



Chronic
Illness
Alliance

Best Practice Framework in Peer Support

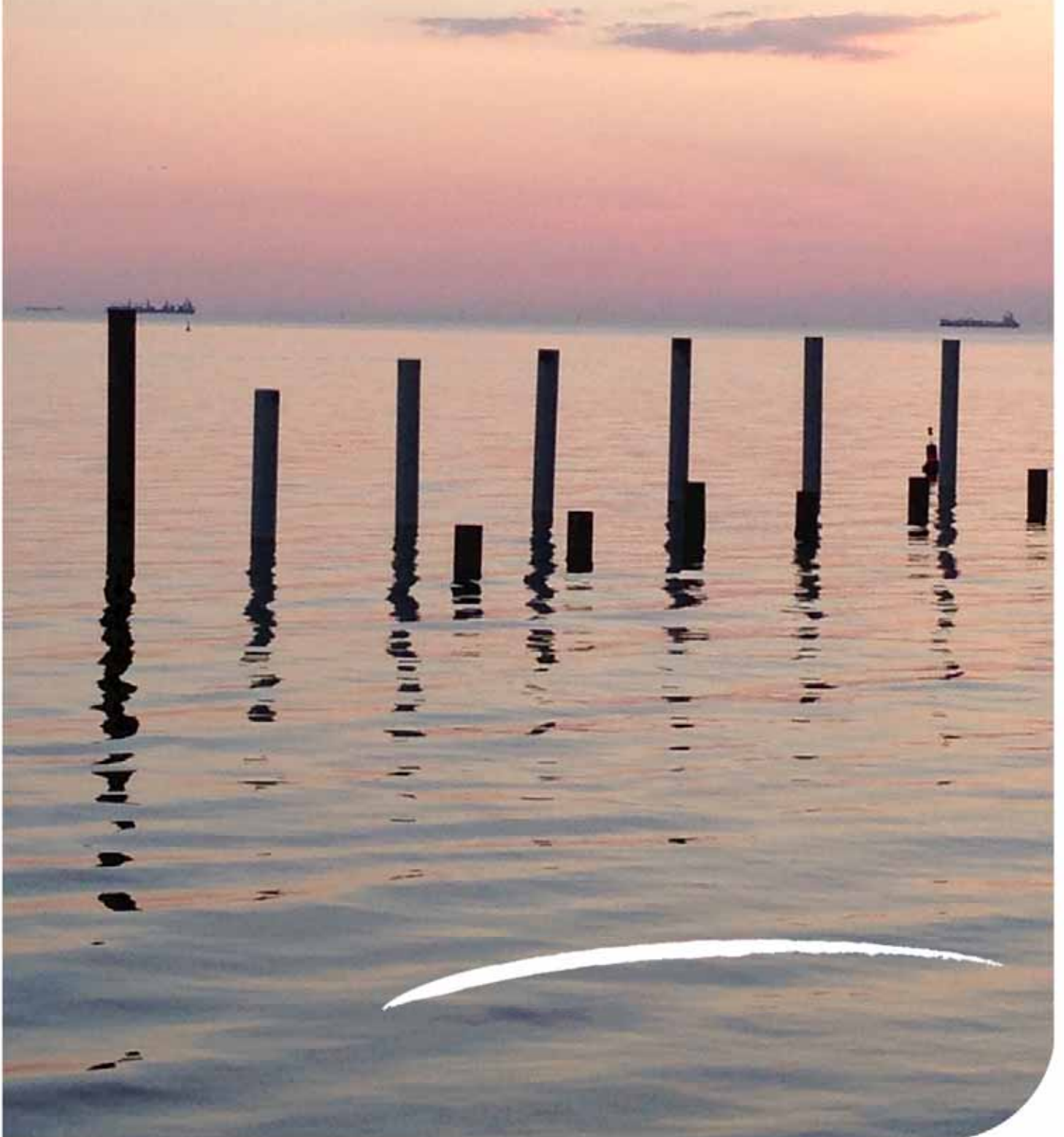


Table of Contents

1. Preamble	3
1.1 Acknowledgements	3
1.2 Introduction	3
1.3 How to use the framework	4
2. Getting Started	6
2.1 Needs Analysis and Research	6
2.2 Choosing the best program for your organisation	7
2.3 Vision and Purpose	9
3. Program Planning and Development	11
3.1 Resources	11
3.2 Program development	11
4. Program Operations	13
4.1 Organisations providing peer support programs	13
4.1.1 Recruitment, selection and screening by organisations	13
4.2 Recruitment, selection and screening of peers by community members	15
4.3 Training and Development	16
4.3.1 Providing peer support.....	16
4.3.2 Boundaries of the peer relationship	16
4.3.3 Support, mentoring and backup.....	17
4.3.4 Community-based peer support groups	17
4.4 Program Models	17
4.4.1 Group support.....	18
4.4.2 Online support	18
4.4.3 Telephone Support	20
4.5 Promoting your program	21
4.6 Supporting peer leaders or peer supporters	22
4.7 Record keeping	22
5. Management and Governance	24
5.1 Statement of purpose	24
5.2 Relationship of the peer support program to its governing body	25
5.3 Policies	25
5.4 Position descriptions	25
5.5 Procedures	26
5.6 Financial arrangements	26
6. Program Evaluation	27
6.1 Why evaluate?	27
6.2 Scope of evaluation	27
6.3 Who is involved in the evaluation of the program?	27
6.4 When to evaluate	28
6.5 Areas to be considered	28
6.6 Collection of data	28
6.7 Evaluation findings	29
7. To the future	30
8. With thanks	31

1. Preamble

1.1 Acknowledgements

This first version of the Best Practice Framework was prepared for the Chronic Illness Alliance by Jan Hayes and Mary Cahill from the Oxfam Skillshare program in 2004 through a grant from the Ian Potter Foundation. Their generosity in providing their considerable time and expertise is much appreciated.

In 2015, following a Health Conditions Support Grant from the Department of Health and Human Services Victoria, the Alliance began a revision of the framework.

We would also like to acknowledge the contribution by members of the Chronic Illness Alliance Peer Support Network who have input time and advice over the years, particularly during the most recent review and all those who participated in a workshop in October 2015, focussing on current peer support.

The resulting framework is the culmination of much hard work, effort and lived experience of those at the 'coal face' of peer support.



1.2 Introduction

A peer support program provides a structured environment in which people who share the same chronic illness or condition can safely share their experiences. Research shows talking with someone who has shared a similar experience may make a significant difference. Peer support has a wide range of both practical and emotional benefits. Many people with a chronic illness (especially those recently diagnosed) benefit from receiving practical advice they can apply to their day-to-day living to better manage their condition. The emotional rewards of realising that one is not alone cannot be overstated and, paradoxically, this often inspires peers to become more independent. More experienced peers may also be empowered by being able to pass on their skills and experience and in the process, remind themselves of all they have learned about dealing with their condition.

