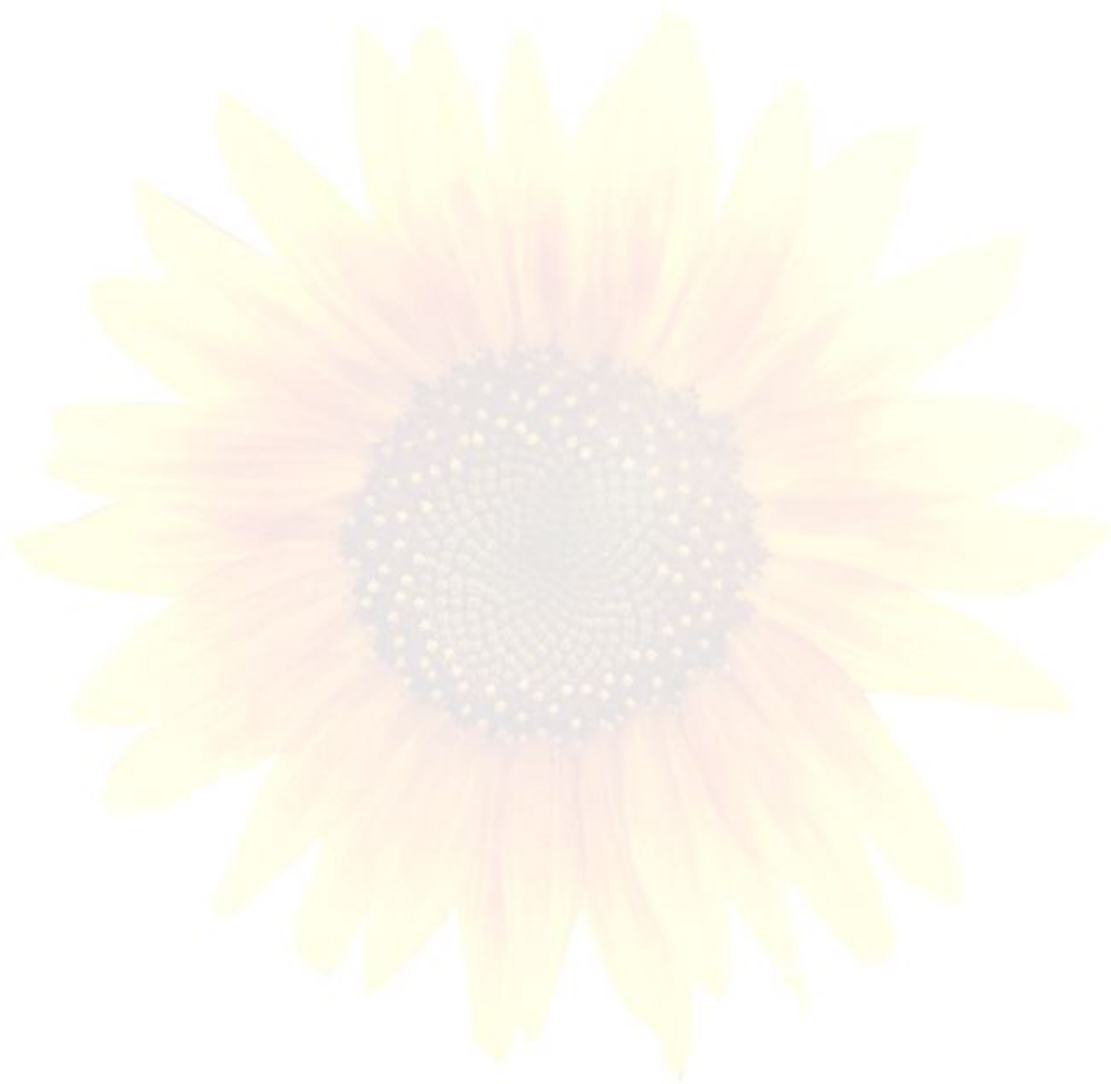




Support Group Guidelines



SUPPORT GROUP GUIDELINES

Introduction

What is a Support Group?

