

A Guideline for Self Help and Support
Groups

Towards Good Practice

ConnectGroups Support Groups WA

Lifeline WA

Meniere's Australia

Cancer Council WA

Neurological Council of WA

The Genetic Support Council of WA

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A. INTRODUCTION

Support and self-help groups like yours do amazing work! You play an essential role in the community and fill a vital gap in health care provision, by offering people with health (and mental health) issues an affordable and sustainable way to access information, help and understanding. Did you know that on average your groups function on an annual budget of just over \$1,000.00 and engage over 1,500 people a year at an average cost of \$0.70 per person?

However, the importance of support and self-help groups is often underestimated, particularly by medical practitioners and other health care professionals. Part of the reason for this is that there has never been a recommended set of guidelines under which support and self-help groups can operate thereby ensuring the sustainability of the group and its professionalism, effectiveness and overall quality of service to others.

The following set of guidelines are not intended as a set of standards to be imposed on groups but rather as a resource you might find useful in evaluating and improving on the work your group already does but, more so to assist you.

In order to develop the guidelines a reference group was established between Lifeline WA, ConnectGroups, Neurological Council of WA, The Genetic Support Council of WA, Meniere's Australia and The Cancer Council WA, and the following **Terms of Reference** were established:

1. Background

“There is a need to unify not the information but the advice being provided as to how self-help groups should run...” (1990 Edward J Madara)

There are realistic concerns surrounding support groups' perceived level of professionalism, their effectiveness and overall quality of the help offered to their members by both the community and medical sector. Without a baseline framework used by support groups there is and will continue to be negativity and a lack of confidence in whether or not these groups are run both ethically and responsibly. The reference group was formed to look at the development of such a framework without stifling the individuality and creativity of the Self Help and Support Groups; and to ensure that the true intent and ownership of the groups is not lost.

The reference group looked at the existing standards developed by Lifeline Australia and adapted them into a framework suitable for adoption across all self help and support groups.

2. Vision

- A) That all WA self help and support groups have access to a set of guidelines which, if adopted, will assist them to establish good governance practices, ensure the safety of the group, professionalism, effectiveness and overall quality of service
- B) That WA Health professionals are confident in referring clients to groups based on the adoption of part or all of these guidelines.

3. Purpose

To develop a resource to:

- a) Assist self help and support groups to address the safety and wellbeing of the group.
- b) Promote good Self Governance.
- c) Promote the guidelines for a voluntary code of conduct and set of principles to guide practice.
- d) Provide a mechanism for consultation and conversation between the reference group and self help and support group associations and consumers (self help and support group members)
- e) Create and maintain referral pathways from Healthcare Professionals to Groups which 'choose' to adhere to the guidelines/standards.

B. How to use the Manual

Not all sections will be relevant to you depending on –

- Size of group
- If group is incorporated
- How long group has been running
- Type of group i.e. Self-help or facilitated Support Group

We would encourage you to consider the resource as a “toolbox” where you will find best practice models that you could strive to reach, based upon the actual needs of your group and its members.

We recommend that you commence by glancing through the four major components of the resource which sit under the following sub headings -

1. Support Groups establishment and maintenance
2. Self Help and Support Groups philosophy and concepts
3. Self Help and Support Groups Facilitation and Management
4. Self Help and Support Group Services

And then identify which is relevant to you. Newly formed groups may well want to commence by reviewing the Governance section and then working through the remainder of the manual.

We hope you find either all or parts of this resource useful. ConnectGroups are here to support you through training of how to best utilise this resource. We can be contacted on 08 92284488 or via info@connectgroups.org.au.

1. Self Help and Support group establishment and maintenance

1.1 Aims and objectives

Description	Attributes
A statement of the self help and support group's aims and objectives is made available publicly.	<p>The statement includes the purpose and vision of the support group. Consideration for inclusion in the purpose might be outcomes such as managing emotions, thoughts and behaviours, adjustment, integration, sharing experiences, strategies to cope with daily and significant events, managing interactions with family, friends and colleagues, connection, normalisation, and/or social support, etc.</p> <p>Considerations for inclusion in the objectives are:</p> <ul style="list-style-type: none">• the safety principle "Above all, do no harm"• sensitivity• confidentiality• respect, etc.

