

STARTING A HEALTH SUPPORT GROUP

INFORMATION BOOKLET



— CONTENT —

Introduction.....	3
What is a health support group?	4
What are the benefits of belonging to a health support group?.....	4
Types of support groups.....	5
Setting up a support group - where to start	6
How to find members.....	8
Finding a venue.....	9
Funding.....	9
Facilitating a peer support group	10
Guidelines for running meetings.....	10
Encouraging positive group dynamics.....	12
Tips for handling difficult situations.....	15
Some other things to think about	16
Selecting a group leader or facilitator.....	16
Ground Rules and developing a shared vision.....	17
Who will manage finances?.....	18
How will your group maintain confidentiality?.....	18
Making the support group a success.....	19
Information links and references.....	21
Notes.....	22

— INTRODUCTION —

This booklet has been developed to provide information and guidance to people who are planning to start up a Health Support Group or who are already in a leadership position within an existing support group.

It is also useful for all support group membership. If a support group that meets your needs is not available, then this booklet provides all the information you need to set one up yourself.

Research shows that people who have health conditions can benefit hugely from being able to share their own experience and interact with others who understand because they are in a similar situation. Being part of a support group provides opportunities not only to gain support, but also to help others.



— WHAT IS A —
HEALTH

SUPPORT GROUP?

Members of health-based support groups usually have similar health conditions. They meet to share knowledge, experiences, strengths, hopes and for a sense of community.

People join support groups for many reasons including to learn “self-help” techniques, to seek support for themselves and also to offer support to others and thereby increase their own and others’ wellbeing.

WHAT ARE THE BENEFITS OF BELONGING TO A HEALTH SUPPORT GROUP?

The benefits of belonging to a support group can include the following:

- Gain knowledge about the condition
- Meet others who have the same health condition
- Share experiences
- Learn tips that others have used to manage the condition
- Receive support in putting ‘self-help’ strategies in place
- Be able to talk freely about the condition
- Receive good practical advice about treatment options
- Develop a clearer picture of what life is like with the condition
- Gain information about where good resources are available
- Reduce anxiety, depression and distress
- Feel less isolated and alone
- Offer emotional and moral support
- Meet new people and form new friendships
- Feel better equipped to support friends of family with the condition.

TYPES OF SUPPORT GROUPS

There are many different types of support groups. The type of support group you set up will depend on your needs and the needs of others with the same health condition, as well as on the resources available to you. A few of the different types of support groups are listed below. Sometimes, groups will include a mixture of these types.

- **Peer-to-Peer Support Group.** People with similar health problems (for example, diabetes or asthma) come together to share their experiences. The group is run by the members themselves. Health professional(s) may be called on occasionally to provide advice, information, education or clinical support. In this group, members have a sense of belonging and feel supported in a safe environment.
- **Clinical Support Group.** This type of support group is set up by a health professionals and is professionally facilitated. This group usually provides information including current research findings, education and advocacy.
- **On-line Support Group.** Some organisations run online support for people who are house-bound or have little or no time to attend meetings. They may also live in rural areas where there is no close support from a local community or from health services. This group may also target the younger population as young people are often very (and more) familiar and comfortable with online interaction.
- **Culturally Specific Support Group.** Some support groups are culturally specific to meet the needs of people who feel more comfortable with others who have similar cultural experiences, eg refugees, Pasifika people, Māori.



— SETTING UP A —
HEALTH
**SUPPORT
GROUP?**

WHERE TO START?

Before starting a support group, first take a look to see if one is already running in your area. To find information on existing support groups take a look in the MidCentral DHB Support Group Directory <http://bit.ly/1e4yVXD> or ask your local G.P., hospital, health service or Citizens Advice Bureau.

A PLACE TO START

When establishing a support group it is helpful to have a clear picture about the type of group you plan to setup. Aspects to consider include:

- Which health condition(s) will the group focus on?
- What do you want to accomplish?
- Will the group be social, formal, informal, activity-based, with or without regular professional input?
- Are support people, such as partners and children able to attend?
- Is the group targeted at a specific age range or cultural group?
- How many members will the group (ideally) have and how will new members be recruited?
- Do you want to set up, in conjunction with a larger organisation?
- How frequently and where will the group meet
- What time of day will the group meet? It can be useful to do a small poll when you start a group about what days and times work best for most people
- Once the group is established how long will it continue?
- How will the costs of running the group be covered?
- Is a committee necessary or is a sole group coordinator sufficient?