A Support Group follows the belief that individuals who have lived experience of life issues such as disability, mental health, and/or a life-changing event, can better relate to other individuals trying to deal with similar issues.

By listening empathetically, sharing their experiences and offering suggestions based on that experience, people with a lived experience are uniquely able to help others like themselves. When people find affiliation with others they feel are 'like' them, they feel a connection. This connection, or affiliation, is a deep, holistic understanding based on mutual experience where people are able to 'be' with each other without the constraints of traditional (expert/patient) relationships.

Sharing lived experiences provides multiple perspectives of the experience, thereby broadening understanding. The accumulated knowledge drawn from the lifelong learning journeys of many people becomes an invaluable source of insights and an unmatched source of support and inspiration for people dealing with life-changing events.

The Support Group approach promotes a wellness model. Assisting a person to find and develop their own personal resources empowers the individual with the belief that they can, and do have control over their life.

A Support Group offers an additional approach which can be either complementary to clinical services or, in some cases (depending on the severity of the illness), stand-alone. A Support Group is not based on psychiatric models and diagnostic criteria.

Program Objectives

In line with Scleroderma Victoria's vision, we aim to support our members and their families with Scleroderma and ensure they are provided with a positive and transparent attitude with the promotion of Support Group activities.

A Support Group program provides a vital link for individuals and carers to ensure there is a renewed sense of self-respect, understanding and belonging through being part of a circle of a caring community, with knowledge that they are NOT isolated.

A Support Group Program aims to:

- Increase self-esteem
- Enable better decision-making skills
- Improve social functioning
- Lower rates of isolation, larger social networks, increased support seeking
- Greater strength gained from realising that they are an important part of both a group and the community and take that strength out into the community
- Provides opportunities to make authentic connections that increase well-being socially, mentally, physically and spiritually
- A means to alleviate stress and improve well-being for carers
- Gain and share knowledge of skills, treatment pathways and tools that have proven useful

Models of a Support Group

1. One to One Support

One-to-one Support usually occurs where an individual based on a similar set of circumstances and/or medical based comparisons. The dates and times for the face to face meetings are established between the volunteer and individual and are based on the key principles of respect, shared responsibility, and mutual agreement. One to One Support is often aimed at people newly diagnosed with Scleroderma and typically include an aspect of Support Group. In this case, the volunteer is essentially providing a role model of their lived experience.

2. Informal group support

An informal support group generally operates independently and can simply arise from a question asked by one peer to another; or the group in general. These groups work on an ongoing basis whereby peers get together to share information and experiences. These may be primarily social events, or peers may choose to organise relevant speakers for themselves, including medical professionals but also suppliers of relevant goods and services or other relevant topics.

Operational Structure

The Scleroderma Victoria Support Group Program is a formally managed program. The success of such a program greatly depends on its structure (framework), the methodology on how it is implemented and the policies and procedures that govern the program.

1. Program Governance

Best practice in Support Groups help to define the guiding principles. This document forms part of the Policies and Procedures have been adopted specifically for the program to ensure that Scleroderma Victoria Support Group Leaders are supported (and where necessary protected) by the program. In addition, individuals in vulnerable situations need to be provided with confidentiality, privacy and are safe-guarded at all times.

2. Policies and Procedures

These Guidelines form the policies and procedures relating to how the program is managed and the governed and is undertaken to ensure the longevity and 'safe keeping' of the program, it's Support Group Leaders and recipients.

3. Program Management

It is necessary to ensure that there are allocated responsibilities to oversee the operation and delivery of the program, and a local Support Group Leader is appointed. The purpose of this is to safeguard the program and ensure best practice is undertaken in order to mitigate risk.

