



Cancer Support Groups

A guide to setting up
and maintaining a group



Cancer Council Helpline

13 11 20



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The publication *Keeping Things on Track: A guide to managing challenging situations for leaders of cancer support groups* (Medical Psychology Research Unit, University of Sydney, 2007) was used as source material, particularly for information in Chapter 7, *Dealing with challenging situations* (pages 47–56). Full references are listed on page 70.

Project Managers: Susan Goldie and Kim Pearce

Editor: Laura Wuellner

Designer: Luisa Chisari

Printer: SOS Print + Media Group

Note to reader

Always consult your doctor before beginning any health treatment. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your doctor's or health professional's advice. However, you may wish to discuss issues raised in this booklet with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication.

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Cancer Council Australia

Cancer Council Australia is the nation's peak non-government cancer control organisation. Together with the eight state and territory Cancer Councils, it coordinates a network of cancer support groups, services and programs to help improve the quality of life of people living with cancer, their families and carers. This booklet is funded through the generosity of the people of Australia. To make a donation and help us beat cancer, visit Cancer Council's website at www.cancer.org.au or call your local Cancer Council.



Cancer Council Australia

Level 14, 477 Pitt Street, Sydney NSW 2000

Telephone 02 8063 4100 **Facsimile** 02 8063 4101

Email info@cancer.org.au **Website** www.cancer.org.au

ABN 91 130 793 725



About this book

Support groups connect people affected by cancer and help them cope with the disease. They provide a place for group members to give and receive emotional support and share information. Most people find it rewarding to talk with others who have been through a similar experience.

How you set up and coordinate the support group is up to you – each group is independent. Cancer Council isn't responsible for how groups are established or how well they run, but we hope this book provides valuable information to help you:

- think about community needs for cancer support groups
- determine a group's purpose and format
- learn how to form, run and maintain a face-to-face group
- promote a group to the community
- review how things are done
- deal with challenges that may come up
- reinvigorate or close a flagging group.

This publication has general information and guidelines – it doesn't cover all types of support groups, and not all the information will apply to your situation. If you want more specific details or if you want to enquire about support group leader training, see the resources list on page 70 or contact your local Cancer Council.

Who this book is for

This book is for community members who are interested in leading a face-to-face cancer support group. It's also useful for leaders of established support groups who want to make improvements, and people involved in working parties (see page 13).

You don't need any previous experience with support groups to benefit from the information, and you can live anywhere in Australia.

Health professionals may find this book useful, especially if they refer patients to groups, run and/or facilitate groups or provide other kinds of assistance to support group leaders.

How this book was developed

This national guide was developed through research and anecdotal evidence about support groups. Input from support group leaders and members has been included to provide ideas and tips.

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You may be interested in reading other books about leading support groups, or visiting some cancer-related websites. This chapter lists resources that may be relevant.

“ It helps to hear the journey that others are experiencing, support others through the interaction, and be helped by others too. It is also a safe place to discuss topics that you may not want to burden your family with. You pick up bits and pieces of information about various treatment and medicines etc. It is also a good place to have a laugh too about some of the embarrassing side effects. ”

Rural support group

“ We set up a bank account with the neighbourhood centre. We have a Christmas in July and raffles with donated prizes to raise money to pay for things like flowers for people not doing well. We realised we couldn't run meetings for nothing, so we charge members \$3 for each meeting. ”

Regional support group

“ I run the group with a breast care nurse who takes a low-key role but is very supportive. Her knowledge and information are vital. ”

Regional support group for young women with breast cancer

“ Our meeting venue is safe and welcoming, and the staff are wonderful and supportive. The women really appreciate this, especially when they are dealing with so much. We all feel like princesses. ”

Metropolitan support group for young women with breast cancer

“ We asked breast cancer nurses to send a survey to women who had been diagnosed with breast cancer in the past three years, to gauge their interest in a group and what type of group they would like. ”

Regional support group for young women with breast cancer

“ A local FM radio station is really behind breast cancer. One of our members has built a relationship with the station and does regular interviews. ”

Regional support group

1

Key questions

Introduction

This chapter has information about what support groups are, how they are organised and run, who joins and what keeps members coming back.

There is also a story from a group leader of a men's prostate cancer support group.





Q. What is a support group?

A. A support group is a number of people who come together regularly – in person, over the phone or online – to discuss shared experiences.

Cancer support groups can provide a safe place where people affected by cancer are able to:

- give and receive support
- feel less isolated
- feel heard and understood by empathetic people
- develop friendships
- learn how other people are coping
- share thoughts and ideas
- listen to each other in a non-judgmental and caring way.

Support groups can also help participants become more informed about cancer-related topics, such as treatments, side effects, exercise and nutrition, relationships and life after cancer.

Q. Why do people join support groups?

A. According to research⁽¹⁾, the top five reasons people join support groups are to:

- feel that they are not alone
- hear about current medical research from health professionals
- learn how to become more informed about cancer treatments and side effects
- hear how other people deal with cancer and compare their experiences
- relax with others who understand what they're going through.

People often look to support groups for encouragement, optimism, inspiration and hope for a life well-lived – either after cancer or in spite of cancer.

While support groups meet the needs of many people, they aren't for everyone. Some people already have enough support, while others want to deal with their cancer privately.

Q. Do support groups work?

A. A survey of 184 groups in NSW⁽²⁾ found that cancer support groups are a powerful way to improve wellbeing.

“It's a very safe place to cry in. We've talked about death. You can't talk about that anywhere else.”

Rural cancer support group

The survey found that support groups help people with cancer and their families by:

- reassuring people that their reactions are normal
- providing information about treatments and side effects from health professionals
- increasing their sense of control
- reducing feelings of isolation
- sharing practical tips on coping with cancer
- providing a place to express feelings, relax, joke and just be themselves.

“Support groups are not only a place for the serious business of cancer – to vent feelings and frustrations – but also a place for laughter and having fun. We need a place to let our hair down and cry. We also need to laugh until we feel good and feel like just another person, not a cancer victim.”

Rural cancer support group leader

Q. How are support groups organised?

A. Support groups vary according to several factors, including how people come together for group meetings, how people join a group and the purpose of the group.

How people come together for group meetings

Support groups can bring people together in different ways. Although most groups are run in person (face-to-face), some groups meet over the phone or internet.

Each type of group can work equally well. Telephone and online groups may suit different needs – for instance, a person may live in a rural area and be unable to travel to a meeting, or prefer to write rather than talk. Sometimes people would like more privacy than a face-to-face group can provide.

Phone and online support groups are often facilitated by professionals, as there are added challenges to creating a safe and friendly space when people cannot see each other.

There are national telephone support groups available through Cancer Council – call 13 11 20 for more information.

Types of groups

There are two main types of groups:

- **Closed groups** – Groups of people who meet for a set number of occasions. This type of group is usually run by a health professional for an educational or therapeutic purpose. New members can't join the group after the first meeting.

There are many other ways of describing different support groups.

Your local Cancer Council may have more information. There are also some recommended resources listed on page 70.



- **Open groups** – Many groups – including most of the groups run by people using this book – meet all year round, with members joining and leaving at different points along the way. These open groups may be run by either health professionals or trained community members.

The purpose of the group

An effective support group has a clear sense of purpose. People come together because they share something in common and they want to engage with each other in an agreed way.

A support group might bring people together who share the experience of developing cancer at the same stage in life. For example, parents of children with cancer might form a support group. Other types of groups may include people interested in the benefits of exercise or young people who have cancer.

For more information about developing a group purpose, see page 12.

Q. Who runs the group?

A. People need to establish the support group, take care of administration tasks, and facilitate each meeting.

- **A group leader** – The person who manages a support group. This person should have good listening skills, the ability to self care (see page 43), some administration and computer skills, promotional skills and the passion to be involved with fellow community members. Group leaders manage and attend each meeting and are responsible for maintaining the group. For some examples of tasks, see page 40.
- **A trained group facilitator** – Someone with specific group facilitation skills and experience. Health professionals such as social workers, occupational therapists, psychologists or nurses trained in facilitating support groups can serve this role. Sometimes community members do extra training to become a trained group facilitator through their local Cancer Council.
- **A working party** – A small group of people responsible for tasks such as promotion and ongoing administration. The working party collaborates closely with the group leader and sometimes with the trained facilitator.

Q. How do people join a group?

A. A support group might have several founding members who are involved from the start. In most cases, though, newly formed groups have to recruit members.

People in the community usually find out about a support group through:

- word of mouth (other members, health professionals or the Helpline)
- public information sessions (see page 14)
- promotional materials (see page 21).

Some people actively seek out the group, while others become interested after they learn it's available.

For most established groups, membership ebbs and flows over time. Sometimes the leader or working party will need to actively recruit new members. See pages 21–22 for information.

Q. Why do people stay in support groups?

A. Once people join a group, certain factors encourage them to stay:

- **A sense of belonging** – Group members feel they are not alone. The support group can act like a family, where members feel understood, supported, cared for and accepted.
- **Reducing isolation** – Groups develop a sense of community through shared feelings and experiences. People feel connected with other members, which can help them to cope better.
- **Empathy** – People outside a support group may not understand the experiences of people who have cancer, or they may dismiss their feelings. People are heard and understood in the group.
- **Feeling safe** – Inside the group, people feel protected and safe to express their feelings. Outside the group, they sometimes feel they have to hide their feelings to protect others. Support groups are often seen as the safest place to talk about emotions and difficult subjects, such as concerns about death.
- **Humour** – People feel comfortable to have a good laugh, to relax and feel at ease. Humour builds warmth in the group and helps members cope with confronting issues.

New group members

To ensure a good fit between a new member and a group, the group leader should have a conversation with a new person before they attend a meeting. See page 15.



John's story: Central Coast Prostate Cancer Support Group (NSW)

I'm the group leader and working party chairperson of a prostate cancer support group on the NSW Central Coast. The group purpose is to provide information and support to men affected by prostate cancer and their carers/partners.

How did you first find out about the support group?

I was visiting my urologist for a follow-up appointment about six months after I'd finished my cancer treatment, and I picked up a support group flyer at the front desk.

I'd been feeling a bit stressed about what I'd been through, so I called the number on the flyer and talked to the fellow who was leading the group. He invited me to attend the next meeting.

Describe your first meeting.

The leader talked about confidentiality, then I was asked to stand up and recount my experience. It's a vulnerable feeling to talk in front of a group of strangers, but I'm not a shy person so I was able to talk about it.

How did you become the group leader?

When I joined, the group had been established for a long time – almost 15 years. Shortly

thereafter, the leader left and I ended up taking on the role. I'm retired and I had some time and leadership experience.

As the new leader, I retained a lot of successful practices that were already in place. The group had a clear purpose and a steady attendance of about 40 people each meeting. The venue was a local church function hall, and meetings were always on the last Friday of every month.

Did you make any changes?

The first thing we did as a group was set up a working party. We created roles like Treasurer, Secretary, Newsletter Editor and Resources Officer to share the responsibilities.

Half of each meeting is for a guest speaker and the other half involves group discussion. However, since we have so many members, we now break into 3–4 small groups of about 10 people each. I think this is a better approach for our group because it allows everyone a chance to contribute, and it helps draw out some of the quieter people.

Do you work with a facilitator or co-leader?

The group has the support of two co-facilitators who

are continence nurses. They attend meetings and use their professional contacts to arrange guest speakers.