This Best Practice Framework aims to set out some of the guiding principles behind developing and operating peer support programs. Whilst the overall goals of peer support programs are generally similar, programs can vary significantly in design. In some of these peer support programs, there is no clear division between those receiving support and those providing it – the focus is one of informal mutual support by sharing knowledge and experience. In other cases, those providing support have been selected and trained and have a distinctly different role to those being supported.

These guidelines have been specifically written with peer support for people with chronic illness in mind. We believe that the same issues apply to peer support for those with a disability and for carers of those with a chronic illness or disability.

We have chosen to mention several brand name products (mainly software) in this framework. These products are mentioned only in order to provide concrete examples and we do not specifically endorse any of them.

1.3 How to use the framework



This framework was written with several different audiences in mind. One audience is an organisation, generally a ‘not for profit’ that provides peer support as one of its services to its clients. Examples of this are:

- Epilepsy Foundation
- MS Australia
- Haemophilia Foundation of Victoria
- Cystic Fibrosis Victoria

Another audience is stand-alone peer support groups, usually incorporated associations based in their local communities and established by members of the community who have perceived a need for support for a particular condition or illness. They may or may not have some affiliations with larger organisations. Examples of this are:

- Heartbeat Victoria-Bendigo
- Type1 Diabetes Network
- Croydon Stroke Support Group

At times this framework will address the needs of the ‘organisation’, that is a ‘not for profit’ creating or rejuvenating a peer support program while at other times it will address a peer support group or peer support group participant or facilitator, that is those involved with a peer support group in the community.

Where the framework refers to ‘programs’, this means the structure and content an organisation adopts for conducting a peer support program in the community or the structure and content of a small, community-based peer support group.

This revised framework has dropped the term ‘volunteer’ in favour of ‘peer leader’ or ‘peer supporter’ to describe those delivering peer support. Not all who undertake this role do so in a voluntary capacity. Instead we have adopted the term ‘peer leader’ to describe someone who leads a support group, whether it is affiliated with a larger organisation, is community-based or on-line. Those who provide peer support on a one-to one basis, such as a telephone support or buddy system, we have called ‘peer supporters’.

It will assist:

- organisations wanting to start a peer support program for people with whom they work or represent;
- those organisations with an already established peer support program that want to undertake a review of them;
- members of a community who perceive a need to support people with an illness by establishing a program.

There are also organisations that are part of the way along this road with a program in place but looking for ways to improve or expand the support offered and this document will provide some new ideas to meet their needs.

2. Getting Started

This section is for those organisations or individuals who are considering starting a new group. You may like to read the [Peer Support Literature Review \(link\)¹](#) or look at the [Peer Leaders On-Line Training \(PLOT²\)](#) program as you read this section.

2.1 Needs Analysis and Research



The success of any program depends on addressing the needs of those involved, so the starting point for planning a peer support program must be to assess the needs of those who will potentially be served by that program.

You may feel that you already know this information about your members or the group you are hoping to involve, but the most appropriate design of a peer support program will depend on a range of factors about those who may be using the program such as:

- Age;
- Education level;
- Gender;
- Work occupation and situation;
- Location;
- Languages spoken;
- Culture;
- Access to technology (phone, Internet);
- Mobility;
- Physical wellbeing; and
- Emotional wellbeing.

This type of demographic information is important because it impacts on the choice of peer support – for example, if many of the potential support group members work during business hours, then a support group program that meets during the day on weekdays will be of little use to them. Inclusiveness is another important issue to consider. With approximately 23% of Australians speaking a language other than English, a language-specific group may be

¹ <http://www.chronicillness.org.au/?s=peer+support+literature+review>

² <http://www.peerleadersonlinetraining.net/>

more appropriate in some areas. Information about potential users of the support program can be obtained by:

- Survey – You can send a survey out via email links or include it in a newsletter that goes to potential support group members. Mail Chimp and Survey Monkey are helpful tools to conduct on-line surveys and for small numbers may be free. **Search on-line under 'survey tools' for more options;*
- Conducting one or more brain-storming sessions;
- Face-to-face or telephone interviews;
- Interviews with clinicians and/or other health professionals.

A needs analysis should establish:

- What problems people with a specific chronic illness or condition face that could be addressed by (additional) peer support?
- Approximately how many people would be interested in giving and/or participating in peer support?
- The demographic picture of the people who are interested, i.e. where they live, when are they available to participate;
- Whether they want to use IT or social media;
- Any disability factors to consider?
- Who will be involved in the program (at least initially) – only people with a chronic illness or also carers or other family members?
- Cultural factors such as whether groups should be gender-specific, language, etc.;
- If there are already support groups in the area helping this condition, what this new group has to offer that is different?



Checklist: Key factors for successful needs analysis are:

- *You have taken demographic data into account.*
- *You have consulted with relevant stakeholders.*
- *Your support group offers something different or serves a different demographic to any already existing groups.*

2.2 Choosing the best program for your organisation

Having established what people with a chronic illness are looking for by way of peer support, the next question is what type of program your organisation should choose. This depends not only on the peers themselves, but also on the capacity of your organisation (including personnel, financial and other resources).

The following table describes some of the general advantages and potential pitfalls of different forms of peer support.

Table 1: Forms of peer support: the advantages and pitfalls

<p>Support Education</p> <p>Some organisations run peer support programs that consist of a series of workshops or meetings of a small group of members, usually running for approximately eight sessions.</p>	
Advantages	Potential Pitfalls
Group members participate in adult learning for a short period and then incorporate it in their daily life.	Some people want continuing support.
<p>Ongoing Groups</p> <p>Other peer support groups are ongoing and may even operate more as social events simply providing an opportunity for networking.</p>	
Advantages	Potential Pitfalls
Repeated face-to-face contact promotes trust and sharing of experiences.	Requires access to a central meeting place with appropriate facilities.
Gives any individual group member access to a range of peer views on any specific topic or issue.	Can require a regular time commitment at a specific location, thus busy people may be reluctant to get involved.
Allows longer-term exploration of issues over a series of meetings.	Requires a 'critical mass' of participants and hence less likely to be available in regional areas.
Provides a positive role model.	Can be difficult to find peer facilitators.
Informal social events can provide a non-threatening way for new people to become involved.	The group can become very insular and exclusive in its outlook.
<p>Social Media and Online Groups</p> <p>There is a range of Internet-based options for peer support. The minimum effort is one based on email with a list of subscribers (such as Yahoo Groups). <i>*Search online using 'online support groups'.</i> Remember that social media platforms (e.g. Facebook) and mobile phone apps are increasingly being used to deliver support.</p> <p>For a larger group of users, and more diverse discussions, a full online forum web site could be appropriate.</p>	
Advantages	Potential Pitfalls
Such systems are user-driven so the topics that have most attention are by definition those of most interest.	Only accessible to those with the skills and facilities necessary to use the Internet. Individual agendas may dominate.
The online nature provides immediacy of support at times that suits the users.	Online options have all the potential pitfalls of online interactions generally. You can never be 100% sure with whom you are communicating.