HOW TO FIND MEMBERS

There are many ways to get the word out about your group:

- **Use referrals.** Let doctors, social workers, nurses, health agencies, the hospital, and others know about your group and encourage them to tell people about it.
- **Use the media.** Create posters and flyers and place them in local community newspapers, church bulletins, supermarket notice boards, chemists, public library, hospitals, and G.P. waiting rooms. In the advertisement, be sure to outline the intention of the group and provide your contact details. Talking to media personnel will likely also provide you with additional options for advertising your group.
- **Use personal invitation and word of mouth.** Tell everyone you can about the group and ask them to tell others. When your group starts meeting, encourage members to tell others about the support group.

Once you have spread the word, contact those who have expressed interest to let them know the date and time of the first meeting. It's a good idea to give plenty of notice (at least two weeks) and to follow-up with a phone call, email or text message two or three days prior to the first meeting.

It can also be very helpful to ask those who have expressed an interest what topics they would be interested in hearing about in relation to their health condition. This can provide information which can then inform discussion topics for future meetings, as well as which speakers might potentially be invited.

It can be useful to invite a health specialist (eg a nurse) who is likely to be familiar to the group members. This can not only provide a familiar face for members, but can provide a source of support for the group leader/facilitator especially in the early stages of the group's development.

FINDING A VENUE

There are many places in the community where you can hold a support group. These include:

- Members' homes
- Church halls, community lounges, community halls, cafés, schools, sports clubs, local libraries and hospitals, or other health facilities
- Some motels and hotels have conference meeting rooms but these may involve a cost
- The local council may provide a list of free or low cost venues where meetings can be held.

When organising a venue, look for places that have access to public transport, good disability access and have good parking facilities. Additional considerations might include a venue with: an appropriate amount of space (not too small, not too large); access to kitchen facilities (or tea/coffee making facilities); good security; and be aware of responsibilities for opening, closing and cleaning the premises.

FUNDING

Running a support group will incur costs. Costs may be related to:

- Renting a room/venue
- Advertising to recruit new members
- Newsletters to members
- Refreshments during meetings
- Photocopying and printing
- Phone calls

It is important to decide how the costs of running the support group are going to be covered. Members might be happy to pay a small annual fee or a gold coin toward costs. However, it is essential to inform members before they join the group how much they will be expected to pay. You might also seek donations or small grants to cover costs.

GUIDELINES FOR RUNNING MEETINGS

- **Set an agenda**

It is useful to set an agenda prior to the meeting and send it out to members in advance so that everyone knows what to expect from the meeting.

- **Prepare yourself for the meeting**

Prepare and review the topics for discussion. Look over any notes you took from the last meeting. If you plan to make any announcements of community events or activities, make sure you have them ready. Arrive early to arrange the room and set up refreshments. Arranging the room can also include setting out relevant resources (pamphlets, information boards etc). It can also be a good idea when advertising the meeting, for members to include both the starting time of the meeting and an indication of when the doors will be open as people can often arrive quite early. Have a pen and paper ready to take notes during the meeting. As people arrive, greet them by name and make eye contact.

- **Start the meeting**

Start the meeting on time with “let’s get started”.

— FACILITATING —
A PEER

**SUPPORT
GROUP?**



- **Welcome**

Welcome the members to the group. Introduce yourself and have others introduce themselves. (For larger groups you may encourage people to break into smaller groups to introduce themselves.) Provide any relevant health and safety information eg fire exits, where the toilets are. Encourage discussion and agreement about confidentiality within the group. If there are new members, go over the “ground rules” again (see p. 17). Sometimes it can help to get things started by having a prepared introductory activity. For example, you might ask members to get into pairs and tell the other person three things about themselves such as favourite colour, food and movie.

- **Begin the discussion**

Touch on a topic that has been mentioned by one of the members or start with a prepared agenda item.

- **Round table discussion**

Encourage members to talk about what has happened as a result of, or since the last meeting. Members are encouraged to listen to each other, offer support to one another, talk about themselves, and problem-solve.

- **Coffee/tea break**

The coffee/tea break may also be scheduled at the end of the meeting especially if some members (or speakers) are pushed for time.

- **Discussion**

This set agenda item may be on a specific topic, eg the latest research on the topic, new medications, new medical procedures available, physical activity options, dietary recommendations, having a positive attitude. (Use this opportunity to let members know of any new resources, workshops or books available.)