The continence nurses also provide support to me as the group leader. After meetings, we have a chance to debrief and discuss how things went and what we could improve.

What kind of promotion do you do?

Some of the local urologists are happy to refer patients to us, and we also advertise in newspapers and through the Prostate Cancer Foundation website. We don't have to do much promotion. We have 1–3 new members each meeting, just from referrals. Some guys come along and once is enough; others are regular attendees.

What do you get out of the group?

The most rewarding part of the group is helping men who haven't yet decided on treatment. Of course, we don't give medical advice, but they are able to come to the group and talk to other men who have been through a similar experience. Chatting to men and connecting with the continence nurses helps them make sense of things and feel less anxious.

2

Forming a new group

Introduction

This chapter will help you create a new support group.

The main steps include:

- researching what exists
- planning the approach, including the group's purpose, membership and establishing a working party
- finding a group leader and trained group facilitator
- recruiting members – for example, by hosting a public information session.





Research

Firstly, it's important to find out about other groups already established in your area. This will help identify gaps and avoid duplication.

For example, there may already be a general cancer support group in the community, so a cancer-specific group may be another way to support people. Or, a health professional may be running a group that provides mainly information, so a self-help group focusing on emotional support might be a useful addition.

Consider how many people could join. If you live in a rural area or small town, there may not be enough people with the same type of cancer for a cancer-specific group to be established.

Ask local health professionals or people affected by cancer if they know of any existing groups. Cancer Council also has information on the location and type of existing support groups in your area.

Who is the group for?

Some important questions need to be asked before establishing the support group. The answers will help to clarify who the group is for and what type of group will work best for those people:

- Will it be for people with any type of cancer, or a certain type of cancer?
- Will it be for newly diagnosed people, or people with advanced cancer?
- Is the group for men or women only? Or is it for both?
- Is it open to people with cancer, carers, or anyone affected?
- Is it for a certain cultural, language or age group?

What is the group's purpose?

Every group needs a short, clearly written purpose. Is the purpose of the group to provide:

- up-to-date medical information about cancer through speakers?
- social support through informal get-togethers?
- emotional support for carers of a family member living with cancer?

A well-defined group purpose will make the group easier to plan and run, with a clear idea of what it's trying to achieve. Plan a group that meets the needs of people in the community, and bear in mind that the needs might change over time – see page 57.

“ The monthly meeting is open to all people with cancer and survivors, along with their families, friends and carers. Every second month I organise a speaker to address the group, and every other month is a chance for members to informally discuss their cancer journey with others in similar situations. ”

Regional cancer support group

A clear group purpose will also help in the writing of a group agreement, which is a simple list of rules to help the group stay on track. For more information about group agreements, see pages 25–26.

Working together

It's always better when a few people work together to establish a support group and share the responsibilities. Even the most skilled and committed people can burn out quickly if they work alone.

Some people like to keep their roles very informal, with people taking on various jobs as they come up. Others want to be more formal, by assigning roles within a working party. This can help to match the right people to the right tasks and to share the workload.

If you opt for a working party, you should discuss the roles and agree on the best person for each role. If two people want the same role, they can share it or agree to switch later. It's a good idea to review roles annually and hold elections if there are designated positions.

Take minutes or notes of each working party meeting and write an action list. Everyone who has a task to do should understand what it is and its timing.

“Our working party met before the first meeting to draft the group agreement. We were able to show it to members and discuss it.”

Metropolitan cancer support group

Role	Responsibilities
Chairperson	runs the working party meetings
Secretary	responsible for paperwork and takes working party minutes if required
Treasurer	responsible for incoming money, paying bills and keeping accurate books
Group Leader/s and Facilitator/s	organise and/or co-lead each group meeting
Membership Officer	maintains the membership database
Catering	organises food and drinks for meetings
Resources Officer	collects and manages online and print resources for the support group
Publicity Officer	responsible for promoting the group through the media, the group's newsletter, flyers and emails

In some states or territories, a Cancer Council staff member can be involved in initial working party meetings and provide contacts, advice and support during the formation of a new group. Contact your local office for information.



Finding people to join a working party

Gathering a group of interested people will bring together a range of skills and talent, help share the workload and ensure that decisions reflect the views of a range of people.

The working party might include people with cancer, cancer survivors, health professionals, carers, family and friends.

Although the initial working group only needs to include a few people, more is better. Where possible, it may be beneficial to include a staff member from your local Cancer Council office or a health professional. This person may be part of the working group, or simply an ongoing contact for advice and suggestions.

Finding people to join a support group

One way to let people know about a new support group is to hold a public information session. This is aimed at community members affected by cancer who are interested to know more. You can advertise this session in various ways, such as printed flyers – see the examples on pages 64–68.

Where possible, this information session will involve your local Cancer Council and/or a local health professional.

During an information session, you could:

- briefly describe why the working party started (or wants to start) a cancer support group
- discuss who the group might be appropriate for and why
- ask a health professional to speak about a relevant topic and outline why joining the group may help address that issue
- give an overview of how the group works
- ask for expressions of interest.

If someone is keen to join the support group, take down their contact details and organise a convenient time to phone them within the next few days.

“ Sometimes we’ve had to actively recruit members. We’ve hosted a few information sessions to promote the group. Each session led to at least a couple of new members. However, we generally have a steady membership, so we haven’t had to recruit much over the years. ” *Metropolitan cancer support group*

Following up with people who are interested

When someone is interested in joining a group, it's important to chat briefly with them by phone beforehand.

This will help to ensure that:

- the group's purpose meets the person's needs, expectations and interests
- the person is a good fit for the group
- it's the right time for this person to join a support group – for example, it may not be appropriate immediately after diagnosis or during difficult treatment.

Think of this conversation as a two-way process: the person also needs to find out what the group expects of them, and might need more information before making a final decision about joining.

If it sounds like the person is a good fit, you can ask if they would like to attend a meeting. At this time, you should get the person's contact details, such as email, postal address and phone number. It's important to keep all contact details private – see page 20 for information about storing people's personal information.

Not everyone is the right fit for a support group. If someone isn't ready to give and receive support in a group setting, or if the group purpose doesn't match the person's needs, other support options may be suitable. Encourage the person to call Cancer Council Helpline 13 11 20 for information about other types of support.

Suggested questions to ask a person interested in joining a support group

- What is your name?
- How old are you? (optional)
- Are you a person with cancer or a carer?
- If you have cancer, what type do you have?
- Do you feel ready and comfortable to both give and receive support through this group?
- What do you hope to gain from the support group? (E.g. meet people in the same situation, get emotional support/treatment information.)
- What are your main topics of interest? (Answers provide ideas for guest speakers.)
- Do you have any specific dietary or physical needs?

“It’s great to have someone to work with. There are times when members need one-on-one attention, so one of us can stay and look after the rest of the group. It’s also great to have a person to learn from, to debrief with and to share challenges.”

Metropolitan support group for young women with breast cancer

Finding a leader

Every support group needs a leader. This may be you, another person skilled in running support groups, or two people working together as co-leaders.

Try to think about how leadership can be shared. It’s best to have two leaders (co-leaders) to share the load. This also makes it less likely that people will burn out (see page 43).

The leader is a vital role in the group so it’s important to choose carefully and ensure the person is suitable. For some information about characteristics of effective leaders, see *Being a group leader* on page 39.

It’s also important to think about how leadership can change over time. These changes can benefit the group in many ways. For more information, see *Changes in leadership* on page 59.



Leading a support group can be a demanding role. If you’re in the middle of treatment or just finished, we recommend you wait 18 months to two years until you are more able to emotionally support others and your energy levels have returned.

3

Practical issues and administration

Introduction

There are several practical business issues to sort out so the group can function efficiently and according to any relevant state or territory regulations. Dealing with these administrative issues will make life easier. Although it takes time, in many cases, it's a one-off task.

It's also strongly recommended that the leader or working party talk to an accountant or solicitor about the financial and legal aspects of running a support group. The information in this chapter is a general guide only.





“ Our treasurer is a retired accountant, so that makes it easier for us. We set up our bank account with three signatories. ”

Rural prostate cancer support group

Mailing address

A support group needs a mailing address for correspondence. Unless the group is affiliated with a hospital or treatment centre or has its own office, someone's home address or a private post office box is fine. A post office box is best for consistency and privacy, but there is a rental fee.

A member of the working party may also like to create a general, shared email account for correspondence.

Fundraising, ABN and taxation

Many groups want to raise money and request donations from businesses. Each state or territory has regulations about fundraising – for example, in NSW, anyone who raises money from the public has to be registered as a charity with the Office of Liquor, Gaming and Racing.

If a business making a donation wants a tax-deductible receipt, a group may need to be registered as a deductible gift recipient with the Australian Taxation Office. Ask your accountant about your state regulations.

You may want to register for an Australian Business Number (ABN). You don't have to get an ABN, but you may need it if the group applies for funding, because some funding bodies only deal with organisations that have an ABN. While you don't need an ABN to apply for a bank account, it may also make this process easier. Applying for an ABN is free, and it only takes a few minutes on the Australian Business Register website (www.abr.gov.au). You can also ask for an application form to be posted to you.

Although many businesses have to register for Goods and Services Tax (GST), this doesn't apply to most cancer support groups. Not-for-profit organisations that have a turnover of less than \$150,000 are not required to register for GST. The main reason to register is to claim back the GST which the group pays on goods and services. However, if the group is registered, it also has to charge GST on any payment received and pay it to the Australian Taxation Office. Business Activity Statements must also be lodged, so consider whether the extra paperwork is worth the effort.



For more information about an ABN and taxation issues, talk to an accountant or call the Australian Taxation Office on **13 28 66**.

Bank accounts

If the group receives and spends money, it should have a bank account. You should set up the bank account in the name of the group (business account), rather than as a personal account of anyone in the working party. The account should have two or more co-signers as a safeguard.

It's worth spending some time investigating banking options, as fees and benefits vary greatly between banks. Some banks have specific account types for not-for-profit groups or offer fee-free community business accounts for not-for-profit organisations.

If the group has bills, it's generally best to pay using a cheque account and/or electronic funds transfer (EFT) rather than cash. This is a clearer way to keep track of payments.

The working party should ensure that bank account details (bank name, branch and account numbers, interest rate, fees, co-signers, where statements are sent) are carefully recorded and decide on a single location where all banking, taxation and other records will be held securely.

Resources and expenses

Every support group needs some resources to run the group.

They may include:

- a post office box
- coffee, tea and snacks
- cups, spoons and napkins
- someone to design flyers or newsletters
- somewhere to print or photocopy flyers or newsletters
- postage for mailouts
- a computer, printer and external hard drive/USB drive
- internet access
- a TV, DVD player or laptop for presentations and film resources.

If the group is affiliated with a hospital, local club or other service organisation, it may cover some or all of these costs.

You may be able to attract donations without spending lots of time fundraising. Businesses and local community organisations are often willing to help cancer support groups with small jobs in return for an acknowledgement, such as in a support group newsletter.

There are state and territory regulations regarding fundraising activities – see page 18.

Questions to ask a financial institution

- What are my account options?
- Do you have fee-free accounts or can the fee be waived for a small community group? If there's a monthly account fee, how much is it and what does it cover?
- What is the minimum amount that must be in the account, and what is the penalty for going under that amount?
- What is the interest rate of the account?
- Can I write cheques or use an ATM or debit card?
- Can I have two or three people (signatories or co-signers) on the account? If I want to change this later, how do I go about it?