Advantages	Potential Pitfalls
Can provide support independent of physical location, so suitable for supporting a wide geographical spread of members, or members whose mobility is limited.	There is a significant level of investment in time and skilled resources to get an online peer support system up and running.
It is cheap to run once established. No postage, printing, copying, phone calls or travel.	Requires peers with the maturity, time and skills to take on the role of moderator.

Telephone peer support programs

Telephone peer support programs typically operate by a coordinator matching a trained peer supporter or a 'buddy' with a compatible peer. The peer supporter then calls the peer at prearranged times for a series of conversations exploring issues that the peer is experiencing.

Most organisations require phone records to be kept by the peer supporter and specify a maximum limit to the number of calls to be made.

There are other telephone support programs where a health professional is employed to act as a 'coach' to a client.

Advantages	Potential Pitfalls
Flexible location and flexible time to suit individual pairs of peer supporters and peers.	Can be confused with emergency support and counselling. Calls are to be made by the peer supporter at pre-arranged times.
Encourages self-direction and addresses issues of specific relevance to the peer.	Inappropriate advice or disclosure can be a problem in this type of support if interactions are not monitored.

These options provide the basic types of support groups but peer support comes in many forms: it can be from friends phoning one another, or attending a camp or another get-together or even through newsletters or mobile phone texting.

Never underestimate the benefits of simply providing a forum where peers can get together, socialise with people with whom they have something in common and share their stories of living with a chronic illness. Not all interactions need to be heavily structured and managed.

2.3 Vision and Purpose

Once you have completed a needs analysis and chosen the initial form your peer support program will take, it is good practice to investigate the need for a formal structure. These days, to access any kind of funding as well as having insurance cover, it is necessary to adopt a legal structure. Support groups may decide to become incorporated associations in their own right or they may be covered by a parent organisation. Incorporated associations will have a statement of purpose that is legally binding. However, it is good practice for all peer support groups to have a statement of purpose that all members agree represents the aims of the group.

Such a statement needs to specify, where appropriate, if the program involves only those individuals who have/had the chronic illness and whether carers can also be included. Guiding values are likely to include such qualities as empowering, supporting and partnering.



Checklist: Key factors for success in choosing the form of your peer support program are:

- *The form of your program is the best option to cater for the needs of your target population.*
- *The structure of your program has requisite resources.*
- *Where a peer support program is part of a larger organisation, its program complements the activities and goals of its parent organisation.*

3. Program Planning and Development



3.1 Resources

This step is similar to management of any project. Issues to consider are:

- Resources (skills, physical space, equipment);
- Budget; and
- Schedule for implementation.

Based on the type or types of programs you have chosen, the first step is to firm up your estimate of the resources you will need so you and your organisation understand what you are taking on. You will need to prepare a budget to cover the initial program development and start up, and a budget for the on-going support of the program. Among the items to consider in preparing each budget are:

- Staff salaries;
- Expenses for staff and peer leaders or peer supporters (e.g. travel, telephone);
- Specialist fees (e.g. web design);
- Equipment;
- Training costs (e.g. venue hire, printing, equipment);
- Promotion costs (e.g. printing and advertising);
- Web hosting fees;
- Venue costs; and
- Catering.

The need for a [basic budget](#)³ applies to any peer support program – from a totally peer leader or peer supporter-run self-help group, to a larger more formal program with staff and facilities. It is a question of planning for resources and any related expenses.

3.2 Program development

Once you have established the basic form of the program and determined that you or the organisation have the resources to go ahead, the next step is developing the details of the program content.

³ http://www.ourcommunity.com.au/management/view_help_sheet.do?articleid=69

It is important to consider appointing a coordinator (either paid or voluntary) who will have ongoing responsibility for the program. A peer support program will always be subject to change. As you progress, peers will find what works for them and what does not. Also consider how the performance of the program will be monitored and evaluated. The first step is to adopt a method of data/information collection so monitoring and performance evaluation at a later date will be much easier.

These issues can be covered in a simple project plan including the aims, the timeframe and resources needed. If you know what you are aiming for, you will know the data to collect to measure how you are working towards meeting those objectives.

If you are creating a community-based peer support group, you may get some useful ideas on fundraising from the [Our Community web site](https://www.ourcommunity.com.au/)⁴. If an organisation intends to fund a program using grants, note that many funders will not give grants for ongoing operations. It may be best to seek a grant for seed funding, i.e. for a specific project to get the peer support program established, then use other forms of funding to cover ongoing operating costs. Seed funding may be available from a number of different types of organisations depending on who takes an interest in your area.

In seeking for funding sources, remember to consider:

- Various arms of state and federal governments including those with an interest in health, self-help and disability;
- Local councils;
- Individual benefactors;
- Hospital auxiliaries;
- Health promotion organisations;
- Philanthropic trusts;
- Drug companies or other corporations; and
- Local businesses.

Some organisations may not provide financial support but may have useful in-kind goods and services.



Checklist: Key factors for success in developing your peer support program are:

- *Develop a project plan.*
- *The program has a clear statement of aims.*
- *You have a budget.*
- *You have means to raise any funds the group requires to maintain itself.*
- *You have considered the need for a coordinator.*
- *Your program fits with available financial resources.*

⁴ <https://www.ourcommunity.com.au/>

4. Program Operations

4.1 Organisations providing peer support programs



If you are an organisation establishing (or already have) a peer support program, you need to determine where control and responsibility for the delivery of peer support will rest.

Some organisations employ a peer support coordinator whose role is to create quality controls, undertake the training of peer support leaders, provide resources and ensure the overall program meets all legislative requirements. Peers identified as capable of providing support are recruited, screened and trained (usually as volunteers) to run the groups by the coordinator. Monitoring of groups by the coordinator means the support groups comply with the standards expected of the organisation. Where peer leaders or peer supporters are volunteers, there is a set of [Australian National Standards for Volunteer Involvement](#)⁵ for managing volunteers covering many of the general issues for setting up a volunteer peer leader or peer supporter-based program. There are great advantages for support groups in this relationship as peer supporters and leaders receive ongoing training and education, support and assistance with administrative activities.