1.2 Access and membership

Description	Attributes
People are able to access support through the self-help or support group when they need it and when they are in a position to benefit from the self-help or support group.	<p>Any membership conditions set are clearly articulated, such as:</p> <ul style="list-style-type: none">• age• gender <p>The entry process to the self help and support group is clearly articulated. Applicants are advised of possible outcomes of the entry process including referral to other services. Applicants are advised about the support group format, such as length of support group program and length of sessions. The self help and support group targets people with a similar condition.</p> <p>Assessment of potential members is undertaken by the facilitator of the self-help or support group to ensure that people will benefit from their participation. Group members are informed of this process and understand its necessity. Assessment is undertaken either face-to-face or by telephone with the aim of checking that the potential member will be able to benefit from the self-help or support group and will not cause harm to themselves or other members.) This may not be relevant to all types of groups, e.g. Open peer led social and educational support groups where people attend the group meetings voluntarily and the group is publicly advertised. People may be channelled to other more appropriate services (refer standard 4.4 referral services below).</p> <p>Assessment processes are culturally appropriate.</p>

Members are able to access venues/technology as needed to participate.	Physical meeting space is easily accessible for members. Where required, members have availability and guidance on use of technology for participation. Meeting space is neutral, safe, comfortable, inviting and private when required. Meeting space has a withdrawal area if possible.
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1.3 Organisational and management structure

Description	Attributes
Roles and responsibilities of key personnel are defined.	Key personnel and their responsibilities are defined, including the self help and support group co-ordinator, co-facilitators, management team and administrative assistance. Job descriptions or role statements are provided to all paid and volunteer personnel.
Key personnel are qualified to take on their roles.	Key personnel have the required skills and training for their role.
The number of self help and support group facilitators and their characteristics accommodate the size and nature of the support group.	<p>A minimum of two group facilitators for each self help and support group is maintained to assist with self-care, peer review (refer standard 1.5), and demands of the role (refer standards 3.1 and 3.4).</p> <p>Consideration is given to the number of support group facilitators required for the size and nature of the support group. A ratio of facilitators to self help and support group members is applied for groups of 10 members or more.</p> <p>Consideration is given, where possible, of inclusion of different gender group facilitators to provide an appropriate role model for group members and potential group members.</p> <p>Consideration is given, where possible, of inclusion of Aboriginal or culturally and linguistically diverse (CALD) group facilitators for groups with Aboriginal or CALD members (refer also standard 3.1).</p>
The way in which the self help and support group will operate is defined.	Whether the self help and support group is open and ongoing or whether it is time limited and closed for a specific period is identified and potential members advised accordingly.
Develop group Policies & Procedures.	Which will benefit the self help and support group to maintain good governance process' in place.

1.4 Ethics

Description

Codes of Ethics are developed and adhered to by self-help or support group facilitators and members

Attributes

A written code of ethics for self help and support group facilitators is adopted which addresses factors such as:

- confidentiality and privacy
- relationships with support group members
- training in skills needed to facilitate the group
- adoption of organisational/support group policy and procedures/protocols
- conflict resolution
- personal gain or conflicts of interest
- commitment to cultural safety
- commitment to self-care
- duty of care, including the “Above all, do no harm” principle (refer also to standard 4.5).
- complaints and grievances

Group guidelines or ground rules for self help and support group members are developed, adopted and available which address factors such as:

- confidentiality
- acceptance and non-judgement
- sharing of experiences
- respect and empathy
- differences of views and opinions
- networking amongst group members outside of meetings (refer standard 4.2)
- time out during sessions
- exiting the support group.

Consequences for not adhering to the code of ethics are clear and processes for managing such situations are included in the organisation’s/self-help/support group’s protocols.

The self help and support group will identify and meet legislative requirements.

Legislative requirements are identified and processes to ensure adherence are established, as part of groups policies and procedures.

Self help and support group facilitators are aware of legal requirements and incorporate these into their practices.

Attention to child protection requirements and Working with Children checks may be a requirement for a self-help or support groups providing services to children or young people.