Cancer Council may offer public liability insurance to recognised cancer support groups. This covers a group in the 'party premises', which means the usual room and facilities where group meetings are held.

It may not cover the group for other activities, such as working party meetings, fundraising, social events, exercise classes or other physical activities. Contact Cancer Council before undertaking these activities to ask what is covered.



Insurance

A support group's insurance needs depend on how it is set up, where it meets, and if it is affiliated with other organisations, such as a hospital.

This is general information only – you will need to get specific advice on insurance. Consult an insurance broker or solicitor when making decisions about insurance.

Public liability insurance

This type of policy protects a group against the need to pay compensation to a person who is injured or suffers property damage or loss through a mistake. The mistake may be caused by the unincorporated or incorporated body that runs the group, or one of the group members.

A support group may need public liability insurance even if it meets in a place that already has its own insurance policy, such as a hospital, community health centre or club.

Other types of insurance

You can also talk to an insurance advisor about other types of insurance that could be relevant to some support groups (or organisations running support groups). This includes personal accident insurance, directors' and officers' insurance and insurance through affiliated organisations.

Personal details and confidentiality

Part of running a support group is collecting personal information from group members and people in the community. Keeping this information confidential and well organised will make it easier to get in touch with people when necessary, and promote the group to people who have expressed interest (e.g. if you want to promote to a certain group, such as carers).

- Only collect necessary information.
- Keep personal information secure. You may want to keep it in a locked filing cabinet or make a database saved on a password-protected external hard drive.
- Keep people's contact information up-to-date.
- Tell people how their personal information will be used and confidentially stored.
- Consider asking a working party member to become the membership officer and maintain a contact database.
- Back up your information, so you have it in more than one place.

Promotion

Publicising the group is particularly important when the group is new, so people know it's available. However, it's also something that the working party might need to do periodically over the life cycle of the group – see *Ongoing promotion* on page 34.

There are a number of ways to spread the word about the group. This might include posters, flyers, a press release for the media, or a short announcement for community papers, radio stations and newsletters. This book has some templates to help develop these materials – see pages 61–68.

Reaching the target audience

Before distributing promotional materials, think about the target audience and where they are likely to see the notices. For example, if a support group is for people having cancer treatment, it makes sense to put promotional material in hospitals and cancer care centres.

Aim to promote the group widely so you can attract large numbers of interested people. Suggested locations for posting promotional material include:

- hospitals (cancer care centres) and community health centres
- GP practices
- supermarkets and shopping centres
- clubs, churches and libraries.

Ask permission before putting up posters or leaving flyers.

Approaching a local newspaper

A media release is basically a summary of a story idea with facts and figures and comment from expert spokespeople. It's used to inform the media about a topic and make them interested.

Journalists receive many media releases each week, but writing a media release is not the only way to get a story in the local paper. You can try these steps:

- **Identify a new angle** – This could be that the support group is new; that the group is celebrating an anniversary, there is a special guest speaker, or the positive impact that it's having on the local community.
- **Find a good case study** – This could be a person from the support group who has an interesting story to tell about their cancer experience



Naming the group

A clear name for the group can help to promote it to people who might be interested. For example, the Bosom Buddies Breast Cancer Support Group.

●● We promote the group on all fronts: business cards for doctors to give to patients; patient packs for the case manager to give to patients; newsletters; hospital websites; word of mouth; presentations to medical professionals and community organisations; and regular contact with the local media. ●●

Metropolitan prostate cancer support group

and why they have joined the group. Only approach a group member who is comfortable to talk to the journalist and to have their photo taken. Their story will provide the local human-interest angle to engage readers and provide the opportunity to promote important messages about the support group.

- **Find a journalist to call** – Look through the local newspaper to see who is writing human interest stories. Call that journalist and mention some of their other articles, then mention the group as a story idea that might interest them. If you can't find a particular journalist, call the editor.
- **Pitch the story** – Now 'sell' the story to the journalist. Emphasise why it would interest their readers – that it is local (mention how many local people are part of the group); the new angle (see point 1); and the good local case study they can feature. Follow up with an email to confirm the discussion and provide more relevant details. For an example email, see below.
- **Arrange the interviews** – Let them know the availability of the person for the case study and pass on their contact details, if you have permission to do so. The journalist will contact the person directly to arrange an interview. They are likely to send a photographer as well. If it's a smaller newspaper, you can offer to provide a digital photo of the person.

Sample email to journalist

Dear [insert name of journalist],

Many thanks for your time this morning. As discussed, we are launching a new cancer support group for local men and women affected by cancer and will be hosting our inaugural meeting on [insert date].

Our group facilitator [insert name] is available for an interview at [insert time] and can be contacted on [insert details].

It would be wonderful if the group details could be listed at the end of your article so potential new members can contact us for more information – our details are as follows: [insert group contact name and phone number].

We know from research that people greatly benefit from speaking to others who have been through a similar cancer experience. Thank you for helping us spread the word and we look forward to providing much needed cancer support to local residents affected by cancer.

Kind regards,
[insert name]

4

Planning the first meeting

Introduction

Once the preliminary work has been done – e.g. the group has a clear purpose and working party members have done the necessary administrative and promotional steps – it's time to plan the first meeting.

The first meeting is important because it will help set the tone and future goals.

The group leader or working party will have to draft a group agreement and decide where and when to meet. See pages 25–26 for more information on group agreements.





Finding a venue

One of the first steps will be choosing a venue to hold the first group meeting and subsequent meetings.

Try to find a place that:

- is free, private and pleasant (e.g. perhaps airconditioned)
- has easy parking, is close to public transport and is convenient
- is accessible to people with disabilities (has wheelchair access) and people with reduced mobility
- has coffee/tea facilities
- has audiovisual equipment if required
- has nearby toilets (wheelchair accessible, if necessary)
- has comfortable furniture that can be easily rearranged
- can be reserved for every meeting for a year.

A member of the working party can scout out possible meeting rooms. Community health centres, town halls, libraries, church halls or hospitals often have rooms available. In some areas, the local Cancer Council office may have an available meeting space.

Meeting spaces need to be neutral and equally accessible for all members, to ensure that the group will function smoothly and support everyone equally. For this reason, and because of insurance issues, Cancer Council strongly recommends against holding the group meetings in someone's house.

Timing

Support group meetings should be at the same time, preferably monthly, or fortnightly, depending on what suits the working party.

Consider the following issues when deciding a day and time:

- What are the characteristics of potential members? Are they likely to work during the week? Are they still in treatment? Will they want to travel during the evening?
- When are the leaders and/or facilitators available?
- When is the meeting room available?
- Will the group overlap with another activity or event that may be disruptive (such as choir practice in a room next door)?

It's often best to hold meetings from Monday to Thursday, as it can be difficult to get guest speakers and participants to attend on Friday nights or on weekends.

Welcoming people to the group

- Although there is a lot to accomplish at the first meeting, the most important thing is to make people feel welcome so they want to come back.
- People may feel nervous or unsure about coming to a support group for the first time. Help people feel at ease as soon as they arrive. There may be someone who can greet people at the door.
- If people arrive early, allowing them to help you set up may help them to feel more comfortable.
- If people arrive late, don't make them feel disruptive. Instead, remind them privately of the start and finish times of future meetings.

Jobs for the first group meeting

Before the meeting	At the meeting	After the meeting
<ul style="list-style-type: none"> • Prepare the format for the group (see pages 27–28). • Bring pens, pencils and name tags. • Photocopy and bring the attendance list and guidelines (including contact information for relevant working party members). • Make and bring flyers advertising the next meeting. • Put up signs directing people to the room. • Set up the chairs in a circle or another suitable arrangement. • Make sure to set out tissues, snacks, hot water, coffee, tea, sugar, milk, cups, spoons and napkins. • Confirm any guest speaker/s and send them guidelines (see page 30). 	<ul style="list-style-type: none"> • Have one or more people greet participants at the door. • As people come in, ask them to fill out their details on the attendance list and give them a name tag. • Go through housekeeping issues, such as the location of the toilets, emergency evacuation procedure, etc. • Provide everyone with a copy of the group agreement, if it's already prepared – see below. • Finish on time. • Remind everyone of the date of the next meeting and/or hand out a flyer about next time. 	<ul style="list-style-type: none"> • Rearrange furniture if necessary. • Collect the attendance list. • Clean and lock up. • If you are the leader or facilitator, take time to debrief (see pages 43–44).

Group agreement

One of the key tasks of the first meeting is to establish rules for everyone to follow. This is called a group agreement and it should:

- outline communication and behaviour standards
- allow people to share responsibility and ownership for the meetings and discussion
- help to maintain a focus on the group purpose
- keep the facilitator and leaders on track
- help the group work effectively and minimise conflict.

Ideally, the working party will already have drafted a group agreement for discussion at the first meeting. The agreement should be referred to at each meeting, and it can be reviewed and updated by the group from time to time.



Example group purpose

A monthly support and information evening for women between the ages of 45–60 who have been diagnosed with gynaecological cancer.

Example group agreement

This is an open group focused on welcoming and supporting new and existing members, whatever their stage on the cancer journey. The primary aims of the group are support, education and information.

Everything discussed in group is confidential.
Individual identifying information is not shared outside the group.

Group members are encouraged to share their skills, insights, strengths and hopes, and to recognise that everyone in group has expertise in dealing with cancer.
Individual health professionals should not be named/identified.

Group members are respectful of each others' feelings, views and concerns at all times.

Group members are respectful of everyone's right to participate equally in the discussion or not to participate, if that is their wish.

Group members are courteous to each other at all times.
This includes not interrupting or talking while someone else is talking and listening attentively when another person is speaking.

Group members take responsibility for the success of this support group by maintaining their focus on the issues and coping strategies specific to the group and the topic being discussed.

Group members are encouraged to use "I" statements so that everyone speaks in the first person.

Group members are responsible for their own wellbeing and are encouraged to look after themselves and seek support if they are upset before, during or after group.

Format of the first meeting

The group leader and working party need to plan the format of the first group meeting. The leader (along with the trained facilitator, if one is involved), runs the meeting.

1. Start the meeting by welcoming everyone and introducing themselves and any guest speakers.
2. Introduce the working party members who helped to start the group. Each member should say who they are, and talk briefly about their cancer story and why they are involved with this group. Not all working party members will be part of group meetings, but it is good for everyone to know a little about them anyway.
3. Mention that the most important rule is confidentiality: what's said in the room stays in the room.
4. Introduce the other people in the room. Consider using a conversation starter or icebreaker, such as "Where have your shoes been today?" or "What have you been up to this month?" to make people comfortable. Then ask if they are willing to briefly share:
 - who they are
 - their experience of cancer
 - why they've come to the group.
5. Provide a brief summary of the group's development and plans, e.g.:
 - why the support group was formed
 - how the group was formed
 - who was consulted.
6. Discuss the group agreement:
 - distribute copies of the agreement
 - go over the group agreement – ask whether anything has been missed or if anyone disagrees with anything
 - plan to bring a laminated copy to group meeting each time to put up on the wall, if possible.
7. Discuss the group's format and content:
 - determine how each meeting should be run
 - plan and suggest topics/guest speakers as appropriate
 - select dates for meetings in the next few months
 - give out flyers for the next meeting and encourage people to return.