In some instances peer support might be facilitated by a health professional or a health professional who provides administrative assistance: sending out notices of meetings, organising venues, undertaking training of peer leaders or peer supporters, and contributing to the program content. Many support groups appreciate this level of involvement from a health professional as it provides them with a ready source of expert advice and access to other resources.

4.1.1 Recruitment, selection and screening by organisations

The first stage in bringing the planned program to life is to recruit both peer leaders or peer supporters and peers to be involved. This is often done by a peer support coordinator, who is either employed or a volunteer. A coordinator requires a position description and training.

Recruitment strategies need to consider both peer leaders or peer supporters and peers. The cheapest and most effective strategy to get a program started is often to use existing networks and to invite peers that you are already in contact with to spread the word about the program to their own networks. Other ways of getting in touch with new potential members of the program are:

⁵ <http://www.volunteeringaustralia.org/wp-content/uploads/National-Standards-Document-FINAL-3004.pdf>

- Referrals from clinicians – this can be especially important for newly diagnosed peers;
- Asking other related organisations to send notification through their networks – newsletters, online announcements etc;
- Creating an Internet or social media presence;
- Referrals from staff in other parts of your organisation;
- Asking and/or encouraging graduates of your program to return as peer leaders or peer supporters.

It is a good idea to highlight the incentives that you can provide such as:

- Opportunity to meet and socialise with others in a similar situation;
- Participation in other activities like conferences and meetings;
- And for those who play a leading role;
 - Job references or letters of recommendation (for those who develop specific skills as a result of their involvement); and/or
 - The opportunity to train others.
 - When recruiting peer leaders or peer supporters it is very important that the peer leader or peer supporter is well adjusted to their illness and does not use their support role to further explore their own experience of loss or grief. It is equally important that they are able to listen and share their own experience as an example of how *they* coped, not how everyone should cope.

There may also be risks in introducing peers to each other that you may need to manage. Consider whether your peer leaders or peer supporters should be asked to undertake a police check. This legal requirement helps to protect children (under 18 years of age) and other vulnerable people from harm by checking a person's criminal history for serious offences. For further information, **search the Internet for Police Checks and Working with Children Checks for your state or territory.*

Screening of applicants is important for those people who wish to become peer leaders or peer supporters. Desirable qualities in a peer leader or peer supporter are:

- Well-adjusted to their own condition, i.e. have effective mechanisms of their own for coping with their condition;
- Accepting of individual differences;
- Committed to personal development (their own and others);
- Excellent communication skills;
- Desire to give back to the community (or organisation);
- Commitment to the goals and objectives of your organisation;
- Sufficient time to undertake training and then provide peer support; and
- Warmth, sensitivity and flexibility.

Apart from an idea of the personal qualities listed above, you will need some basic information from the potential peer leader or peer supporter in order to ensure their suitability and to make the best match, for example:

- What is their availability to provide support (where and when)?
- What do they believe they will gain as a result of providing support to others?

- Age, gender, cultural background including languages spoken and occupation;
- Mobility issues;
- Experience with the condition (as relevant e.g. years since diagnosis, stage of condition);
- Any specific comments on the type of person they would (or would not) like to support?
- Referees.

Some of these factors may be specified in a formal position description as inclusion/exclusion criteria on participation. For example, you may decide to take peer leaders or peer supporters who have a minimum of two or three years since diagnosis.

Although peer leaders or peer supporters may be referred to the program through networks, perhaps because of their existing involvement in your organisation, it is best practice to ask them to complete a recruitment questionnaire and to conduct a basic interview to ascertain their suitability for the program. This may be awkward if there is an existing relationship, but it is preferable to confirm expectations on both sides at this early stage than recruit someone in to a program that does not suit them.

An important tool in recruitment for both you and potential peer leaders or peer supporters is a formal position description.

Ensure that potential peer leaders or peer supporters understand the time commitment required from them. It is good practice to have a written agreement between your organisation and the peer leader or peer supporter. This helps to ensure that all obligations are clearly understood.

4.2 Recruitment, selection and screening of peers by community members

Much of the above information can also assist community members wishing to recruit peer leaders or peer supporters. Instead of a coordinator undertaking these duties, they might be undertaken by a small executive group. Having a Code of Conduct and position descriptions as well as ensuring all current legal obligations, such as police checks or Working with Children checks, are met can save a lot of heart-ache.

The screening of potential peer leaders or peer supporters might include having people complete a questionnaire or conducting an interview by a third person as many applicants are likely to be known to one another throughout the community. Asking all potential applicants to provide a reference that addresses what they will bring to the group allows members to see their relevant strengths.



Checklist: Key factors for successful recruitment, selection and screening of peers for the program are:

- *There is a documented role for the coordinator or a documented process for a community-based executive.*
- *There is a clear process on how peers can join and/or be referred to the program.*
- *There is a Code of Conduct to which all members, regardless of their positions, must adhere.*
- *There is a position description for the peer leaders or peer supporters.*

- *Relevant safety checks (e.g. referee reports, police checks and Working with Children checks) are conducted.*
- *The selection process of peer leaders or peer supporters identifies those with the desired qualities.*

4.3 Training and Development

When peer leaders or peer supporters join the program, opportunities for training can be very helpful. Peer leaders or peer supporters will have a wide range of starting competencies and skills in areas relevant to providing peer support. Training is an opportunity to develop new skills or strengthen existing ones. Many organisations provide induction and training and community-based support groups have the opportunity to use [Peer Leadership On-line Training](#)⁶. Other opportunities exist in larger communities across Australia.

In addition to covering the scope of the program itself and the role of the peer leader or peer supporter within the program, issues to be covered fall into four general areas:

4.3.1 Providing peer support

Peer leaders or peer supporters should receive some basic training in how to communicate with peers in order to provide support, whether this is one-on-one or facilitating a group discussion. Topics to cover include:

- Opening a conversation with a new peer – introductions;
- Sharing one's own experience;
- Active listening skills (not using terms such as 'you should' or 'you ought to');
- Group facilitation skills;
- Ending a session on a positive note;
- Self-awareness;
- Dealing with distressed or angry peers;
- Dealing with grief and loss;
- Understanding different values and culture;
- [Ethics and confidentiality](#)⁷.