- **Finish the meeting**

Most support group meetings last between one and two hours. It is generally best to finish meetings at the agreed time. Finish the meeting by summarising the topics that were discussed. Highlight any positive observations or solutions that came up. Ask for suggestions for future activities, topics or ideas for future speakers. If possible, (ie if this has already been decided), let everyone know the time and place of the next meeting. If you need help with donations, refreshments, transportation, ask for volunteers now. Finally thank everyone for coming, say goodbye, and encourage them to come again.

- **Make final notes**

Once you get home, make some brief notes about what happened at the meeting. Use these notes to jog your memory as you prepare for the next meeting.



ENCOURAGING POSITIVE GROUP DYNAMICS

- **Encouraging members to listen to each other**

A good listener shows they are listening and understanding what is being said. They do this with body language, eye contact, brief encouraging statements or non-verbal encourages, nodding, repeating or rephrasing the speaker's last phrase to let them know you understand.

- **Offer support**

This is the main reason support groups exist. Support involves listening for feelings expressed by the member and addressing those feelings, making statements that show you understand and sympathise, or expressing appropriate body language.

Encouraging positive group dynamics is important to the success of your support group. Role modeling the following behaviors goes a long way toward setting a positive tone for meetings.

- **Encouraging members to offer support to one another**

While being supportive yourself, you must also help others in the group learn how to be supportive of each other. Use listening tips above while members are speaking. Once they have finished, wait 10 seconds or so and then, if no other members have done so, offer support. Group members will usually pick up on this and start offering support themselves. If they don't, you may ask them if any members of the group have anything to add.

- **Encourage members to talk about themselves**

Support groups can create an atmosphere where members are willing to reveal personal information and work through personal experiences. This gives other members a chance to offer support, ideas, and assistance. It also encourages other members to share their own experiences and fosters an atmosphere of trust. Asking open ended questions (those that cannot be answered with a 'yes' or 'no') can be very useful.

- **Help members solve problems**

It is the facilitator's job to help members learn how to help each other with problem-solving.

The steps to problem-solving include:

- **Clarify the problem.** If you aren't sure what the problem is, ask questions to get more information.
- **Talk about alternatives.** Bring up possible solutions to the problem in a way that doesn't give advice. For example, "I wonder what it would be like for you to try this." Telling people what to do is not the purpose of a support group. You can also ask the person with the problem what they think might work, or ask other members to tell what has worked well for them in a similar situation.
- **Have the group discuss the pros and cons of each suggestion.** You can then let the person with the problem come to a decision in their own time. Let them know the group cares and wants to know how things turn out.
- **Offer help.** Sometimes members may offer to assist each other.



TIPS FOR HANDLING DIFFICULT SITUATIONS

Sometimes difficult situations can arise in a support group. Members will have different experiences, viewpoints and personalities, despite having a common health condition. It is important to provide a warm and safe environment in which different perspectives are discussed and respected. To facilitate this, it is important that group members demonstrate behaviours which support and foster the positive group environment. If problematic behaviours situations arise, it is important to address these. If left unchecked, they can decrease group enthusiasm and cause people to leave the group. Difficult behaviours may include some of the following:

- Frequent lateness to meetings
- Talking too much, preventing others from speaking
- Rejecting every suggestion that others make
- Constant negativity
- Putting others' viewpoints down
- Discussing problems that are more than the group can handle
- Interrupting others or bringing up inappropriate or irrelevant subjects
- Bringing up problems that don't match what the group was set up to address.

It is important that the facilitator directly addresses problems within the group inoffensively without insulting members.

The following steps can assist to address the difficult group situations:

- Show that you understand each member's position
- Gently but firmly correct the behaviour by explaining that a change in behaviour is required and explain why you need to change the situation
- Suggest what you would like to have happen instead of the negative behaviour
- Get agreement on positive alternative behaviour by making sure there is understanding about what is being asked and agreement to do it.

— SOME OTHER —
THINGS TO
**THINK
ABOUT**

SELECTING A GROUP LEADER OR FACILITATOR

When deciding on the person to facilitate support group meetings, consider someone with the following qualities:

- Is friendly, trustworthy and supportive
- Is able to keep the group focused
- Can encourage others to participate and talk about themselves
- Is able to create an atmosphere where people feel safe and are able to participate
- Is a good listener
- Can handle difficult situations as they arise
- Will manage the group to develop and stick to basic ground rules
- Is able to share their own experiences
- Is able to guide people to appropriate services
- Has a desire to do the job.

A facilitator may at times need support and supervision, and clinicians or health professionals may be able to help.