“The main things that made the first meeting go well were introducing everyone and giving them the chance to talk about their cancer journey. This really got the discussion going. Talking about the group agreement gave everyone a chance to have a say on how meetings should run.”

Rural women's cancer support group

Keeping on time

One of the basic rules about support groups is that meetings should begin and end on time, but you can allow a little extra time for the first meeting.

●● We take a tea break in the middle of the meeting, between the guest speaker and our discussion. It's a good break and an opportunity to get up and stretch our legs. ●●

Regional support group leader

8. Have an informal tea and coffee break, where people can talk. Some groups prefer to have the tea break in the middle of the meeting, rather than at the end. Some people may leave as soon as the structured part of the meeting is over, missing an important chance to chat and share.
9. Prepare people to move away from group time with a closing question, such as "What will you do when you leave this meeting?" or "Name one thing you are looking forward to during the coming week".
10. After group members have left, allow time to reflect on how the group went and talk about any issues (debrief). This will be important to do after every group meeting, not just the first one. For a list of debriefing questions, see page 44.

Do notes need to be taken?

It's not appropriate to take notes of personal sharing during group, because this information is confidential to each group member.

However, you should take a written record of who attends each meeting, so you can follow up with people who are not able to join regularly or who have been

absent for a while. This will also help you track how well the group is travelling, based on attendance.

It is also appropriate to take notes about decisions made by the group, or to record what a guest speaker says. Ask the speaker for a handout or a copy of their presentation, if possible.

5

Maintaining a support group

Introduction

Once the support group is established and the first meeting has been held, good organisation and careful planning by the working party – including the group leader – are vital to ensure the group thrives.

This chapter includes information about:

- planning ahead
- organising guest speakers
- maintaining a library
- staying in touch with participants, donors and health professionals.





Planning ahead

The support group will operate smoothly if people involved make an effort to be organised. This may involve:

- writing down what needs to be done
- leaving plenty of time to do it
- sharing the workload through a working party.

For a list of jobs to do before each meeting, see page 25.

A good way to get organised is to allow plenty of time to plan meetings. The working party should meet at least four times a year. This will allow enough time to do tasks, such as book speakers, and print flyers and other advertising material.

Last-minute issues will crop up from time to time, but if there's a crisis every month, the working party needs to look at the way the group operates.

Guest speakers

One of the key roles of some support groups is to provide access to qualified guest speakers. Not every group has speakers – some groups focus on mutual support and prefer not to have speakers.

Although many speakers will be health professionals, other people can contribute to the group, such as artists, writers, yoga instructors, welfare workers or massage therapists. What they should all have in common is a skill or a story to share with a benefit to participants. Having an oncologist talk about medical issues may be relevant, but it may be just as valuable to have a workshop about relaxation skills.

The working party and group participants may have ideas about suitable topics and speakers. The group's annual evaluation can also provide an opportunity to collect ideas and plan ahead for the next year – see pages 62–63 for a template.

Finding guest speakers

There are a few ways to track down suitable speakers:

- The working party can request speakers from a cancer care centre, local hospital, a GP, Cancer Council, and professional organisations. Check with professional associations for the names of accredited practitioners.

Always research the speaker. Never let anyone present who is not well known or recommended.

Cancer Council encourages an evidence-based approach to information about treatments, whether medical or complementary. Call your local Cancer Council for guest speaker suggestions.



- Ask people involved in other support groups for recommendations.
- Keep a record of any information gathered about potential speakers. For example, write down the details of someone mentioned in the newspaper.

Groups in remote areas

For groups in a rural or remote area, it may be hard to find a variety of guest speakers. There are sometimes ways around this:

- Ask a local company or organisation to sponsor the speaker's trip and pay for their travel and accommodation expenses.
- Share a speaker between several groups.
- Work with cancer treatment centres and Cancer Council to find out in advance if people are coming to the area for other reasons, and ask if they will come to speak at the support group as well.
- Check with local hospitals or the Cancer Council if they have any recordings of guest speakers who have presented. Guest speakers don't have to be there in person – you may be able to use a recording or video clip instead.

Briefing the guest speaker

Giving some guidance to speakers will help them know what to expect, and help ensure the group receives a suitable presentation.

Send the speaker information about:

- how to find the venue
- how much time they have for their presentation and questions
- the kind of information the group members want (or don't want)
- the group purpose, culture (for example, 'informal')
- whether they should stay for the support part of the meeting
- speakers and presentations that have been well received in the past.

Ask the speaker if they need any equipment (such as a laptop, DVD player, whiteboard and pens) or would like anything photocopied in advance. Call the speaker a week before the meeting to confirm.

It can be useful to keep the names of past guest speakers on the mailing list, to let them know how the group is progressing and for possible future support.

“ Having guest speakers allows the group members to have access to information they may otherwise miss out on, and it's also delivered in person, which makes a big difference. It's good for the group to hear from experts so they can be empowered to make decisions. ”

Metropolitan support group for young women with breast cancer

Working with guest speakers

- Most speakers will present at a support group meeting on a voluntary basis.
- Some speakers, such as counsellors or psychologists in private practice, may expect to be paid. If funds are a problem, some speakers may consider charging a lower fee. Be upfront about what the group can afford to pay when the speaker is invited.
- For all speakers, it is good to give a small gift of appreciation or send a thank you note after the meeting.

Finding reliable information and creating a library

Support group members sometimes ask where they can find accurate, reliable and up-to-date information about cancer. There is a lot of information available in print and online, but not all of it is trustworthy.

Cancer Council has a variety of free publications that are reviewed and updated regularly. We encourage groups to create a library from these resources, which cover all aspects of cancer, from medical information to dealing with its emotional impact. Call the Helpline on 13 11 20 or visit the Cancer Council website for more information about these resources.

Resources may also be available from:

- other charities or organisations
- your local hospital, cancer treatment centre or GP
- online (internet)
- a Cancer Council library (resources on loan available in some state and territory offices).

We also recommend nominating a member of the working party to become a Resources Officer. This involves collating reputable information and keeping track of what's been borrowed. If the group maintains an updated list of resources, it will be easier to spot any gaps in resources and let people know what is available.

Evaluating online information

More likely to be reliable

- ✓ The article is based on research
- ✓ The source of the information is a scientific report or journal
- ✓ The author is clearly identified and their qualifications are listed
- ✓ The organisation that funded any research is a government or non-profit organisation with a well-known reputation
- ✓ The information is recent
- ✓ The website has been recently updated

Less likely to be reliable

- ✗ The article is about a personal story or an idea
- ✗ The source of the information is the mass media
- ✗ The author isn't clearly identified
- ✗ The organisation funding the work has a financial interest
- ✗ The information is old
- ✗ The website hasn't been recently updated

Staying in touch

It's important to maintain good communication with current support group members, potential new members, health professionals, and any donors.

- **Current group members** – People will have a sense of belonging through regular communication. Reminder emails and newsletters can link, support and encourage people between meetings. This can also ensure that members feel connected if they miss meetings due to illness or treatment.
- **Potential members** – People may express interest in the group but decide they aren't ready to open up about their cancer story. Some people could be too unwell or preoccupied to join the group. However, staying in touch with these people can give them support and make them feel welcome, if they do decide to attend.
- **Local health professionals** – The support group is more likely to get member referrals if local health professionals are familiar with the group and regularly updated.
- **Donors** – Try to be involved with any donors (such as service clubs or local businesses) year round, not just when you need something from them. Acknowledge donors in any newsletters or updates and send a thank you note highlighting the benefits of their donation.

Providing support between meetings

Sometimes a group member might need some extra support or information between group meetings.

Communication can come from the group leader or another member of the working party, such as the Membership Officer.

Producing a newsletter

A newsletter can help keep support group members, health professionals and the public up-to-date. It can be used to:

- summarise what happened at previous meetings
- advertise talks and events
- highlight contributions to the community
- pass on new and reliable information, such as websites and research results
- stay in touch with people who can't make it to meetings but still want to be involved.

The newsletter shouldn't include medical updates or personal, private health information about named group members without their permission.

Content

The first task is to decide who will edit the newsletter. The editor is the person who will work out the newsletter format and what should be included.

tips

- Look at other groups' newsletters for ideas about what might work well.
- Think about the target audience and who will receive the newsletter: people already in the group, people who might be thinking about coming, health professionals, other support groups, or the general public.
- Think about who will contribute to the newsletter, e.g. support group members or health professionals.
- Consider a variety of stories (e.g. personal stories or clinical articles).
- Ask group members for feedback about types of articles they want to read.
- Decide if every submitted article will be included or if the editor will select some.
- Consider sending an email newsletter (rather than print).
- Add a disclaimer to each copy of the newsletter to emphasise the importance of medical advice. For example, "The information in this newsletter is not intended to be a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of a qualified health professional."

Design and printing

There are many ways to design and print a newsletter, ranging from photocopied sheets to professionally designed and printed publications. The design and style of the newsletter will depend on budget and the skills of the people in the working party who are producing it.

Think about whether the design and printing can be donated, or if the working party has money in the budget to pay for it. Try taking a creative approach – speak to a local TAFE, professional design training school or local high school, and ask whether a design class would be willing to take the newsletter on as a design project.

“I’ve produced a newsletter for the past two years. I have 40 people on the mailing list and send half by mail, half by email. The neighbourhood centre prints it for us.”

Regional breast cancer support group

Ongoing promotion

After the initial effort to recruit members to start the support group, periodic promotion to attract new members will keep the group strong.

The group’s history and current activities can be used to promote to the target audience (e.g. people with a particular type of cancer, carers and family members).

There are two issues worth revisiting every year or so:

Is the promotional strategy working?

Answer these questions to work out if promotions are reaching the right people:

- Has the promotional material been placed in the right places?
- Is it generating any kind of response?
- Are there areas or ways to expand the promotion?
- Are there places where no one is taking the information available?
- Does the working party have a media strategy?

Asking new and existing members if they remember where they first heard about the support group (keep track of their answers) may help determine the most effective promotional material.

Does the promotional material need updating?

- Does it need to be updated or redesigned? There may be someone who could donate some time and expertise to help with designing or printing promotional materials.
- Evaluate the content as well. Does it accurately describe what happens in the support group? Is the language appropriate for the target audience?

Welcoming new people into the group

From time to time, new people will attend the support group. Someone joining an established group may feel anxious or uncertain. Similarly, existing members may feel a bit unsure about new people. They might wonder how new members will affect the feel of the group and the trust between people.

To help a new person feel at ease, you can:

- contact them before the first meeting and give them a copy of the group agreement to read
- explain where they will be greeted
- tell them about the group – e.g. how many people usually attend, the ‘feel’ of the group (for example, ‘informal’) and how long it’s been established
- ask existing members to introduce themselves and share some of their story, then ask if the person is comfortable doing the same
- assure the person that they don’t have to speak if they don’t feel up to it straightaway.

Don’t worry if the new person is not ready to share much at their first group – they may be shy or unsure how they fit in.



Creating a website

Some larger groups have their own website or private facebook page to promote the support group and keep their members up-to-date.

Basic websites shouldn’t cost a lot to establish (or they may be free). If the group has a website, someone should keep it updated with the meeting schedule or a copy of the newsletter.

Whether or not the group has its own website, you can call your local Cancer Council office to ask if the support group may be listed on its website or directory.



Jann's story: Southern Highlands Cancer Support Group (NSW)

How did the group start?