4.3.2 Boundaries of the peer relationship

Generally speaking, peer leaders or peer supporters are not trained as counsellors and they should be mindful that they are not to provide medical advice or enter in to a counselling relationship with people they are supporting. The nature of the relationship is one of sharing stories and experiences – letting the peer know that they are not alone and that their problems share many commonalities. Peer leaders or peer supporters should at all times be aware of their own needs and not put themselves into situations that may be uncomfortable or unsafe for them in any way. It is always possible that the peer leader or peer supporter becomes aware of (or may be directly asked about) issues with which the peer needs professional assistance. This includes (but is not limited to) such issues as depression, suicidal thoughts or problems with carers. Peer leaders or peer supporters should be trained

⁶ <http://www.peerleadersonlinetraining.net/>

⁷ <http://www.peerleadersonlinetraining.net/>

in how to deal appropriately with such issues when they are raised, and whom to contact to report serious potential problems. Peer leaders or peer supporters should never provide any specific advice but should be aware of the resources to which peers can be referred.

4.3.3 Support, mentoring and backup

Given the sometimes challenging nature of supporting others, peer leaders and peer supporters need access to a trusted person who can assist them with support, advice and mentoring.

These activities are normally provided at no cost to peers who participate. Some organisations are able to reimburse peer leaders or peer supporters (and sometimes peers) for out of pocket expenses directly associated with taking part. Community-based peer support, whether groups, on-line or telephone based, can contact Departments of Health in their States to check if they are eligible for any assistance.

4.3.4 Community-based peer support groups

Many community-based peer support groups grow 'organically' and much of the above is learnt by experience rather than formal training. However, reviewing the recruitment strategies and training and support of people offering to take on important roles in a peer support group may reveal important gaps and looking for additional support for new recruits may avoid some of the pitfalls.

An experienced support group facilitator might offer to train others in the support group to take up their role. Additionally, affiliating with a larger organisation may open up training opportunities. Peer support groups can undertake the [Peer-Leaders On-Line Training](#)⁸ (PLOT) program or look out for sessions run by the [Health Issues Centre](#)⁹.

Many community-based peer support groups also establish links with health professionals through health services so that they can call on professional advice or guest speakers.



Checklist: Key factors in training and development of peer leaders and peer supporters:

- *There are opportunities for training.*
- *Peer leaders and peer supporters understand the boundaries of support they offer.*
- *There is information about support and mentoring for peer leaders and peer supporters.*

4.4 Program Models

The three general types of peer support programs – groups, online support and telephone support – are discussed in turn in the following sections. However, note that passive use of on-line groups and information seeking is also a form of support.

⁸ <http://www.peerleadersonlinetraining.net/>

⁹ <http://www.healthissuescentre.org.au/>

4.4.1 Group support

Group programs of various kinds are popular ways to deliver peer support. Some organisations choose to run group-based programs with a fixed duration and a pre-determined program. These are often aimed at people newly diagnosed with a specific condition and typically include an aspect of peer support. In this case, the peer leader is essentially providing a role model of how to live with a chronic illness. This opportunity for interaction may be part of a broader program including sessions run by health professionals.

A good example of fixed duration course is the eight week course for young carers developed by [Carers Victoria](#)¹⁰.

This course assists them to deal with the stress of school and caring and social isolation.

Other community-based peer support groups operate much more independently. They work on an ongoing basis whereby peers get together to share information and experiences and are not always as formally structured as these descriptions suggest. Peer support groups may choose to organise relevant speakers themselves, including medical professionals but also suppliers of relevant goods and services or other relevant topics. An umbrella chronic illness organisation can still assist independent groups in a range of ways (perhaps for a fixed/limited duration) such as:

- Putting new members in touch with the group;
- Publicising events in newsletters;
- Finding speakers;
- Catering costs; and
- Providing a venue.

Groups are normally limited to eight to fifteen members, with one or two peer leaders. They meet at a range of free public locations such as local libraries and community houses.

4.4.2 Online support

Online support is similar in nature to groups – except the group is virtual in nature. People can take part in discussions online without physically moving from their normal routine, and at times that suit them. They may remain anonymous. Being part of an online community also allows peers to share their stories with a broad group of people who may have a range of different experiences and situations. At its best, being a member of an online community can be a rich source of encouragement and support. The Internet is sometimes seen as a tool for younger people, but the 2012-2013 ABS statistics demonstrate that more than 46% of [people aged over 65 access the Internet](#)¹¹. Online peer support can be a cheap and very effective way to connect many people with similar interests.

A good example of an online group comes from CF Victoria: Pep Talk is a closed, moderated Facebook group, which provides a place for people aged between 13-25 who are impacted by cystic fibrosis to discuss, share ideas and get support.

A newsgroup or discussion forum is where messages are posted on a central site and redistributed to members. Messages provoke responses and discussions. The role of the organisers of this type of peer support can vary from simply providing the platform to setting up rules and boundaries to vetting all conversations.

¹⁰ <https://www.carersvictoria.org.au/Assets/Files/lulus-model-feb-2008.pdf>

¹¹ <http://www.abs.gov.au/ausstats/abs@.nsf/mf/8146.0>

An example of a news group peer support arrangement is [Saltmatters](#)¹² This is an Internet support group for people who control their salt intake. There are discussions on low salt diets, particularly in relation to diseases. It also provides help on how to obtain low salt foods, recipes, and other issues related to good control of salt.

The group administrator is an academic with an interest in this field.

Before you set up an online support group you should check out what is already available as this is a very crowded space. Setting up an online group requires IT skills. A person needs to buy a domain name, and then choose a platform provider such as Ning, Forumer or Forumotion. Some platforms are free. The domain name is then sent to the forum platform. Make sure that the forum allows your users to register a unique profile and that it allows you to control membership settings and filter out any items that are abusive or illegal. * *Search [How to Start an On Line Support Group](#)*¹³. This peer support arrangement works well for sharing straightforward information such as asking for assistance with information. Generally speaking, new members will find such a group by word of mouth or from a specialist newsletter or similar.

Online support groups require an administrator who sets standards and guidelines of interaction such as courteous language and regularly posts messages to prompt discussions or keep a discussion on track. The administrator retains the right to exclude email addresses from which inappropriate messages are received. An administrator also needs to ensure the forum is found by new members through web searches and by linking it to other relevant websites. As most online groups are international an administrator is needed on a daily basis.

Groups on [Facebook](#)¹⁴ are easier to set up and require little in the way of IT skills. They also have the advantage of being able to handpick members to join. If you have a Facebook account you can go to groups on the left side menu and click 'create group'. You can add members from your own page, invite others (who may accept or not) and you can edit with a description of the group and with any guidelines and decide on the privacy settings you want for the group.