1.5 Legislative and management requirements

Description	Attributes
<p>Regular supervision of group facilitation practice and debriefing of self help and support group facilitators is provided by suitably qualified and experienced personnel.</p>	<p>Support for self help and support group facilitators in the form of supervision of group facilitation practice and debriefing is provided. Supervision is a process of care and support delivered by a trained supervisor for facilitators running self help and support groups. This may be delivered through a facilitator reference group, the organisational structure, or even through external support arrangements. Group facilitation practice supervision may be in the form of expert supervisors or through processes such as peer coaching or mentoring, depending on the situation and needs of the group facilitators and the requirements of the organisation. These services may be internally or externally sourced, delivered face to face, via telephone or online.</p> <p>Self-care considerations are made as part of the supervision and debriefing processes.</p>
<p>Regular administrative supervision is provided.</p>	<p>Administrative supervision is provided by the organisation or the auspicing organisation as part of the operational arrangements.</p>
<p>Risks are identified and minimised through good governance and strategic planning reflection.</p>	<p>Risks considered include but are not limited to:</p> <ul style="list-style-type: none"> • Accident and injury — public liability cover is in place • Advice and harm — professional indemnity cover is in place • Unsuitability of self help and support group for some members or potential members - referral protocols to other services will be required • Emergency situations — a crisis protocol is in place for potential emergencies including crises in the group or crisis in the group facilitators(s) • Re-traumatising group members — group management practices are in place to reduce the likelihood of such occurrences. • 'Burn out' of support group facilitators — access to debriefing and supervision; co-facilitators may be needed or time away from support group management role may be needed • Conflict between members or facilitators — effective conflict resolution processes included in code of ethics • Media requests — Media guidelines that clarify media release and spokesperson protocols • Quality assurance of group facilitation sessions.

1.6 Marketing and promotion

Description	Attributes
<p>Self Help and Support groups are promoted through relevant agencies so that people are aware of the existence of the support group.</p>	<p>The self help and support group is known about by services which come into contact with the group's activities such as police, coroner, hospitals, general practitioners, allied health providers (psychologists, counsellors, social workers, etc.), Aboriginal health services, churches and religious organisations, funeral directors, and government and community organisations.</p> <p>Self help and support groups consider subscription to central information sources, such as relevant government agencies and community databases which give contact details to the public.</p> <p>Other promotion activities might include advertising through community avenues and/or in local newspapers. Further, a website for or links to the self-help and support group may be considered so that potential group members can easily find services.</p> <p>Marketing initiatives meet appropriate standards such as the Australian Government <i>Mindframe</i> National Media initiative.</p>
<p>Marketing and promotion materials are culturally appropriate and are understandable by the whole community.</p>	<p>Information provided on the support group is written or presented in plain English at a level that the community will understand (approximately a level of 6th Grade).</p> <p>Where information is translated, it is written or presented at an appropriate level of understanding.</p> <p>Information is culturally appropriate and collaboration with relevant cultural groups is in place where needed.</p> <p>Marketing and promotion materials show sensitivity to the issues faced by people</p> <p>Materials that are provided on the internet are culturally appropriate and show sensitivity to the issues faced by people.</p>

2. Self Help and Support Group philosophy and processes

2.1 Philosophy on Members/Clients

Description	Attributes
Values and principles that the Self Help and Support Group holds are identified.	The self help and support group clearly articulates the values and principles that they uphold, e.g. group agreement of mutual respect and non-verbal violence.

2.2 Service delivery

Description	Attributes
Service delivery is client-centred.	Service delivery principles are defined, such as timeliness of service, quality of service, support group topics, closing support group meetings, mode of service delivery including services provided in between group meetings and at the end of the group service. Self help and support group members understand and agree to the group guidelines (refer standard 1.4).

2.3 Inclusiveness

Description	Attributes
A diverse range of people, regardless of background and cultural diversity, are encouraged to participate	Self help and support groups recognise individuality and have strategies in place to include people from different cultural backgrounds, both genders, those less likely to seek help, and those with differences in coping styles and circumstances. Support group facilitators apply flexible group processes to meet the changing needs of clients. (Refer standard 3.1R <i>Roles of Support Group Facilitators</i> regarding representatives from Aboriginal or CALD backgrounds. Practical support may also need to be given where resources are available, such as child care for evening meetings, or use of an interpreter where language is a barrier. Whether the group member can bring a support person to a support group meeting and the degree of involvement in the group meeting by the self help and support person is articulated.