The group was formed after I attended a community meeting hosted by doctors and health care workers in the Southern Highlands area. They hosted the meeting because they were concerned that there was a gap in local support for cancer patients.

I was a cancer survivor, and had been involved with the Cancer Council as a volunteer for some years. As a result of that meeting, I was asked by the health care professionals if I would like to form and lead a support group.

Who else was involved?

A Cancer Council Regional Office staff member provided support to me. Her help in facilitating the group was invaluable.

What was the purpose of the group?

We decided the group would focus on support for all people affected by all cancers, including partners and carers.

Over the years, there were people with a variety of cancers, but there was a predominance of women with breast cancer.

However, group members did not define themselves by their type of cancer – instead, they saw themselves as comrades supporting each other on their cancer journey.

Describe the first meeting.

Through the support of community health, we found a lovely room attached to the local library. It was a warm and cosy atmosphere, and it was free of charge for our group meetings.

Our first meeting was special, because we had a guest speaker give an inspirational talk about the value of peer support. It was very encouraging, and it made the first meeting memorable for those who attended.

What was the atmosphere of the group?

Our group focused on emotional and practical support through an environment that was positive, cheerful, caring and non-judgmental. The members had all 'walked in the same shoes', so they were able to show empathy and understanding.

Did you create a group agreement?

At the second meeting, we discussed a group agreement and everyone had input. We emphasised the need for confidentiality and respect. We also decided on the format for other meetings – we opted to have tea, coffee and biscuits at the end of each meeting to allow people to chat in a social setting and have one-on-one discussions.

How did you run meetings?

For the first year, we met every second month, then we

“Leading the support group was rewarding for me. It could be very sad, I admit. But it wasn't a sad place. There were a lot of laughs, even – surprisingly – about the most difficult things.”

Jann

came together monthly. People contributed a gold coin to attend and we kept a note of who attended. Sometimes the numbers were small, but other times we had a larger attendance – members knew that the group was there for them when they needed it.

Did the group have guest speakers?

We had a guest speaker every second meeting. We had a range from dietitians to psychologists, oncologists to herbalists and massage therapists. Some were better than others, but most were very interesting. In fact, after a while, it was impossible to think of someone we hadn't invited!

How did you promote the group?

There was a lot of interest in the group from the start. We put an ad in the local paper and made flyers for the chemist, library, treatment centres and GPs. The medical oncologists supported us and encouraged their patients to attend.

When the group was established, we created a member newsletter. I wrote the stories and someone else in the group designed it. We had a community grant to pay for printing and postage.

How did you decide to end the group?

When the group started, it was because there wasn't any local support available. Over five years, more services became available:

A cancer centre opened so people were able to have treatment locally. A Cancer Council Information Centre was formed. The McGrath Foundation established breast care nurses. There were cancer blogs and websites where people could chat.

We had a small base of regulars who attended every meeting, but overall numbers were waning and we weren't attracting new members. I felt it was time to consider closing the group, as we had come full circle.

How did you let people know?

We brought up the issue in the newsletter and at the next meeting. Members were disappointed but they felt they couldn't be more involved. Many people were too sick to do so. We agreed the group had run its course and achieved its goals.

How did you wrap up the group?

We created a flyer and community notice to let people know about the end of the group and the last meeting. The flyer mentioned what we achieved; thanked our donors, supporters and speakers; and saluted past and present members. It also highlighted the new support services available in our area.

We finished at the end of the year with a holiday party and a celebration of our success. The local paper also wrote an article about the group, titled 'Celebrating a job well done'. It was a positive experience – the group closed on a high with a feeling of pride.

“As group leader, I encouraged people to speak about anything they wanted to say, but there was never any pressure. It was a successful format because members relaxed. You could feel the group bonding.”

Jann

“ At the end of each year, we survey our members to understand their perspective about the group. It’s really valuable to have this feedback so we know if we are on the right track or how we can improve. ”

Metropolitan support group for young women with breast cancer

The changing needs of a support group

The needs of the support group will change as people’s circumstances change and members come and go.

A successful group responds to members’ needs, but if there are different needs within the group, the working party should decide how to meet everyone’s needs. People’s different needs may create lively and broad-ranging conversations during group.

But in other cases, there may be a feeling that not everyone’s needs are being addressed. For example, there may be tension between the needs of newly diagnosed person and someone with advanced disease, or between someone with cancer and someone who cares for a person with cancer.

There are several ways to assess how well a group is functioning:

- Informally ask people for their views. However, because that involves face-to-face interaction, people may not be completely honest.
- Review attendance records to look for patterns in the number of people who attended and the popularity of discussion topics or guest speakers.
- Ask everyone to fill out a short, anonymous evaluation at least once a year – see the sample on pages 62–63. Be sure to let them know the results.

For more information about changing priorities, see page 58.

6

Being a group leader

Introduction

This chapter provides a brief introduction to the role of a support group leader. It will provide you with some information to get started, even if you have never run a group.

Leading a support group can be rewarding, but it is also challenging and a big responsibility. That's one of the reasons Cancer Council strongly recommends that a group leader, trained facilitator and working party share the load. Looking after your own wellbeing is also extremely important.

Some Cancer Councils offer training and other resources for support group leaders – we encourage you to contact your local office to find out more. Being a group leader is not necessarily a good fit for everyone, so this might help you decide if you are the right person for the role.





What a support group leader does

Your main role as a group leader will be to ensure that the group operates as smoothly as possible, whatever type of group it is, whether its aim is information, support or both.

A leader needs the skills and ability to create a safe environment for group discussion and keep discussion focused. Group members should be encouraged to share their stories and feelings.

Leaders also:

- take responsibility for keeping the group in line with its purpose so discussions benefit everyone
- manage membership (people joining and leaving group) and act as the first point of contact for questions
- plan the format of each meeting, including planning topics, speakers, activities, evaluations, enquiries
- work together with a trained facilitator, including reviewing how the group is doing and supporting each other through debriefing (see pages 43–44)
- work on ongoing administration and planning (sometimes supported by a working party – see page 13).
- understand their own limitations and do not counsel group members.

tips

- Maintain confidentiality. Reinforce the rule of confidentiality at meetings.
- Create a safe, friendly and warm environment in the group.
- Facilitate balanced discussion (lead the discussion, don't dominate).
- Speak in the first person, using "I" statements.
- Be an active listener.
- Allow people to express strong emotions without being rushed.
- Don't give health advice.
- Be comfortable with silence.
- Encourage everyone to participate in the group and to respect the views of others.
- Be honest – if you don't know the answer, say so.
- Find information to answer questions that come up.
- Keep a sense of perspective: don't let the group rule your life.

“Leadership, for me, is about being passionate and giving my time to the group. But it’s also about motivating other people in the working party to contribute their time and energy.”  *Regional cancer support group*

Characteristics of effective leaders

A group leader should be open, objective and have a good sense of humour. Effective leaders are good communicators, well organised and can gently encourage people to participate in a group without being intrusive. They need to be able to lead without being overbearing.

It’s easier to be good humoured if you share the work. Try to ensure other group members are involved in running the support group from the start. Share the tasks as widely as you can, perhaps through a working party. Not only does this reduce your workload, but it also can help identify potential future leaders.

Managing boundaries

Group leaders must clearly manage the boundaries between their own cancer story and those of support group members. If you become a group leader, your focus will be on creating a safe space for group members to share, rather than using group time to discuss the impact of cancer in your own life.

Leaders should also have a boundary between what they know about group members within group and outside of it. If you interact with members socially or in the community, you should not let group conversations flow into daily chat at the shops, at a dinner party, or on the sidelines of a football match.

Managing boundaries can be challenging. It involves exploring your own emotions and knowing how to let others express theirs without allowing yourself to become upset or emotional. In fact, your story might not come up at all.

Running effective groups

Part of being an leader is having an outline for each group meeting, and making sure all the meetings keep in line with the group purpose and agreement (see pages 12 and 25) and run to schedule.

Your local Cancer Council support group staff may be able to help you decide if you are ready for group leadership.

Cancer Council may also run group leader training. This training helps people to reflect on boundaries and explains what leadership involves.

For more information, call the Helpline on **13 11 20**.



Example group meeting format

Welcome and icebreakers Ask people to say their name as a reminder to existing members. It's a good idea to have name tags at every meeting. If any new people are joining, you can ask them to introduce themselves.

These openers can also get people warmed up and talking:

- “What did you have for breakfast/lunch/dinner?”
- “Tell us about one item you’re wearing and why it is special for you.”
- “Where have your shoes been today?”
- “What is something you are grateful for?”
- “Would you like to share something about your week?”

Guidelines Briefly run through the group agreement guidelines – for example, confidentiality and finishing at a particular time. You can also go over any housekeeping issues.

Guest speakers or discussion If a guest speaker is presenting, it's the group leader's job to introduce the speaker. It's best to keep this brief and to the point.

Otherwise, you might start the group discussion by asking people to say their name and anything important that has happened since the last meeting. They might introduce a planned theme to discuss (e.g. changes to relationships, fears about death and dying).

Energisers If you feel people are getting tired and the meeting needs a lift:

- ask people to stand up, stretch and take a deep breath
- introduce a five-minute activity that is funny or silly and get everyone laughing
- have a break for refreshments – this is also a good opportunity for people to chat with each other and take a break from the group conversation.

Closers Although it may be tempting to wrap up quickly, it's important to close the group. This will let members' emotions settle and shift people's focus to daily life. As part of closing the group and helping people wind up the conversation, use a prompt to prepare people to move away from the group:

- “What is one thing you are looking forward to this week?”
- “What will you do when you leave group tonight?”

When you are wrapping up the meeting, remind people about the date and time of the next meeting.

Self care and burnout

Being a leader of a support group can be a big responsibility and it may take a lot of time and energy. This can be draining at times, even for the most committed person.

Even if other people are available to help, group leaders are at risk of burnout. Burnout is a word that's sometimes used to describe exhaustion and reduced interest in a task. Several signs may indicate burnout:

- feeling emotionally, physically and mentally tired
- inability to listen to group members' stories
- no satisfaction in completing tasks
- reluctance about going to group
- not 'switching off' after group
- negative attitudes to tasks
- questioning whether work is valued
- sense of failure, low self-esteem
- frustration and feelings of helplessness and hopelessness.

Anyone involved in running a support group is susceptible to burnout, but it's most common for leaders or trained facilitators because of the amount of work they do. It's important to look after yourself and have your own personal support systems.

Self care

Self care involves taking time to look after your own wellbeing. This involves debriefing, and it may also involve supervision (see page 45).

Self care can take some discipline – leading a support group is time consuming, and it's easy to overlook your own needs. Some people think it's selfish to take time to look after themselves, but if you're feeling stressed or overwhelmed, you probably won't be able to be an effective leader. It can also be hard to support others while dealing with issues in your own life.

Debriefing

Debriefing is thinking about what happened during the support group meeting. It's an opportunity to process any concerns or questions that might have come up. See the following page for a list of questions you can use.

If you have a co-leader, or if you work with a trained facilitator, schedule about 30 minutes after the meeting to debrief with each other. This can be done face-to-face, by phone or by email.



Taking time to reflect

Make time for debriefing either straight after group members leave or within the next couple of days. Leaders who don't have a co-facilitator should debrief in the same way as a self-reflection exercise.