Another method is using [Twitter](#)¹⁵. On Twitter a list is a curated group of Twitter users. You can create your own lists or subscribe to lists created by others. Viewing a list timeline will show you a stream of Tweets from only the users on that list. To create a list you need to have a Twitter account. You can go to the navigation bar and click on Lists and then Create Lists. After naming the list and giving a short description and selecting the privacy level, save the list and then you can add people. Note that, because of the character limits, this form of support might need another means of support as a backup.

An example of a discussion group for peer support is the discussion forum run by the Type 1 Diabetes Network Inc. as part of their Reality Check website.

This discussion forum provides 'a place to bitch, moan, argue or rejoice (yes, really) about having Diabetes'. It has approximately 1,000 registered members with around 200 of them actively participating in discussions (contributing at least once a fortnight).

¹² <http://www.saltmatters.org/site/index76bf.html?page=email-chat-group>.

¹³ http://www.ehow.com/how_5601823_start-online-support-group-website.html

¹⁴ <https://www.facebook.com/help/162550990475119>

¹⁵ <https://support.twitter.com/articles/76460?lang=en>

The discussion forum has six peer leader or peer supporter moderators (all young people with Type 1 diabetes) who operate on a rostered basis to keep an eye on the online discussions and to register new members.

The site also has a clear set of rules that govern the purpose of the discussion forum and the acceptable behaviour of participants.

4.4.3 Telephone Support



Usually a program provided by an organisation, telephone support is valuable to peers who are isolated by location or mobility issues, or are not available to attend regular face-to-face meetings.

It must be clear to everyone involved in telephone support that the service is not for medical emergencies or support in crises. Calls take place at predetermined times and are always made by the peer supporter calling the peer (not the other way around). Many peer supporters make support calls from home and are reimbursed for call costs (as appropriate).

Organisations should ensure that the phone technology used is such that the phone number of peer supporter is not available to the peer. Most organisations also set a limit on the number of calls between any given pair of peer supporter and peer (although the limit varies widely). The limit reminds both the peer supporter and peer that the purpose of the support sessions is ultimately for the peer to become more confident and independent in dealing with their condition.

Organisations may find it useful to ask peer supporters to complete a basic call record sheet. This can be a way to elicit information about any concerns the peer has that require further follow up, as well as a means to evaluate the peer support training program.

When a peer applies for telephone support, the coordinator of the program goes through the following steps:

- Speak to applicant to collect or clarify relevant details and confirm suitability;
- Match the peer with a trained peer supporter;
- Advise the peer of the support that will be provided and the rules that govern the service (such as the maximum number of calls and the scope of issues that can be covered) and inform them of the current privacy legislation;

- Pass on necessary details to the peer supporter (e.g. some organisations operate using first names only for peer supporters and peers);
- Follow up any problems raised by either the peer or the peer supporter;
- Seek feedback from both to for purposes of quality improvement.

Successfully matching peer supporters and peers is as much an art as a science, but matches have a greater chance of succeeding if the two people involved have similar circumstances such as:

- Similar stage of condition;
- Similar age or family circumstances;
- Similar study, work or professional circumstances; and/or
- A common interest or hobby.

You should ensure that both the peer supporter and the peer have a way to opt out of the arrangement if it is not working to their satisfaction. In this case, the coordinator should speak to each of them and try to match them to another person. It must be emphasised that this is a 'no fault' situation and that sometimes individuals do not make a good connection with each other.

Another option is telephone peer support where people are proactively contacted by a peer supporter and offered peer support, rather than having to request it. This is especially beneficial for programs wishing to support people who are newly-diagnosed with a condition and may need assistance finding the services to support them, or to engage new members of an organisation. This form of peer support can be provided by peer supporters working from an organisation's office. It is ideal for more than one peer supporter to be working at a time to allow them to both debrief and share ideas.

The peer supporters go through the following steps:

- Phone peers, based on a list provided by a coordinator or the organisation of new members or people known to be newly-diagnosed;
- Introduce themselves and the organisation and provide clear information about what the peer support service offers (a script is useful at this point);
- Provide information about how the peer can contact the organisation at a future date if required, and when the peer support service is available (e.g. one morning per week peer supporters may be available);
- Keep a resource pack of information to answer commonly-asked questions from peers;
- Follow up any problems raised, often by calling back the peer after doing some research with support of the coordinator and/or other peer supporters;
- Some organisations offer one-on-one face-to-face peer support instead of, or in addition to, telephone support. This is generally organised in a similar manner.

4.5 Promoting your program

The main purposes of promoting your program are to assist recruitment of both peer leaders or peer supporters and peers, plus to secure or maintain financial support. Depending on the stage of development of the program, it would be worthwhile developing a marketing plan of how, where and when to promote the program. You need to determine what publications (print, electronic etc) would be useful. Members of peer support groups will have ideas to contribute here. Firsthand accounts of the value of peer support can be very powerful in the promotion of the program. It is also worthwhile evaluating a program on an annual basis to

show its achievements for participants. This [evaluation](#)¹⁶ will help to promote the benefits of the program to potential members.

If peer support is part of a larger organisation, ensuring other units have an understanding of how peer support contributes to the aims of the overall organisation will assist in internal promotion and can be a source of recruitment.

Collaborating with other peer support programs in an area is likely to be very valuable since resources and ideas can be shared.



Check list: Key factors for successful promotion of the program are:

- *Develop a Marketing Plan.*
- *Use any evaluations to show the strength of the program.*
- *Include firsthand accounts from group members.*
- *Consider evaluations.*

4.6 Supporting peer leaders or peer supporters

It is important to be aware peer support can be emotionally draining for peer leaders and the opportunity to debrief needs to be in place. Peer leaders or peer supporters should always have access to someone who will support them on an 'as needs' basis. This can take the form of regular one-on-one review between each peer leader or peer supporter and coordinator at intervals to be fixed based on feedback from those involved. Peer leaders in a community setting might seek opportunities to debrief with other peer leaders in their communities.

Peer leaders and supporters may also value the opportunity to get together as a group and compare their own experiences of providing support. This can be done in an informal social setting that recognises and rewards the efforts of peer leaders or peer supporters. Other forms of acknowledgement such as certificates may also be appropriate.

4.7 Record keeping

There are many operational records that you will need to keep in order to know what is happening within your program. This may include:

- Contact information for peer leaders or peer supporters and peers;
- Relevant personal details to assist in matching peer leaders or peer supporters and peers such as age, condition, family situation, occupation, cultural background/ languages spoken and hobbies;
- Training records for peer leaders or peer supporters;
- Minutes of all meetings;
- Records relating to legislative and regulatory requirements;
- Policies and procedures manuals;
- Correspondence records;
- Accounts and finances.