2.4 Self Help and Support Group processes will be determined by the purpose of the group

Description	Attributes
Where a psycho-educational model is used, group processes include both psychological support and information about aspects such as psychological processes, practical needs, and coping strategies.	Meetings use group processes where psychological support is provided and education on relevant issues is undertaken
Resources providing information are available or identified (in the case of the internet).	Information may include literature available from related organisations, information on local services, and relevant activities. Such information is checked for sensitivity, for cultural appropriateness and for readability (plain English).
Where a self-help model is used, it includes group processes that provide for emotional support.	Group processes at meetings are structured to provide opportunities for sharing coping strategies, and for a positive closing.

2.5 Appropriate Information

Description	Attributes
Information and resources would be appropriate to the purpose of the group.	<p>Access to literature and resources about issues faced by group participants are relevant to their self help and support group i.e.</p> <ul style="list-style-type: none"> • feelings of anger and/or helplessness • the need to understand why and the search for motive • fear of hereditary susceptibility • family dynamics • loss of basic trust • logistical and legal issues • the therapeutic process of hope • acknowledgement of strengths • resilience and integration • potential for growth • coping strategies and interpersonal tactics. <p>Literature and resources are available in various communication media (e.g. video, DVD, tape, printed documents, etc.).</p> <p>Where resources are of scientific/medical they need to be endorsed by Commonwealth Health or State Government</p>

2.6 Self Help and Support Group facilitation models

Description

Attributes

Self Help and Support Group facilitators use clearly defined facilitation models which are culturally appropriate and promote healing and integration.

Self help and support group facilitators are trained in all facilitation models used. The facilitation model(s) incorporate(s) a communication style which promotes group interaction in a safe way and facilitates group processes.

Self help and support group facilitators' practices adhere to the facilitation models used in line with the support group.

3. Self Help and Support Group facilitation and management

3.1 Roles of Self Help and Support Group Facilitators

Description

The roles of the Self help and Support Group facilitators are clearly defined. Consideration of co-facilitation is made with involvement by both professionals (such as counsellors and social workers) and other people. Where professionals are not involved as Self Help and Support Group co-facilitators, access to professional support is available.

Attributes

Roles may include, but are not limited to:

- pre-assessment of potential group members
- using referral processes for potential members not ready for group involvement
- planning and designing support group processes
- facilitating support group processes and support group dynamics
- adhering to the code of ethics (refer standard 1.4)
- ensuring members know about the group guidelines (refer standard 1.4)
- ensuring new members feel comfortable and safe
- providing direction in structured information sessions
- adhering to the 'Above all, do no harm' principle
- ensuring cultural safety
- mentoring emerging facilitators
- debriefing co-facilitators
- managing self-care
- developing exit strategies for facilitators leaving the self-help and support group

The self help and support group has considered the need for involvement by health professionals (e.g., psychologists, G.P's) and/or by people with similar conditions or situations

Co-facilitation of self help and support groups by Aboriginal representatives may be appropriate for groups with Aboriginal people. Likewise with CALD facilitators and CALD members

3.2 Skills and behaviours of support groups facilitators

Description	Attributes
<p>Self help and Support Group facilitators exhibit skills and behaviours that provide a supportive environment.</p> <p>Strengths and skills of members are identified and members encouraged to develop these skills and attributes.</p>	<p>Self help and support group facilitators have basic communication and interpersonal skills, including:</p> <ul style="list-style-type: none">• ability to organise• ability to empathise• ability to listen reflectively• effective verbal communication skills.• inclusivity skills <p>Self help and support groups have defined the behaviours and attitudes that are expected in their support group facilitators such as, but not limited to:</p> <ul style="list-style-type: none">• respect• compassion• trustworthiness• openness• a non-judgemental attitude• retain confidences• honesty• an approachable disposition• cultural considerations• gender considerations• age relevant considerations• minimisation of expression of their own personal grief• recognition of their own limitations, etc.