Debriefing question prompts

- Was the number of people who attended more or less than expected?
- Did people seem interested during the discussion?
- Did anything unexpected happen?
- How did the group respond to me/us, as leaders and/or facilitators?
- What went well?
- What could be done differently next time?
- How do you feel after group?
- Do you have concerns about a specific group member? If so, what needs to happen next? (e.g. Should someone contact the person to check on them and/or suggest other support, such as calling Cancer Council on 13 11 20?)
- What do you need to do, if anything, before the next meeting?
- What am I going to do now to take some time for myself?

If the group has regular guest speakers, part of the debriefing should also involve discussing how the speaker went. You may also use this time to discuss other speakers that might be relevant for future meetings, and who can organise the speakers (e.g. someone in the working party).

It's not always possible to debrief straightaway, but try to block out some time during the week after the meeting for reflection. Once you get used to taking the time to talk to someone else or self reflect, it often becomes a habit. Debriefing will help you monitor your personal wellbeing and the group in general.

Cancer Council can help you with difficult issues, both before you tackle them and as a sounding board to debrief. It may be possible to link you with another support group leader so you can debrief with each other. Call the Helpline and ask to speak to local Cancer Council Support Group Program staff.

If you can't debrief with someone else, it's still important to take time for self reflection after each group. Ask yourself the debriefing questions and make some notes about what happened. You can also find a colleague who is able to listen to your concerns confidentially, if you need to talk about what's going on.

“The nurse unit manager of the chemotherapy unit was someone I could have a chat with if it got tough. She was also prepared to come to some meetings.”

Regional support group leader

Supervision

This is a more formal process where you meet regularly with a trained supervisor to explore issues in the group.

Supervision can help you find ways to deal with issues as they occur and can help steer the group in a meaningful way, but not everyone is able to access a supervisor. In most cases, you have to pay to have supervision, but if you can't, there may be other options:

- You can ask a health professional in your area, such as a nurse, to meet with you. Although this person probably won't be a professional supervisor, it may be helpful to talk to them about what's going on.
- Some Cancer Councils have programs that provide opportunities for professional development and support – contact the Helpline on 13 11 20 for information.

Managing the impact of burnout



Try to be aware of your feelings. Recognise the symptoms of burnout.



Call the Helpline or talk to a health professional you trust. Always debrief after meetings.



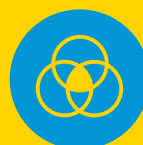
Get more support from your colleagues. Reduce your workload in the group.



Lower your expectations of yourself and group members.



Let yourself enjoy life – take some time out from the group and have a holiday.



Use your belief system for support, i.e. religious or philosophical beliefs.



Use relaxation/meditation and positive self-talk.



Make time for rest, recreation and exercise.

Rewards of leading a group

Although there can be problems and challenges when running a support group, the rewards outweigh the problems for many group leaders.

Support group leaders say the many rewards include:

- seeing the change in people – from the initial shock and distress of diagnosis to becoming empowered and supported and feeling more in control of their lives
- learning more about themselves and new skills through the leadership role
- giving back to the community and providing awareness about health issues
- meeting new people and sharing their stories.

The quotes from support group leaders on page 71 demonstrate the many benefits of running a group.

Troubleshooting or stepping away

Leading a support group isn't always easy. There can be challenging situations that come up – see the following chapter for information and suggestions.

Some group leaders find they don't enjoy the planning, paperwork and

record keeping. Others find the energy and focus required during the meetings can be exhausting.

If your personal circumstances have changed, it may be time to consider leaving the leadership role. See page 59 for information.

7

Dealing with challenging situations

Introduction

As a support group develops, there can be difficulties dealing with a number of issues, such as:

- dealing with personality differences
- accommodating non-English speakers or people who are physically disabled
- debate over controversial topics
- group members getting sicker and dying.

These issues can be stressful for both group leaders and members, and they can disrupt meetings. This chapter deals with challenges that may come up in the group and offers suggestions about how to deal with them.





Someone who dominates the group

There may be a person in the group who takes over. They might seek attention and overshadow everyone else by:

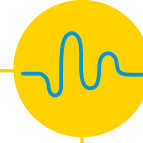
- always having the ‘worst’ problems or being in crisis
- constantly talking, filling silences
- being a know-it-all and ‘knowing’ the problems of another group member (e.g. “I’m like that too”)
- giving advice and using “you should” statements
- behaving aggressively.

People don’t always mean to act this way, and they might be unaware of how their behaviour affects the group. However, their behaviour may cause the other members to hold back their ideas.

Actions

- At the start of the group, remind everyone about the group agreement. For example, there may be a rule about not talking over one another.
- Avoid discouraging the excessive talker; encourage others to talk more and manage personal participation.
- Go around the group, giving each person a chance to talk (perhaps for an agreed amount of time).
- Divide the group into pairs to share ideas, then ask each pair to summarise the other person’s comments.
- Acknowledge a comment, even if it’s not appropriate or helpful, then quickly involve others: “Jim, that was an interesting comment. Barbara, what are your views?”
- If the person is dominating too much, limit eye contact and don’t respond to unhelpful comments. Move on to the next person.
- In a difficult case, change the group agreement (for example, set a time limit on speaking).

“Usually the other group members will help put the lid on anyone who takes over.”  *Metropolitan prostate cancer support group*



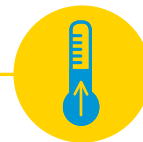
Someone who is angry or disruptive

Anger is a natural emotion when discussing a cancer experience, and it shouldn't always be thought of as a problem. People may be angry at the cancer itself, their doctors, their treatment, their side effects, or at the pain and suffering of their loved ones. The support group could be the person's only chance to express their anger in a non-judgmental place.

Anger can be frightening if it's directed at the group or at you personally, as the leader. However, it's usually not necessary to intervene unless the person doesn't cool off, if they become hostile or verbally abusive, or if they direct their anger at another group member.

Actions

- Clarify the issue. What exactly is the person angry about?
- Ensure the person feels supported. Talking to the person one-on-one during a break may help.
- Keep discussion focused and allow people to finish statements. Encourage "I" statements and active listening. Refer to the group agreement, if necessary.
- Ask the rest of the group if they also get angry and how they deal with it. Hearing how someone else faced a similar situation might be helpful.
- Take a short break to allow the angry person time to cool off.
- End the meeting with an open discussion. Wrapping up this way gives members a chance to have a 'last word' about the meeting.



Someone who annoys you

At times, certain people's behaviour or comments will be annoying. It can be frustrating to have someone in the group who pushes your buttons.

It might help to do some self reflection about the personality traits and behaviours that irk you. Sometimes taking a step back and thinking about it can help calm you down when you encounter this type of person.

“ I’ve had few occasions when I’ve felt my buttons were being pushed. When it happens, I try to make a point of talking to the person during the socialising time to help me to overcome my own prejudices. ”

Metropolitan prostate cancer support group

Actions

- Monitor your reactions to people who annoy you. Group leaders have to be understanding and polite to everyone, not just those they like.
- Ask your co-leader or trained facilitator to deal with the person. Talk about it during your debrief and work on strategies together.
- Pay attention to how others in the group respond. If someone is trying to dominate the group, other members will expect you to deal with it or they will remind them about the group agreement to keep the group on track.
- Acknowledge that nobody is perfect. You may sometimes need to apologise for what you’ve said or how you’ve said it. Say you’re sorry, then move on.

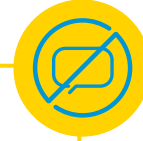


Someone who cries

Talking about cancer is an emotional experience and there will be tears at times. For some people, the group may be the first time they have felt comfortable enough to cry or have given themselves permission to do so. Tears are a healthy expression of emotion so they should be allowed to flow.

Actions

- Make it clear to group members that it’s okay to cry during a support group meeting.
- Always have a box of tissues visible.
- Acknowledge the emotion being expressed without singling out the person. Group members may rush over with a box of tissues or a comforting arm around the member’s shoulders. Although their intentions are good, this may be an unintentional signal for the person to stop crying. A better response is to give them time to cry and ask if they want a tissue.
- Talk with the person quietly, either in group or during a break, and ask what they would like to happen.
- If the person cries a lot or becomes disruptive, explore if they may need other support outside the group.



Someone who doesn't talk


Not all group members will talk as much as each other. Some people will be shy about sharing their feelings or opening up.

This may be a problem if other people in the group start to feel resentful about sharing, or if there are several silent members in the group and not much conversation.

It can be easy to ignore silent members. People might not contribute because they don't like to interrupt, or they might feel shy or worry that they don't have anything worthwhile to say. Be aware of non-verbal cues that show the person is interested – for instance, a person may nod in agreement.

Actions

- Use an alternative format, such as breaking into smaller groups to share ideas. In this setting, a quiet person might be more comfortable to talk freely. A spokesperson from each group can report back.
- Draw the silent member into the discussion by asking questions related to their areas of expertise and interest. Be careful not to spotlight people and be mindful of their right not to speak.
- Reassure the person that they aren't the only one who feels vulnerable.
- Encourage a more active person to gently draw the quiet person out of their shell during group.
- Before a meeting or during a break, check in with the silent group member. Find out if they would like to talk more and how they can be supported. Ask if there is anything in particular they were hoping to discuss. The person may be happy with their level of participation.
- If someone is usually chatty and then becomes silent, it could be a concern. You may want to talk to the person one on one to see what has changed for them.

“As a facilitator I'm mindful to let everyone speak, but I don't push those who feel uncomfortable. I check in with them after the meeting.”  *Metropolitan prostate cancer support group*



Non-English speaking members

Some of the members may not speak English or may not speak it well. Some may understand English but feel uncomfortable when speaking it, and may be limited to listening to the conversations without being able to actively participate.

Actions

- Call the Helpline to see if there is a support group specifically for people from different cultural or linguistic backgrounds. The person may want to attend that group instead.
- If the group is open to family and friends, ask that someone accompany the person with cancer to the meetings to translate.
- Be patient with people who have heavy accents or have difficulty expressing themselves. Don't rush them or attempt to put words in their mouths. Speak slowly and be patient, and don't talk to them loudly.
- After the meeting, ask if the person needs more information. Cancer Council may be able to provide resources in other languages.



Group members with physical disabilities

Some group members may have physical problems – for example, they may have problems with mobility, vision or hearing. It's important to be able to cater for their needs.

Actions

- Ask the group members to tell you about any special needs so you can accommodate them. For example, if someone is vision impaired, you may want to print materials in a larger font size.
- Set aside a few chairs near the doors for people who need to get to the bathroom frequently or urgently.
- Rearrange furniture to make room for wheelchairs or walking frames.



Controversial topics

It is common for support groups to talk about controversial topics from time to time. Some topics can cause lively discussion or debate. This may include complementary or alternative therapies, new treatments, positive imagery or positive thinking, faith and religion.

Everyone has a right to their own opinion – it's the leader and trained facilitator's job to keep their opinions private and keep discussions on track.

Actions

- If the discussion becomes too intense, or if it gets the group off track, refer back to the group agreement.
- Ask if anyone has personal experience with the topic – sometimes it's helpful to have input from someone who has been through it.
- Acknowledge how challenging it is to think about these issues and talk about them. Some people may never be on the same page, and it's okay to have different opinions about issues.
- If someone is misinformed, refer the person to the group's Resources Library, if there is one. You may also be able to invite a health professional to come in to discuss the topic or tell someone to call the Helpline on 13 11 20.
- Keep up with your own self care through debriefing and supervision – it can be very draining to facilitate controversial discussions (see page 43).