ESTABLISHING GROUND RULES

Ground rules are useful to ensure that meetings go forward with open, respectful dialogue and maximum participation and also to ensure they are safe and effective. It is preferable to have participants develop the group ground rules together at the first or second meeting. Ground rules usually cover the following topics: confidentiality, respect, the use of appropriate language, and the importance of non-judgmental attitudes. The most common ground rule for support groups is that 'everything discussed in the group must be kept confidential'. The suggested ground rules are agreed to by all members and then written down.

It can be helpful to display the ground rules at each support group meeting along with the group's vision statement (see below). It is often a good idea to also open each meeting with a reminder about the ground rules. The facilitator is in an ideal position to model the ground rules through their own participation. They can also remind participants about the ground rules as necessary.

DEVELOPING A SHARED VISION

Once members have been identified and a support group formed, a shared vision or purpose statement can be developed. Members can be asked what they would like the group to achieve. Look for common themes from the ideas that people give and incorporate them into a shared vision or statement of purpose. Part of the facilitator/leader's role is to make sure that the shared vision or vision statement is realistic. The vision statement can be placed on the wall, at each meeting, so that it is visible to members.

An example of a shared vision is: *"Coming together to create a safe and supportive environment to maintain wellbeing"* from the Manawatu Supporting Families, Carer's Support Group.

WHO WILL MANAGE FINANCES?

All support groups will need some money to operate. With care, costs can be kept to a minimum. For example, if you are able to secure a free venue, you may only need to have funds for tea/coffee in which a gold coin donation will suffice. Some groups may use gold coin donations to cover a small token of appreciation for the guest speaker.

If membership is large, fundraising may be required. This could involve selecting a treasurer or a skilful person who will know how to fundraise and seek out monetary grants. If a more formal group is established, there may be a need to elect a secretary and treasurer. Some banks offer free accounts for profit-free groups such as support groups.

Other supportive and associated organisations could assist by providing advertising through their newsletters and online networks. Assistance can also be provided such as access to the agency's photocopier, donated post-paid envelopes or free access to meeting facilities.

HOW WILL YOUR GROUP MAINTAIN CONFIDENTIALITY?

Given that discussions at support groups may centre on individuals' personal health or social situations, it can be very important to members that the group maintain confidentiality about personal information shared in the group setting. Group members need to feel safe in the knowledge that their confidentiality will be respected. The facilitator should take appropriate steps to ensure that everyone in the group is aware of the need to maintain confidentiality in respect of personal stories and information shared. As a matter of practice, the facilitator can remind members at the beginning of each meeting about maintaining confidentiality.

MAKING THE SUPPORT GROUP A SUCCESS

Research shows the most successful support groups have a number of features in common. Some of these include:

- Availability of up-to-date and reliable information
- Strong relationships between the support group and the relevant health professionals, and national, and/or local service is strong
- Equal opportunity for participation for all members
- Contact among members is encouraged outside of the group meetings
- Continued recruitment of members
- Members expectations of the support group are realistic
- Queries are responded to promptly and accurately
- Regular meetings and/or newsletters are provided
- Accurate advice is provided on accessing appropriate professional services, eg doctors, therapists etc
- Facilitation/leadership is clear
- Members understand clearly the importance of confidentiality
- Members of the group have trust in one another
- Members participate in meetings on a regular basis
- All members are valued and respected
- Members feel they are benefitting from attending meetings.

If you want to know more about setting up a support group, you may find it helpful to check the information links and references below. In addition, you may find it helpful to use Google search and key in the words 'support groups' to find further information. Another option is to contact a support group which is already operating. Check the list of support groups available from the Support Directory <http://bit.ly/1e4yVXD>.

Starting and running a support group can be a very rewarding for everybody concerned. The benefits for members are many including increased knowledge, sharing experiences and developing new friendships. Thank you for taking the time to consider, and be involved in setting up a health support group. May you, and your group, enjoy every success and benefit.



INFORMATION LINKS

Guide for setting Ground Rules
www.edchange.org/multicultural/activities/groundrules.html Retrieved 22/09/2014.

Creating and Facilitating Peer Support Groups. This online guide provides useful information on how to encourage members to listen to each other, offer and provide support to one another, talk about themselves, and to solve problems. <http://ctb.ku.edu/en/table-of-contents/implement/enhancing-support/peer-support-groups/main>.

www.midcentraldhb.govt.nz

www.centralpho.org.nz

MidCentral DHB Support Group Directory
<http://bit.ly/1e4yVXD>.

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November 2015 C: 2244