Scleroderma Victoria rarely approaches individuals directly to join support groups, as the belief is that people will 'be ready' within themselves to want to contribute to the program.

Support is based on reciprocity and experiential knowledge – that is, support is provided by and for people with similar conditions or experiences.

Experienced Support Group Leaders should display role model qualities that help people become empowered to better manage their health, and to have more confidence in their decisions relating to their recovery or care. Carers and individuals providing support should have adopted and come to terms with their own situation prior to supporting another individual.

Support Group Leaders should possess certain qualities such as:

- The ability to listen and have excellent communication skills
- A desire to give back to the community
- Are committed to the goals of Scleroderma Victoria
- Are non-judgemental to an individual's set of circumstances
- Requests are dealt with in a timely manner
- Meetings are noted for the purpose of compliance and future evaluation (All meetings are to be advised to The Honorary Secretary of Scleroderma Victoria)

Support Group Responsibilities include:

- Be a member of Scleroderma Victoria
- Maintain secure records of those members with scleroderma in your area
- Be a positive influence in the lives of the members in your area
- Be welcoming and friendly to all support group members
- Organise regular get togethers at intervals appropriate to your group
- Choose suitable venue's for each get together ensuring accessibility requirements where appropriate
- Advertise each get together, making sure everyone knows about the event in advance
- Advise the Scleroderma Victoria Secretary of each event in advance so it can be advertised on the Scleroderma Victoria website and other social media

- Guide the conversation during each event, making sure it doesn't get bogged down with the negative side of the disease while allowing members to discuss how they are going
- Make sure every member gets a voice during the events
- Keep members up-to-date on what is happening with Scleroderma Victoria, advertising upcoming events and encouraging participation

All Support Group Leader must ensure they acknowledge a clear understanding of the program methodologies and be aware of the following:

- Their duty of care to Scleroderma Victoria and program recipients
- Scleroderma Victoria's responsibilities to Support Groups
- The individuals responsibilities as a Support Group Leader

Volunteer Program Limitations

As part of the Scleroderma Victoria Support Group Program, there are strict limitations provided to its volunteers which include but not limited to:

- Providing professional counselling
- Giving medical or medical related advice
- Interfering with treatment and or making recommendations to treatment options

Peers and Support Group Leaders share personal lived experience and let the individual know that they are not alone, and are instructed at all times to direct individuals to their healthcare provider for any medical or medically related question or information.

Referral Process

Refer support group members to agencies providing assistance where appropriate.

Lifeline 13 11 14

www.lifeline.org.au

Beyond Blue 1300 224 636

www.beyondblue.org.au

Samaritans 135 247 anonymous crisis support

www.thesamaritans.org.au

Death of group member:

Be prepared to provide support following the death of a member of the group.

Grief is an emotional response to loss and an inevitable part of life.

The family of the deceased member may request donations be made to Scleroderma Victoria at the funeral.

Bequests & Memorial Donations

Losing someone you care about is never easy, but sometimes honoring a loved one with a memorial donation or providing a bequest in your will can be a nice way to be remembered.

Scleroderma Victoria has provided significant support for those living with scleroderma for over 30 years. The aim of our foundation is to support members with educational seminars and to provide information and organise support groups.

Above all, it has been funding essential scientific and medical research into finding the cause of scleroderma and the development of new treatments. Our hope and aim is to find a cure for scleroderma in the future.

If you would like to find out more about a bequest please contact Scleroderma Victoria on 03 9288 3651 or you can [donate online](#).

Additional help may be obtained from:

Australian Centre for Grief and Bereavement 1800 642 066

www.grief.org.au

Grief Line 1300 845 745

www.griefline.org.au

Ethical Considerations

Privacy & Confidentiality

Participation is voluntary and confidential. The anonymity of participants will be maintained at all times, and all personal information kept confidential.

For more information relating to Scleroderma Victoria's Privacy Policy, please go to:

<http://www.sclerodermavictoria.com.au/privacy/>