Complementary and alternative therapies

Complementary therapies, such as meditation, massage and acupuncture, are used along with conventional treatments, such as chemotherapy. This is called integrative medicine.

Alternative therapies are used instead of conventional treatment, and can be harmful.

It can be an exciting decision to try one of these therapies, so it's important that

the group member feels able to talk openly about their choice.

Cancer Council supports evidence-based treatments, which may include some complementary therapies. Anyone using a complementary or alternative therapy should be encouraged to involve their medical team. Even complementary therapies can sometimes interfere with conventional treatment. For more information, call the Helpline.



Dealing with disease progression

Support groups are likely to include a mix of people at various stages of their illness. A member who has been newly diagnosed may be sitting opposite someone whose cancer has recurred or is advanced. Their needs will probably be very different.

People who have just been diagnosed may find it difficult to deal with the possibility of death and simply want basic information on cancer and coping skills. It can be particularly challenging in a group where most people are well and one member's cancer recurs.

People with advanced disease may feel unwelcome at meetings because they believe that others don't want to face the potential of death. They may feel conscious of making others uncomfortable.

Actions

- Acknowledge that people in the group have different needs and that all needs are valid.
- Try to avoid separating people with advanced disease into a different group. You may occasionally break people into subgroups for discussion.
- Try to choose speakers to talk about topics that cover diagnosis through to palliative care.
- Let people know they can talk to you (or the trained facilitator) after the meeting, if you are worried about how they are coping.
- Review the group purpose to ensure that it's addressing the needs of the group members. If not, consider changing it or dividing into two groups.
- Organise a guest speaker to make a presentation about fear of recurrence and advanced disease.

“What do you do when two people have the same disease and one person is becoming sicker and one person is getting better? When a group member goes to the next stage, it affects the way people feel about their own survivorship.”

Rural cancer support group



Being aware of suicide

Although suicide is rarely an issue in a cancer support group, it's important to know what you can do if you think a group member may be at risk of suicide.

If during the meeting, someone says something or does something that leads you to believe their life is at risk, the most important thing is to take this situation seriously and act straightaway. Taking action may be frightening, but it can save someone's life.

Talking about suicide doesn't increase a person's risk of suicide or put ideas into their head. In fact, it's important to let the person know that it is okay to talk about suicide and to get help.

Actions⁽³⁾

- Let your co-leader or facilitator take over the group if you need to take someone who is distressed somewhere quiet and out of earshot.
- The best approach is to ask the person directly: "Are you having thoughts of suicide?" or "Are you thinking about killing yourself?"
- Encourage the person to talk, and listen to them without judgment or advice. Take the person seriously – don't deny their feelings. People often feel relieved when they are able to talk about suicidal thoughts.
- Do not attempt to counsel the person – refer the matter to appropriately qualified personnel as soon as possible.
- You or the person who is distressed can call Lifeline (13 11 14) for support. Lifeline is a 24-hour suicide and crisis prevention service.
- When the crisis has passed, it's important to look after your own wellbeing through debriefing and/or supervision.

Seeking qualified help in an emergency

If a person is suicidal during group, make sure that someone stays with them during the immediate crisis. Tell the person that you need to make sure they are okay, and you are going to seek help. If the person's life is in immediate danger, dial **000** for emergency services. You may feel unsure or nervous about calling, but the staff members are trained to deal with these situations.



When a member dies

Most groups have to deal with the death of a group member at some stage. It is complex, difficult and distressing when a member dies. People in support groups often become close, and the loss of a member can be deeply felt.

The death of a member is one of the hardest issues for group leaders, who have to acknowledge the loss while minimising the impact on the rest of the group – all the while dealing with their own grief.

If a bereavement counsellor is a guest speaker during the year (not when someone has died), it shows that death is an important issue. The session will also allow the group to talk openly about dealing with the death of a member.

Actions

- Deal openly with a group member's death. What the group does after a person dies is highly symbolic.
- At the first meeting after someone has died, announce the death and spend a moment or two remembering what made that person special. People may find it easier to talk more openly if everyone acknowledges how difficult it is.
- Group members can share what the person who died meant to them and what they felt they gave to the person. If people don't want to share this, don't push them to talk. It may be a good prompt for personal reflection.
- Some groups prefer to contact members when the person dies, via a phone call, so no one is surprised at the next meeting. This also allows people to plan to attend the funeral or memorial service, if appropriate.
- After paying tribute to the person, take a break and come back together to continue the group. This way the topic of death doesn't dominate the whole meeting.
- Some Cancer Councils provide workshops for support group leaders on grief, loss and change. Contact your local office to ask what is available.

Memories and tributes

There are many ways to remember people and their contribution to the group:

- Group funds can be used to send flowers or a card to the person's family.
- You can write a note to the family and ask if anyone else in the group would like to include their thoughts or wishes.
- If you have a newsletter, you can include an article about the person in the next edition.
- Plant a tree or flower in a local public garden.

8

Adapting to changes and closing a group

Introduction

Over time, there will be changes to the leadership and membership of the support group. Different members may have different ideas about what the group purpose should be. A group purpose doesn't need to be permanently fixed – many groups change purpose at some point.

If you don't want to lead the group anymore and no one else will take a leadership role, the group may be forced to close. In other cases, the group may no longer be needed. Attendance may wane or members may feel that they no longer need the group.

This chapter covers some of these issues, including how to close a support group.





Changing priorities

Some members might think the group should move in a different direction. For example, some people may want to focus more on advocacy or fundraising and less on information and support.

Organising a yearly evaluation can help determine group members' needs and views – see the template on pages 62–63.

If everyone's needs aren't being met, consider:

- reviewing the group purpose and format (e.g. providing either more or less time for personal sharing or making the group less formally structured)
- refreshing or changing the list of upcoming topics and speakers
- asking members if they want to be on the working party, or offering working party members a chance to swap roles or stop being involved
- forming a subgroup that works on a specific issue, leaving the main group to focus on other topics.

Fluctuating numbers

Groups often go through cycles – sometimes there may be several keen members or a lot of interest from new people, but at other times membership may wane. At times, you may wonder whether the group can carry on.

If numbers are low, it could be a sign of general dissatisfaction with the group. It may also mean that people can't come because of the timing or location of meetings, or that they no longer need the support group. Look for the source of the problem: call a few group members and take a close look at the evaluation results. A few format changes may bring people back to group meetings.

If numbers stay low, it may be that low attendance is part of the natural cycle of the group.

If most people no longer need the support group, the group has done its job for the current group of people. The working party may consider recruiting new people or closing the group.

“Our numbers often see-saw from high to low and back again. While it's not a huge problem, we just have to ride out those times when we have low numbers and sometimes that can be hard.” *Rural cancer support group*

Kylie's story (SA)

I led a gynaecological cancer support group with about six members, and two women died in a short period of time.

After losing those members, the group lost its energy, and the remaining women found it difficult to attend the meetings. They never said, "we're not coming", but they just stopped responding and turning up.

Over a few months, we tried a few different approaches. We moved the meetings to a

different venue. We suggested the meetings change in structure and become more informal. There was still no response.

Personally, I found this hard. I wondered if I'd done everything I should have or if I did something wrong.

However, one woman has started coming along to a different women's support group in our area, so I think that she's still interested. I am hoping she finds a fit with this new group.

Changes in leadership

Leadership can change over time – in fact, these changes can be helpful.

It can help to ensure that:

- no one person (e.g. the group leader) becomes overwhelmed with responsibilities or burns out
- other members get to be involved, especially those who might not do so ordinarily – this may be through a working party
- new ideas keep the support group fresh.

Planning a change

You might identify someone within the group who seems to have leadership qualities or is keen to fill a leadership role in the future. You can offer the person the opportunity to try out co-leading a meeting or two to see what is involved. You may also be able to mentor them.

Although this kind of planning may help someone slot into the leader role, it's not necessarily up to the existing group leader to determine the next leader. The working party will also discuss this issue and, with the outgoing leader, plan for the future.

The working party could approach health professionals who have been involved with the group to see whether they know someone who might be able to take on the role.

“Over time, membership of a support group evolves. Groups have life cycles. I think it's important that a leader recognises when the group needs to close.”

Regional support group leader

If a support group is closing, the leader, trained facilitator or working party should contact the Cancer Council to have this recorded on its state or territory database.



“Some members gradually stopped coming to meetings. I think after a while, they suddenly decided that they were no longer a ‘victim’ of cancer. They did not want to talk about it anymore. And that’s fine.”

Regional support group leader

Closing a support group

At times support groups run their course and need to close. If people no longer need the group, think of it as a success and job well done.

There are steps to follow so the group ends efficiently and with the least amount of disruption:

- If some people are still interested in being in a support group, help them find a new one, or put them in touch with the Cancer Council Helpline 13 11 20. They might like to join Cancer Council’s online community, www.cancerconnections.com.au, or a telephone support group.
- Write a letter or create a final newsletter describing when and why the support group is folding and thanking people for their involvement. Ensure it is also sent to local health professionals and anyone who has made donations to the group.
- Put up notices in treatment centres and send one to the local paper announcing the closing of the group so that people don’t show up for meetings.
- Destroy all records and information except (in rare cases) if there is an obligation to securely store information for a period of time.
- Make sure all outstanding accounts have been paid before closing the group bank accounts. Any money left in the account can be donated to an appropriate cancer-related charity or another community group. An accountant can give you advice about any other action you need to finalise the group’s financial affairs.
- Have a final meeting and farewell party for closure. Celebrate the group’s achievements and thank everyone involved.

9

Useful templates and examples

Introduction

This chapter has an example of a group evaluation form. You may want to photocopy these pages. However, not all questions will be relevant to every support group, so you can also use this evaluation as a starting point for your own questionnaire.

There are also examples of promotional materials, such as flyers and media releases, and radio and TV announcements.



Annual evaluation

To ensure the support group is best meeting your needs, we would like your impressions on how well we're functioning and how we can improve in the future. Please take a few minutes to answer the questions. This is an anonymous survey and your answers will be kept confidential.

1. When did you start attending the support group (month & year)? _____
2. Describe the time that you first joined the support group.
 - ☐ when I was recently diagnosed (within 6 months)
 - ☐ when my family/friend was diagnosed (within 6 months)
 - ☐ during my treatment
 - ☐ during my family/friend's treatment period
 - ☐ shortly after I finished treatment (within a year)
 - ☐ shortly after my family/friend finished treatment (within a year)
 - ☐ a year or more after I finished treatment
 - ☐ a year or more after my family/friend finished treatment
 - ☐ other (please describe) _____
3. How did you find out about the group?
 - ☐ health professional ☐ Cancer Council Helpline 13 11 20
 - ☐ family member/friend ☐ other (please specify) _____
4. How old are you?
 - ☐ 20–29 or younger ☐ 40–49 ☐ 60–69 ☐ 80 or older
 - ☐ 30–39 ☐ 50–59 ☐ 70–79
5. How often do you attend the support group meetings?
 - ☐ every month ☐ a few times a year ☐ only one meeting
6. Which of these factors determine whether or not you come to a meeting? (check all that apply)
 - ☐ topic ☐ timing ☐ speaker ☐ my health
 - ☐ other (please specify) _____
7. How would you rate the length of the meetings?
 - ☐ just right ☐ too short ☐ too long
8. How would you change the structure of the meetings if you could?