¹⁶ <http://www.peerleadersonlinetraining.net/course/view.php?id=6>

If a peer support program is a function of an organisation, record keeping may be part of the overall system. Community-based peer support may find that a spreadsheet (such as Microsoft Excel) is sufficient. If you are using a spreadsheet, then think carefully about what fields (i.e. columns) of data you need so functions like mail merge are simple and easy to utilise.

If you have hundreds of contacts, then you may consider list management programs such as Mailman lists, Mail Chimp or ebase.org.



Check List: Key factors for successful monitoring and supporting of the program are:

- *There are training opportunities for peer leaders and peer supporters.*
- *There is assistance for peer leaders and peer supporters to debrief and receive support.*
- *There is recognition of the contribution of the peer supporters and leaders (e.g. certificates, celebrations).*
- *There is a system for maintaining records.*

5. Management and Governance



All peer support programs require a level of formal management and governance. Governance is about defining the overall purpose and values of an organisation, and ensuring the structures and systems necessary to support them are in place. It is also about regulatory compliance, and risk management to deal with potential problems. Governance is the responsibility of the Board (for a Company) or the Committee of Management (for an Incorporated Association). Management is about action: using the structures and systems to support programs and people.

Responsibility for governance and management will vary depending on whether the peer support program sits within a larger organisation or if it is a stand-alone support group. In small groups, some individuals may have roles that include both governance and management functions as their activities are developed. For example, a small group might require volunteer insurance and any necessary government permits for fundraising activities. If you need assistance in this area, the [Our Community](#)¹⁷ web site link is a good place to start.

On the other hand, if the program is part of a larger organisation, then issues such as insurance and permits may already be managed by others, but you will need to ensure that the program operates within the overall governance structure of the organisation.

Whether support is offered in groups, by phone or on-line, minimum standards of good behaviour, not offering medical advice and adhering to legislative requirements of privacy and anti-discrimination all apply. In some cases police checks may also be required.

The following sections describe some key management and governance issues as they are likely to apply to a peer support program.

5.1 Statement of purpose

As described in Section 2, it is important to have a Statement of Purpose defined when you initially develop your program. This is not to say that the purpose (or the details) cannot change over time. One important governance issue is to ensure that the organisation and its Statement of Purpose (whatever form this takes) remain closely aligned. Regularly reviewing your Statement of Purpose and making any changes necessary to it or to your operations helps to chart the desired direction.

¹⁷ www.ourcommunity.com.au

5.2 Relationship of the peer support program to its governing body

With large organisations, it needs to be clear where the peer support program fits within the management structure. The accountability requirements of the program to the governing body need to be documented, e.g. does the coordinator answer to a supervisor, steering committee, management committee or board? How much autonomy does the coordinator have? How often should the coordinator report? There is a risk that the coordinator can feel isolated, so a small advisory committee can be most valuable. Often the program is reliant on the governing body for funding, so communication needs to be open, regular and strategic.

Community-based support groups that are Incorporated Associations will have Management Committees elected from their membership and the committee is its governing body. The committee will be responsible for finances and policies and will have input into the program. The peer support leader may be part of the committee or subordinate to it. If a community-based group is not incorporated it is still good practice to have a Management Committee to assist with these matters.

5.3 Policies



Where a peer support program is part of a larger organisation, policies may already exist. Small peer support groups may need to adopt their own policies. The policies need to be inclusive, culturally sensitive and recognise the varying health literacy and support needs of the peer leaders or peer supporters and peers.

It is likely that your program will need policies to address the following:

- Rights and responsibilities of the peer leader or peer supporter;
- Rights and responsibilities of the peer;
- Privacy and confidentiality;
- Grievance procedures;
- Occupational health and safety;
- Insurance (employed coordinator & volunteers);
- Inclusiveness.

5.4 Position descriptions

Position descriptions help people understand what they do on a day-to-day basis and what is expected of them. Whether paid or not, there needs to be a position description for the coordinator. All position descriptions should describe the limits and boundaries of the role. A position description might include opportunities for development and emotional support.

Note: Where larger organisations are using volunteers in a peer support or coordinator role, it might be preferable to use the term Peer Volunteer Assignment, clearly designating it as a volunteer role.

5.5 Procedures

As the peer support program matures, you may find it useful to prepare procedures for key tasks and activities. Procedures ensure that information about the best way of working can be passed from one person to another, ensuring consistency. They also help document a group's history, key decisions, learning from mistakes and successes.

Procedures for the activities of the coordinator of the peer leaders or peer supporters can be documented and stored so that they are readily accessible to participants and management. The procedures need to be written in inclusive language and be sensitive to the varying support needs of the participants.

5.6 Financial arrangements

To support and sustain the peer support program, endeavour to obtain reliable, long-term sources of funding from the governing body and/or external sources. Organisations increasingly recognise the value of peer support programs and as a result may appoint a coordinator on a salary; in addition, depending on the size of the program, administrative support is also sometimes funded.

If your support group is not part of a broader organisation, you need to consider incorporation and seek financial assistance from State Departments of Health or local government. Small donations or in-kind assistance may be sufficient for some groups.

Having an accounting system in place so funders know how the money is used assists in attracting future funding.



Check List: Key factors for successful monitoring and supporting of the program are:

- *Governance is in place and understood.*
- *The Statement of Purpose is reviewed regularly.*
- *There are documented policies.*
- *Relevant policies, procedures and accounts are in place.*

6. Program Evaluation

6.1 Why evaluate?

Evaluation allows the organisation and the participants to consider if the peer support program is meeting its objectives. There needs to be commitment to improvement by all involved, who view it as a positive activity.

We would emphasise that the final arbiters in what constitutes effective peer support are always the peers themselves, so we encourage you to continue to seek feedback and listen to what the participants tell you they find useful, and what else they may need.

You need to formulate an evaluation plan covering both ongoing monitoring and regular reviews (about every two years). Larger peer support programs may need a more structured process. Resources, especially time and a budget, may need to be allocated for larger programs. In all instances diligent record keeping practices will be hugely helpful and save a lot of time and resources.

6.2 Scope of evaluation

The scope of any evaluation should be clearly defined in the planning stage. Evaluations generally want to know about what worked well and what can be improved. You may seek to answer questions about the processes you are following in peer support, such as:

- Are processes for recruiting peer leaders or peer supporters being followed?
- Do all peer leaders or peer supporters receive training according to policies and procedures? Does the training meet their needs?
- How long do peers wait to actively participate in the program after they have expressed an interest in being involved?
- Are necessary records kept and are they useful in planning system improvements?

You may also wish to seek feedback on the outcomes of the program, such as:

- How many people are involved as peers and as peer leaders or peer supporters? Is this more or less than you had planned?
- What benefits do peers tell you they are experiencing as a result of their involvement in your program (health, service use, well-being etc.)? How might this be linked to sourcing of future funding?