3.3 Training of Self Help and Support Group Facilitators

Description	Attributes
<p>Self Help and Support group facilitators are trained in basic facilitation models, communication skills and Self Help and Support Group processes.</p>	<p>Self help and support group facilitators are trained in aspects which are most appropriate to the group such as but not limited to:</p> <ul style="list-style-type: none">• role of trauma• mental health first aid• methods for assessing support group applicants• group facilitation techniques• eliciting skills versus lecturing skills• strategies for increasing coping• self-help and support group management skills• the distinction between process and content• methods to bring balance to group processes• assertiveness skills• cultural safety practices• strategies to overcome issues and barriers• crisis intervention processes• health promotional approach to adversity including the awareness and

- value of community capacity building
- client centred, strengths based approach
- pathways to care and referral to other services
- strategies for self-care.
- Grief and loss

Self Help and Support Group facilitators undertake professional development on an ongoing basis.

Self help and support group facilitators take an active role in networks and associations that provide continuing professional development opportunities.

3.4 Self Help and Support Group co-facilitation

Description

Attributes

Where there are co-facilitators, facilitation roles are clearly defined between the co-facilitators. Transition between group facilitators is planned.

Self-help and support group members are advised of the roles of the co-facilitators.

Where group facilitators' change or additional facilitators are introduced, group members are prepared in advance of new facilitators to the support group.

4. Support group services

4.1 Meetings

Description	Attributes
Meetings are well managed to achieve desired goals, articulated in line with the group's purpose and aims (refer standard 1.1).	<p>Meetings are planned and the structure and frequency of meetings is decided upon in advance.</p> <p>The venue for meetings is appropriate. For open support groups, the time of meeting and venue is fixed for a period so that potential members who hold onto information about the group for a long time can access the group. The structure allows support group members to express their feelings, thoughts and behaviours, and explore their needs. Cultural safety is practised.</p> <p>Self help and support group facilitators put in place actions for issues that arise in meetings that require follow-up between meetings, particularly where a duty of care arises (refer standard 4.5).</p> <p>Where appropriate (e.g., closed group format), follow up actions are in place for people who miss meetings or who discontinue. Where this happens, members are advised in advance of this practice.</p>

4.2 Information sharing and networking

Description	Attributes
Information is managed to ensure ease of access, appropriateness and that information is reviewed.	<p>Exchange of information among members is encouraged and supported by the support group facilitator(s).</p> <p>Access to resources is managed so that members can obtain information as required and which is appropriate. Information for the family/social network of the group member is also available. Information for children and young people is age appropriate.</p>
Networking amongst group members is encouraged.	<p>Networking amongst group members is a voluntary choice for the individual.</p> <p>Group members are encouraged to network and connect with other members outside of the group, although this is not a mandatory requirement. Group guidelines or ground rules cover networking amongst group members (refer standard 1.4).</p>

4.3 Range of services

Description	Attributes
Individuals have different needs and services are flexible and adaptable to meet differing needs.	<p>Services can respond to individual needs.</p> <p>Referral protocols are in place with other support services in the community such as counsellors and other services (refer standard 4.4 below).</p> <p>Self help and support groups have considered requirements for services between meetings and provide information for members on ways to obtain support between meetings.</p> <p>Where a group operates with a closed format (i.e. finishes after a certain number of meetings), members are prepared for the close of the group and are provided referrals as necessary.</p> <p>Strategies for members exiting the group are in place to ensure that constructive group dynamics are maintained. Recognition is made of an individual's needs and timeliness for progressing to other stages of their process where the self help and support group is no longer needed.</p>

4.4 Referral services

Description	Attributes
The Self Help and Support Group has a network of relevant services to which it can refer persons as necessary and or the provision of contact details of other relevant community orgs and support group networks.	<p>A list/database of relevant and up-to-date services in the local community is easily accessible and is used as necessary.</p> <p>Services might include, but are not limited to:</p> <ul style="list-style-type: none">• medical practitioners• hospitals• housing services• financial management services• funeral services• legal services• translation services• 24 hour crisis services• telephone counselling services• grief counselling services• clinical psychological services• mental health services• mental health community teams