9. How well do you feel the support group is meeting your needs?
 - ☐ quite well ☐ not well enough ☐ well enough ☐ not at all
10. Tell us how the group could better meet your needs. Please be as specific as possible.

11. How satisfied have you been with the guest speakers this year?

- ☐ extremely satisfied ☐ satisfied ☐ dissatisfied ☐ extremely dissatisfied

12. How would you rate the breakdown of time spent with speakers and time spent in general sharing?

- ☐ just right ☐ more time with speaker ☐ more time in discussion

13. Should we have speakers at every meeting?

- ☐ yes ☐ no, we should only have speakers at _____ meetings a year

14. On what topics would you like to have speakers next year?

- | | |
|-------------------------------------------------------|--------------------------------------------------------------|
| <input type="checkbox"/> medical issues | <input type="checkbox"/> complementary therapies |
| <input type="checkbox"/> services/resources | <input type="checkbox"/> media reports about new discoveries |
| <input type="checkbox"/> coping strategies | <input type="checkbox"/> diet/nutrition |
| <input type="checkbox"/> treatments and side effects | <input type="checkbox"/> relationship/sexuality issues |
| <input type="checkbox"/> other (please specify) _____ | |

15. What topics would you like to see addressed in group discussions next year?

16. How satisfied have you been with the group's leadership?

Group leader:

- ☐ extremely satisfied ☐ satisfied ☐ dissatisfied ☐ extremely dissatisfied

Trained group facilitator:

- ☐ extremely satisfied ☐ satisfied ☐ dissatisfied ☐ extremely dissatisfied

Comments:

17. Please tell us how attending the support group has helped you.

18. Do you have any final comments or suggestions for how to improve the group?

Thank you for filling out this evaluation. We will report back on the results at the next meeting.

Sample flyer promoting an information session

Community Cancer Information Evening

Have you or your family been affected by a diagnosis of cancer?
Are you currently having cancer treatment?
Have you finished your cancer treatment and feel
that your life has a 'new normal'?

You're invited to attend an information session for people affected by cancer.

Date: Thursday 4 November

Time: 7pm for 7.30pm start, finish by 9.30pm

Venue: Garden City Library – located in the Garden City Shopping Centre,
corner Logan and Kessels Roads, Upper Mt Gravatt

Parking: Free in the car park

A small group of community members, led by a local doctor and Cancer Council staff, would like to find others who may be interested in joining a local cancer support group. Come along to hear:

- Visiting medical oncologist Dr George Vardolos speak about the latest developments in cancer treatments.
- Regional oncology nurse Karen Stewart present on the side affects and management of cancer treatments.
- Cancer Council staff member Jane Kelly talk about Cancer Council services available to our town.
- The leader of the working party, Bryan Chung, give an overview of the group's purpose.

There will also be open discussion and a chance to ask questions about the proposed support group.

Supper will be provided, so please register your interest and RSVP for catering purposes. Contact Bryan Chung on (07) 0000 0000 by 1 November.

Sample invitation to promote support group meetings

The Sunbury Bowel Cancer Support Group

Do you live in the Sunbury area?
Have you been diagnosed with bowel cancer,
or are you currently having treatment for bowel cancer?
Have you finished bowel cancer treatment and feel
life is not the same?

Then this group could be for you.

The Sunbury Bowel Cancer Support Group is a community-based group for men and women who have been diagnosed with bowel cancer. It's an open group providing information and support.

When: First Wednesday of each month

Time: 2–4pm

Where: A local venue in Sunbury – contact us for information

Cost: Gold coin donation to cover tea and biscuits

We regularly invite guest speakers to talk on topics like diet and exercise, relaxation and meditation and understanding cancer, and we have discussions about cancer-related issues.

The group is led by a member of the community who has had an experience of bowel cancer, and it's co-facilitated by an oncology nurse.

For more information and to see whether the group is right for you, please contact Gavin Brown on 0400 000 000.



Media release

Heading or subject line

Write a short and compelling sentence that introduces a story about the cancer support group. You may be announcing a new group, advertising for new members or promoting something the group has achieved. You could also use a startling statistic as your heading to draw in the journalist.

News release date and timing (e.g. immediate release)

When was the information sent to the journalist and when is it available for use? It's easiest for journalists if they can use the news release immediately.

Name

Mention the support group's name.

Opening sentence

The first paragraph is the most important – it should 'grab' journalists and give them the relevant details, including what happened, where it took place, why it occurred, etc. Journalists receive many media releases, so they may not read beyond the lead paragraph.

Further details

Give more information about the story, keeping the most important things at the top. You might want to include some quotes that the journalist can use.

Closing

Finish the copy off with "Ends".

Contact details

Add a name, email address and phone number for further reference.

Local cancer support groups provide support to 50 men with prostate cancer

Date: 15 March 2013

North Adelaide Prostate Cancer Support Group

Prostate cancer is the most common male cancer, with 18,500 Australians diagnosed each year. For the past two years, the North Adelaide Prostate Cancer Support Group has been the only prostate cancer-specific group in North Adelaide, and it's provided a safe, supportive place for men affected by this disease. The group, established in March 2008, reached its fiftieth member in March 2013.

The support group was founded by Ken Lao, who was diagnosed with cancer in January 2007 at the age of 57. "Like many men, cancer came as a complete shock to the system," Ken says. "The prostate is part of my body I never gave a second thought to, but after I was diagnosed, it was all I thought about."

Ken had surgery to remove his prostate (radical prostatectomy). After his recovery, he started the support group as a way to connect with other men and talk about cancer, treatment and ongoing side effects. "It was embarrassing, but I knew I wasn't the only one going through it," Ken says. "Talking can really help."

The group started with four members meeting once per month. It slowly and steadily grew, and there have now been 50 men who have attended one or more groups.

"I feel like the group has become really valuable to South Australian men affected by this disease, and being involved in the group is so rewarding," Ken says. "We are always happy to welcome men to group."

For information about the North Adelaide Prostate Cancer Support Group, contact Mr Lao on (08) 0000 0000 or go to www.napcsg.com.au.

Ends

Sample radio or television announcement

Radio announcement

The best way to promote a support group on the radio is to prepare a brief script that the local radio announcers can read when they have space in their program. This is called a radio read. An example of a radio read is below – you can adapt it to suit the group.

Attention: radio announcers

Please mention the message below if you have space in your program:
“Unfortunately one in three people in our community will get cancer in their lifetime. However, there is no need to go through it alone.

A new support group is available for people who have been diagnosed with cancer so they can talk to others who are going through a similar experience.

Talking about cancer can really reduce the burden – you may find out ways to deal with treatment or meet new friends who understand exactly what you’re going through.

Call the local cancer support group on (02) 0000 0000 now. It has helped others in your community and it can help you too.”

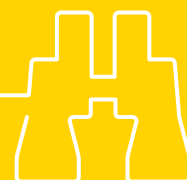
If you need more information or you would like an interview, please call Judi Martin on (02) 0000 0000.

Television announcement

In some areas there are also opportunities for free community announcements on regional television. Contact the television channel manager to ask about this.

10

Where to find more information



Recommended reading



These books and resources may be available from Cancer Council's library (available in some states and territories), or on the Cancer Australia website (www.canceraustralia.gov.au).

Cancer Support Groups: A guide to setting up peer facilitated supports

Cancer Australia, 2009

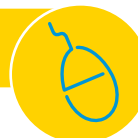
Cancer Support Groups: A guide for peer facilitators

Cancer Australia, 2009

Effective Support Groups: How to plan, design, facilitate and enjoy them

James E. Miller
Willowgreen Publishing, 1998

Websites



The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of reliable information.

Cancer Council Australia.....	www.cancer.org.au
Cancer Australia.....	www.canceraustralia.gov.au
Bereavement Care Centre.....	www.bereavementcare.com.au
National Association for Loss and Grief (NSW).....	www.nalag.org.au
beyondblue (National Depression Initiative).....	www.beyondblue.org.au
Cancer Voices Australia	www.cancervoicesaustralia.org
Canteen.....	www.canteen.org.au
Breast Cancer Network Australia.....	www.bcna.org.au
Gynaecological Cancer Society of Australia.....	www.gcsau.org
Gynaecological Cancer Support.....	www.gynaecancersupport.org.au
Palliative Care Australia.....	www.palliativecare.org.au
Prostate Cancer Foundation of Australia.....	www.prostate.org.au

References

- 1 Ussher, J., Butow, P., Wain, G., Hobbs, K., Smith, K., Stenlake, A., Kirsten, L., and Sandoval, M. *Research into the Relationship Between Type of Organisation and Effectiveness of Support Groups for People with Cancer and their Carers*, February 2005.
- 2 Ibid.
- 3 Adapted from: Kitchener, Betty Ann & Jorm, A. F., Orygen Research Centre 2006, *Mental health first aid manual*, Reprinted and amended January 2007, ORYGEN Research Centre, University of Melbourne, VIC.

“ I’ve learnt a lot about myself along the way and I’ve met some amazing women, so I think ‘privilege’ is probably the word that leaps to mind. ”

Regional support group for young women with breast cancer

“ Running the group has been extremely gratifying. I couldn’t imagine anybody being the leader of a support group who wasn’t motivated by the desire to help other people. ”

Metropolitan prostate cancer support group

“ The bit I really enjoy is the challenge. It’s challenged me to look at my own beliefs and at all the taboo things in our society. ”

Rural cancer support group

“ It’s given me the chance to watch people work their way from the dark place in the tunnel and then come to the light at the other side. ”

Metropolitan cancer support group

“ As a leader I hear people say, ‘This is the only place that I can really talk about my cancer and how I feel even years down the track’. When I hear this I know that what I do is so worthwhile. ”

Metropolitan support group for young women with breast cancer

How you can help

At Cancer Council we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls Night In and Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

Make a donation: Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

Buy Cancer Council sun protection products: Every purchase helps you prevent cancer and contribute financially to our goals.

Help us speak out for a cancer-smart community: We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.

Cancer Council Helpline 13 11 20

Cancer Council Helpline is a telephone information service provided throughout Australia for people affected by cancer.

For the cost of a local call (except from mobiles), you, your family, carers or friends can talk confidentially with oncology health professionals about any concerns you may have. Helpline consultants can send you information and put you in touch with services in your area. They can also assist with practical and emotional support.

You can call Cancer Council Helpline 13 11 20 from anywhere in Australia, Monday to Friday. If calling outside business hours, you can leave a message and your call will be returned the next business day.



Cancer Council websites

Cancer Council Australia
www.cancer.org.au

Cancer Council ACT
www.actcancer.org

Cancer Council Northern Territory
www.cancercouncilnt.com.au

Cancer Council NSW
www.cancercouncil.com.au

Cancer Council Queensland
www.cancerqld.org.au

Cancer Council SA
www.cancersa.org.au

Cancer Council Tasmania
www.cancertas.org.au

Cancer Council Victoria
www.cancervic.org.au

Cancer Council Western Australia
www.cancerwa.asn.au

For support and information on cancer and cancer-related issues, call Cancer Council Helpline. This is a confidential service.

The logo for the Cancer Council Helpline. It features a yellow stylized flower icon to the left of the text "Cancer Council Helpline" in white. Below this, the number "13 11 20" is displayed in a large, bold, white font. The entire logo is contained within a blue circle.

Cancer Council
Helpline
13 11 20