own needs and to begin to take care of themselves. It also provides the satisfaction which comes from sharing with and helping others.

The role of a support group is mutual support. Members may want to undertake other tasks such as raising money for research or campaigning for better services but these should be kept as quite separate activities.

What it cannot do

A support group cannot solve all problems, nor can it replace the services of a doctor or other health care professionals.

It is important to remember that a support group is not a help for everyone. Some people are not comfortable sharing personal feelings with a number of others.

How to get started

It is important before starting your own group that you ensure no group already exists in your area. If it appears that there is no group in your area to meet your particular need, you might consider the following questions before starting.

First ask yourself:

- Do I have the necessary time and energy?
- Do I have the needed support from family and friends?
- Can I cope with the additional demands of organising a support group?
- Do I wish to hear about other people's difficulties?

Getting help:

- Are there other caregivers you can talk to? Will they help you? Share responsibilities?
- Are there local or national organisations who might help – for example, an Alzheimer's association?
- Are there any professionals, doctors, social workers, health workers, nurses etc. in the community who might help by:
 - spreading the word about the group?
 - facilitating the group?
 - providing information about dementia and caregiving?

Planning the first meeting

Getting started can take some planning and effort. The following are some of the items to consider when preparing for the first meeting:

Aims of the group

It is a good idea to work out what the aims of your group might be. This will help you in explaining your ideas to others and enlisting their help. These aims should be reviewed by group members once the group is formed.

Aims can be very simple such as:

- To enable caregivers to meet on a regular basis to provide mutual support
- To enable caregivers to meet others in the same situation and share their feelings and experiences
- To provide caregivers with an opportunity to learn more about dementia and caring

Who might be in the group?

A self-help group is not for everyone, but many family members and friends of those with dementia find them helpful.

Publicising the meeting is important in order to recruit those who might be interested in taking part. The following are a few of the many ways to advertise a meeting.

- Radio and television stations often provide free advertising for community events
- Local newspapers often publish notices of meetings. Check first to see if there is a charge for this
- Places of worship are also a good source of new members. Mention might be made of the meeting in their regular bulletin, notice board or announcements

- Posters can be placed in doctors' offices, community centres, nursing homes, libraries, pharmacies, food stores
- By word of mouth

There may also be others that are specific to your community.

Any publicity should include:

- Date and time of meeting
- Place of meeting
- Name, telephone number, or place where contact person can be found

Numbers

It is probably best not to worry about the numbers at first. Some members may not be able to attend every meeting. Attendance may also drop after the initial meetings. If the numbers become too large and it becomes difficult for everyone to participate, then dividing into two groups might be considered. Do not be upset about too few people attending the first meeting – in time numbers will grow.

Place

In selecting a place to hold the meetings you might want to consider:

- Convenience - can people get there easily?
- Size - is it large enough? are there enough chairs?
- Comfort - is it quiet and private enough to allow for a comfortable exchange between group members?
- Are there toilets/washrooms?
- Cost - is there a charge for its use?

Schools, places of worship, community centres can be considered. It may even be convenient to hold the first meeting in someone's home.

It is important to use the same place whenever possible, so if a caregiver misses a meeting he/she will know where the next one will be.

Time

How often? Monthly? Every two months? Usually members of the group will make this decision at the first meeting. Most groups meet on a regular basis. It is easier for everyone to remember if the day of the week and the time are the same for each meeting.

What time? Morning? Afternoon? Evening? It all depends on what is convenient to members of the group.

A note about choosing a convenient time – it is impossible to find a time that is always convenient for everyone. However, if members exchange telephone numbers, a member who is unable to attend a meeting still has a way of being in touch with others.

Cost

Self-help groups should be free of charge. Finding a free room and having members take turns bringing refreshments is best. If you do end up with expenses, it is usually preferable that these are paid for by the group, not by one or two individuals.

The first meeting

It is important to consider the purpose of the meeting:

- Is it for support only?
- Is it to provide information?
- Is it a combination of support and information?
- Should there be invited speakers?
- Is it to find out if there is a need for a group?
- If there is a need, how does the group wish to proceed?
- For how long should the group be in existence?

Practical arrangements

Having the right environment where participants feel welcome and comfortable is important. You may wish to consider the following as you prepare for the first meeting:

- Arrangement of the room - are the chairs in a circle to help create a friendly atmosphere?
- Temperature of the room - is it too hot? or too cold?
- Welcome person - has someone been given the task of greeting members as they arrive and to make sure new members are made to feel welcome?
- Someone needs to know how to make contact with all the members of the group
- Resources - are there any booklets or pamphlets to be displayed which may be of interest to the group?