4.5 Duty of Care

Description	Attributes
The Self Help and Support Group has processes for proactive monitoring of potential risks as a duty of care to each other	<p>Self help and support group facilitators review the risks and recognise potential signs that could jeopardise the well-being of the group member. Hence, takes active steps to promote the member's safety by linking them with further help.</p> <p>Appropriate codes of ethics and protocols are in place (refer points 1.4 and 1.5).</p> <p>Self help and support group facilitators are sensitive to unresolved issues that may arise for members and provide appropriate follow-up and referral (see standards 4.1 and 4.4) as needed.</p>

4.6 Use of alternate delivery modes

Description	Attributes
Where deemed appropriate, Self Help and Support Groups are made available through alternate delivery modes (e.g. telephone or online).	<p>Facilitation of self help and support groups through alternate delivery modes undertake additional measures such as but not limited to:</p> <ul style="list-style-type: none">• ensuring that the potential group member has the right to or authority to use the telephone number through which the service will be provided• encouraging group members to have a private and safe location to participate in the telephone support group• giving consideration to time zone differences• e-mailing or posting written information for members in advance• developing additional support group ground rules to overcome non-verbal communication barriers• using facilitation techniques to ensure involvement of all members• managing the size of the group — a smaller group as compared to face-to-face support groups may be required to address the complexities of managing a group by telephone. <p>Safeguards due to ethical considerations are put in place to ensure that communications are interpreted correctly.</p>

4.7 Review and evaluation of services

Description	Attributes
<p>The Self Help and Support Group reviews and evaluates its services regularly.</p>	<p>Self help and support group facilitator(s) adopt self-evaluation and continuous improvement practices, perhaps in conjunction with supervision (refer standard 1.5). Group facilitators conduct evaluations of their services delivered and meetings facilitated.</p> <p>At least an annual review of services provided is undertaken. Where possible, consideration is given to an external review on a regular basis to provide an increased level of objectivity.</p> <p>Where members are involved in reviews and evaluations, they are informed in advance of any requests for their feedback.</p>

D. Glossary of Terms

- *Self Help - Self-help groups, also known as mutual help, mutual aid, or support groups, are groups of people who provide mutual support for each other. In a self-help group, the members share a common problem, often a common medical condition or addiction.*
- *Support Group - A group of people, sometimes led by a facilitator, who provide each other moral support, information, and advice on problems relating to some shared characteristic or experience.*
- *Psycho Educational Group - A specific type of group therapy that focuses on educating clients about their disorders and ways of coping. Many psycho-educational groups consist of members that all share the same diagnosis. In this case, the education tends to focus on coping with that specific disorder. In other groups, members may have very different diagnoses, and the educational focus is on practical life skills such as living within a community or accepting rules. Psycho-educational groups may be taught by mental health experts, peer counsellors who share a similar diagnosis, or members of the community.*
- *Facilitator - is someone who helps a group of people understand their common objectives and assists them to plan to achieve them without taking a particular position in the discussion and ensures the safety of the group.*

A facilitator is also one who guides and directs a group meeting or gathering. The group may be a family therapy group, a reference group, an educational group, a self-help group or a group with some other focus. A facilitator can also work with groups in organisational and community settings to enhance communication, initiate meetings, contribute to plan development, seek needed resources, provide information, and pursue goals. In the facilitator role, the person is intended to be a 'helper' in group process, and to encourage the contributions of individual group members in order to accomplish the optimal result for the group as a whole.

- *Enables - an enabler provides support, encouragement, and suggestions to members of a broad cross section of a community or client system so that they may complete tasks or solve problems more easily and successfully. In the enabler role, a worker helps a client system cope with various stresses, ranging from crisis situations like divorce or job loss to community issues such as inadequate housing or day care.*
- *Confidentiality - relates to the duty to maintain confidence and thereby respect privacy. The unauthorized disclosure of personal information provided in confidence would be deemed a breach of confidentiality.*
- *Nonjudgmental - is about being open-minded enough to understand that other people have different points of view, and that in their worldview, they may be correct.*
- *Non agency person - A person not employed or volunteering for a business or other organisation providing a specific service.*

- *Burn out - To become apathetic or depressed, and cease to function effectively, due to the fatigue and frustration of prolonged stress and overwork.*
- *Quality assurance - a system for evaluating performance, as in the delivery of services or the quality of products provided to consumers, customers, or patients.*