6.3 Who is involved in the evaluation of the program?

There should be opportunities for all participating in peer support, or their representatives, to be involved to a greater or lesser extent in the program evaluation. Consider using the evaluation as a way of seeking external input on the program – from health professionals and others who may refer new members, and from other potential new members of the program, too.

The responsibility for ongoing evaluation will usually lie with the coordinator or the peer support group leadership. With the conduct of a formal review, it is recommended to form a panel consisting of representatives of the peer leaders or peer supporters, peers and management; it may also facilitate the process to appoint or involve someone who is independent of the program.

6.4 When to evaluate

Ongoing evaluation to improve processes, especially in a developing program, is very helpful. Once the process is established it becomes integrated into the regular group's activities. Some peer support programs that run over a defined number of sessions lend themselves to the cycle of 'establish/activate/conclude/evaluate', so improvements can be made to the next program. It is advisable to conduct a formal review about every two years.

6.5 Areas to be considered

With ongoing evaluation occurring, modifications to the program, mostly operational, will occur. The following areas are likely to need to be considered in a more formal review:

- Types of peer support offered;
- Coordination and governance structures;
- Support given to the program by the governing body;
- Recruitment of both peer leaders or peer supporters and peers;
- Selection and screening of both peer leaders or peer supporters and peers;
- Training of peer leaders or peer supporters;
- Job descriptions;
- Operational and communication issues;
- Record keeping practices;
- Resource issues, including financial arrangements; and
- Public relations.

6.6 Collection of data



You can collect data through the use of surveys, focus groups, interviews and statistics (drawn from the records). Comparisons with other peer support programs can be made or use the key factors contained in this framework to serve as a checklist. If possible, both quantitative and qualitative data should be collected on an ongoing basis. You need to reassure individuals that their feedback will be treated in a confidential, respectful manner. Often with sensitive opinions, material needs to be de-identified.

Possible sources of data are:

- Statistics regarding requests for peer support (nature, frequency, source);
- Peer leader or peer supporter availability and retention rates;

- Ongoing feedback/debriefing from peer leaders or peer supporters and peers;
- Feedback from peer leaders or peer supporters at the conclusion of training;
- Statistics and feedback from referring agencies;
- Numbers of compliments and complaints; and
- Feedback from the coordinator and the governing body.

6.7 Evaluation findings

Evaluation findings can be used in a report document to promote the program to prospective funders and for recruitment purposes as well as identifying gaps in support and learning where to improve. Where the evaluation identifies a need to improve, recommendations should be made for discussion and further consultation. Participants who were involved in the evaluation should have access to the report.

Make sure the evaluation identifies all the successes so the group can celebrate them!



Check List: Key factors for successful evaluation of the program are:

- *You have a systematic process of ongoing evaluation.*
- *Regular reviews occur.*
- *The evaluation process reflects the objectives of your program.*
- *A person is nominated to be responsible for the evaluation process.*
- *You consider both outcomes and processes.*
- *Is there is a system of record-keeping to support evaluation?*
- *In evaluation, you use a range of data.*
- *All stakeholders (or their representatives) have the opportunity to contribute.*
- *In evaluation, all levels of the program are covered including peers, peer leaders or peer supporters, coordinators and any other paid support staff.*
- *The findings of the evaluation are reported to all relevant stakeholders.*
- *Recommendations from the evaluation or review are reported.*

7. To the future

With peer support gaining greater mainstream recognition as another aspect of support for those living with a chronic condition, this field will continue to evolve and grow to become an established tool in the arsenal of treatment for the chronically ill.

The Peer Support Best Practice Framework is exactly that – a framework on which we can build and expand the benefits peer support can bring to alleviate the burden borne, not only by those living with a chronic condition but those who care for and support them.

In many ways, this is a living document that is underpinned by other tools developed by the Chronic Illness Alliance. The Peer Leaders Online Training course and Peer Support Group Evaluation Tool contain helpful information upon which to expand or set up your own peer support group.

We encourage you to investigate these at www.chronicillness.org.au

The rewards peer support provides cannot be underestimated and it is through people like you who are the beneficiaries of what peer support can offer, or who are facilitators or leaders, health care providers and the wider public will learn how invaluable peer support is as an adjunct to traditional methods of treatment.

We look forward to new developments in peer support in the years ahead.

~ Dr Christine Walker – Executive Officer, Chronic Illness Alliance Inc.

8. With thanks

The Chronic Illness Alliance and the Chronic Illness Alliance Peer Support Network express their appreciation for the contribution of their members and participants in the Peer Support Best Practice Framework Workshop held in Melbourne in October 2015.

This document is the culmination of the hard work and lived experience of those for whom peer support has provided both encouragement and assistance in their journey living with a chronic illness.

In addition to the Victorian Government whose Health Conditions Support Grant funded this review, we thank the following:

Representatives of

- Heartbeat Bendigo
- Goulburn Valley Epilepsy Support Group
- Cystic Fibrosis Central Victorian Country Families
- Bendigo Cancer support Group
- Bendigo Arthritis Club

Susanne Baxandall – Diabetes Victoria

Kate Bindu – Hepatitis Victoria

Karen Brick

Emily Buchanan – Inner North West Primary Care Partnership

Sarah Burns – Cystic Fibrosis Victoria

Jane Caffrey

Rebecca Colcott – Asthma Foundation of Victoria

Celina Day – Alzheimer's

Jan Donovan

Claire Emmanuel – Alzheimer's

Twanny Farrugia

Annemarie Ferguson – Ovarian Cancer

Marie Gill

Bill Hanlon – Chronic Illness Alliance

Kellie Holland – Breacan

Kim Hyman – Breast Cancer Network Australia

Anna Jarmolowicz – Murdoch Children's Research Institute

Alistair Kerr – Cardiomyopathy Australia

Esther Lim – Health Issues Centre

Marina Mazza – Hepatitis Victoria

Natalie McLean – The Children's Tumour Foundation of Australia

Fiona McRae – Breacan

Kristina Naray – Diabetes Victoria

Melissa Noonan – Limbs4Life

Jane North

Gerry O'Brien – Victorian AIDS Council

Robert Pask – Chair, Chronic Illness Alliance

Elise Perillo – Diabetes Victoria

Angela Pollock – Darebin Community Health

Will Scott – Hepatitis Victoria

Micky Sinopoli – Whirled Foundation

Ken Vincent – Barwon Health

Corinne Waddell – Ovarian Cancer

Christine Walker – Chronic Illness Alliance

Fiona Waugh – Limbs4Life

Edmond Wong – EACH Social and Community Health



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