Choosing a group leader

This may be the most important decision you will make in setting up your group. The role of the leader is vital to the success of the group. A leader must be comfortable speaking in front of a group and have the ability to:

- Encourage participation and ensure all members who wish to get a chance to take part
- Listen without judgement
- Ensure that the rules agreed to are respected
- Share information about the disease and caregiving
- Identify if a particular individual may require more support and assistance than the group is able to offer

It is a good idea to have at least two people leading the group. In this way, if a member gets upset and needs one-to-one support away from the group, the group will not become leaderless. Also, if a new member with urgent and differing needs comes, they can be given an individual welcome and some one-to-one support.

Do not overlook the fact that the leader may also require support. Leading a group can be emotionally draining, so being able to talk to someone else about this is crucial.

Basic rules

Early in the life of a group, it is important for the group to agree on some basic rules. These help members develop a sense of trust and allow them to more easily share their feelings and experiences. The group should ensure that:

- All information about members and discussions within the group is kept confidential
- Members of the group listen and support each other without criticising or making judgements
- No one is expected to be the 'perfect' caregiver
- Each member is respected and all are made to feel equal in the group
- Each member has a chance to speak if he/she wishes
- Each member's situation is respected. What is right for one person may not be right for another

The meeting

To assist the flow of the meeting it may be helpful to set aside a specific amount of time for each part. It will be up to the leader and group to determine the order and the time for each part.

The group leader may wish to begin each meeting by:

- Welcoming all members, as caregivers are likely to be from different backgrounds with varying levels of comfort in sharing personal information. It is important that new members are greeted in a friendly way and made to feel comfortable and welcome.
- Stating the purpose of the group
- Reviewing the rules
- Helping people to learn from the experiences of others
- Sharing any information about events that may be of interest to the group
- Asking members to share information that may be of interest to the group
- At some point people should be invited to talk about themselves

Beginning the discussions

The group leader may begin a discussion by talking about a topic and asking members for their reaction or to share similar experiences. Depending upon the topic and the response, this may be all that is needed. The leader may also be prepared to ask such questions as:

- Have you any financial, medical or legal problems that you would like some information on? or some suggestions for dealing with?
- Where have you found support? within your family? community?
- How has your life changed since you were faced with dementia?
- It is preferable to allow for, and encourage interaction between members

Summing up

When it is time for the meeting to end, the leader may ask one, two or several members to share their thoughts regarding the meeting. The leader may also wish to summarise the discussion and ask the members if they agree with his/her impressions. The date and time of the next meeting should be decided upon or announced.

Refreshments

If available, refreshments provide an opportunity for people to get to know each other, find out that they share other interests besides caregiving or continue the meeting's discussions if they wish.

What about the person you are caring for?

Attending a meeting may be difficult for the caregivers who cannot leave the person they are caring for by him/herself. Ways to help are:

- Getting another family member or friend to provide relief
- Providing supervised activities for the person with dementia, in a room close to the group meeting

Keeping the group going

It is a good idea to review, on a regular basis, how the group is working. The needs of caregivers change and it is helpful to ask members such questions as:

- Is the meeting place, day and time convenient?
- Do you feel welcome?
- Do you have the opportunity to say what you wish?
- Do you find the meetings helpful?
- Do you think new members are made to feel welcome?
- How can we improve the group?
- What topics would you like to see addressed?
- Should the group size be controlled?

Former caregivers

Members whose relative has gone into care or who has died may continue to need the support that comes from attending the group for a while. The group may be able to help them through their loss and they in turn can contribute their experience. It is up to each group to decide for how long former caregivers should be encouraged to attend.

Alzheimer's Disease International

– a source of help for you

Alzheimer's Disease International (ADI) is a federation of national Alzheimer associations around the world. These national associations offer information and help to people with dementia and their families.

In each country, our member works to develop support groups and education programmes for affected families and the general public. Each has a medical and scientific component. Some members also provide counselling, day centres, home care and other types of respite care programmes.

You can contact ADI for:

- More information about Alzheimer's disease and other dementias
- Updates on advances in research
- The address of the Alzheimer association nearest you
- Guidance in developing an Alzheimer association in your country
- Contact with Alzheimer's associations in other countries
- More information about developing support groups

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