

# Cancer Support Groups

A guide to setting up  
and maintaining a group



For information & support, call

**13 11 20**

## **Cancer Support Groups**

A guide to setting up and maintaining a group

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The publication *Keeping Things on Track: A guide to managing challenging situations for leaders of cancer support groups* was used as source material, particularly for information in Chapter 7, *Facing challenges* (pages 45–53). Full references are listed on page 67.

## **Note to reader**

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

## **Cancer Council**

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit [cancer.org.au](http://cancer.org.au) or call your local Cancer Council.



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# Cancer Support Groups

Support groups connect people affected by cancer and help them manage the challenges they may face. They provide a place for people to give and receive emotional support and share information. Research shows that this kind of support has a positive impact on quality of life and emotional wellbeing.<sup>1</sup>

How you set up and coordinate a support group is up to you. 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 set up, run and maintain a support group
- promote a group to the community
- deal with challenges that may arise
- reinvigorate or close a flagging group.

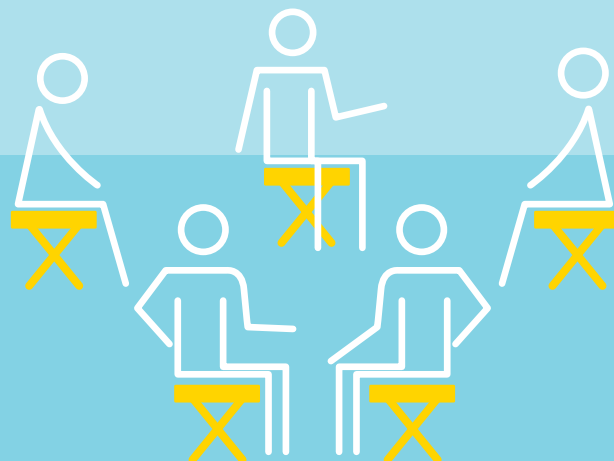
This publication has general information and guidelines – it doesn't cover all types of support groups, and not all the information will apply to your situation. For more specific details or to inquire about support group leader training, call your local Cancer Council on 13 11 20.

## Who this book is for

This book is for community members and health professionals who are interested in setting up and leading a cancer support group. It's also useful for leaders of established support groups who want to make improvements. You don't need any previous experience with support groups to benefit from the information, and the information is relevant to people anywhere in Australia.

## 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.



## How to use this book

Each chapter of this book explores a particular aspect of setting up and maintaining a cancer support group. You can choose to read the entire book from cover to cover, but you may only need to refer to particular chapters depending on your situation – for example, if you already lead a cancer support group, you may choose to skip the *Forming a group* chapter. However, some people may still find the book useful to review and compare how their current support group is working.

Throughout the book, you'll find colour-coded boxes that highlight particular kinds of content:



**Tips**



**Information**



**Personal story**

If you need help with any cancer-related issue, call Cancer Council 13 11 20.

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Key

# questions

Support groups offer people with cancer emotional support at a time when they may feel alone, vulnerable and frightened. This chapter includes information about what support groups are, how they are organised and run, why people join, and what keeps members coming back.



## Q: What is a support group?

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

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

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

### Being informed

As well as providing emotional support, groups can also help people 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:** 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. Research<sup>1</sup> shows that the main 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 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.

While support groups meet many people's needs, they aren't for everyone. Some people already have enough support, while others want to deal with the cancer privately or require specialised care, such as counselling.

## Q: Do support groups work?

**A:** A survey of 184 groups in NSW<sup>1</sup> found that cancer support groups are a powerful way to improve wellbeing and help people with cancer and their families by:

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

## **Q: How are support groups organised?**

**A:** Support groups vary in several ways, including how people meet, whether the group is open or closed, 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 face to face, some meet over the phone or online.

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 or remote area and be unable to travel to a meeting, or they may prefer to write about their feelings and opinions rather than talk. Sometimes people would like more privacy than a face-to-face group can provide.

Telephone support groups are often facilitated by trained health professionals, as there are added challenges to creating a safe and friendly space when people cannot see one another. Cancer Council delivers a national telephone support group program. Call 13 11 20 for details.

### **Types of groups**

There are two main types of support groups:

**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.

**Closed groups** – A closed group is when people meet for a set number of occasions. This type of group is usually run by a trained health professional for an educational or therapeutic purpose. New members are unable to join the group after the first meeting.

### **The group purpose**

An effective support group has a clear sense of purpose where people come together because they share something in common. A group might bring together people who share the experience of cancer at the same stage in life – for example, parents of children with cancer might form a support group. Other types of groups might be aimed at people who are interested in the benefits of exercise after cancer treatment, or at young people who have cancer.

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



## Online support groups

Cancer support groups are increasingly being set up online, particularly as closed Facebook groups. A closed group means that while anyone with a Facebook account can see the group's page, they're unable to see the content. Joining a closed Facebook group involves sending a request to the group administrator (admin).

Online support groups should consider the same issues as face-to-face groups, particularly the following:

**Confidentiality** – Online groups need to be particularly careful to preserve members' anonymity and to ensure their information

is not revealed to other members or people outside the group.

**Group purpose** – The group still needs a strong sense of purpose, preferably determined by the members.

**Member screening** – Group admins may need to develop a screening process to ensure the group meets the needs of potential new members.

**Sharing the workload** – The 24/7 nature of an online group means admins will need to determine how they share the responsibility of replying to members' posts.



## Leaders and facilitators

Some groups have a group leader and a group facilitator, while in other groups, the roles are held by the same person. In this book, the term group leader is used to describe the person (or people) who manages the group and facilitates meetings. What these roles are called and the tasks they are responsible for may differ in your support group.

## Q: Who runs the group?

**A:** You need different people to establish the support group, take care of administration tasks and facilitate each meeting.

**Group leader** – The group leader attends and manages each meeting and is responsible for maintaining the group. The group leader should have good listening skills, the ability to self-care (see page 42), some administration and computer skills, promotional skills and the passion to be involved with fellow community members. Support groups may have more than one leader, and some leaders may be called facilitators. See page 38 for some examples of group leader tasks.

Group leaders who wish to have their group recognised by their local Cancer Council and included in its support groups directory or database are required to undertake specialised training. For details, call 13 11 20 and ask to speak to cancer support group staff.

**Working party** – This group of people is responsible for tasks such as promotion and ongoing administration. The working party collaborates closely with the group leader.



### New group members

To ensure the support group meets the needs of potential members, the group leader should have a conversation with interested people before they attend their first meeting. See page 15 for more information.

## Q: How do people join a group?

**A:** A support group might have several founding members who are involved from the start. However, in most cases, newly formed groups have to recruit members. People in the community usually find out about a support group via:

- word of mouth (from other members, health professionals or Cancer Council 13 11 20)
- 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 page 34 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 offers a place for people to feel understood, supported, cared for and accepted.
- **Reduced isolation** – Group members develop a sense of community through shared feelings and experiences. People feel connected with other members, which can increase their ability to cope.
- **Empathy** – People outside a support group may not understand the experiences of people who have cancer, or they may dismiss their feelings. People within the group feel heard and understood.
- **A sense of safety** – 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, relax and feel at ease. Humour builds warmth in the group and helps members cope with confronting issues.



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## Forming a **support group**

The main steps involved in starting a new cancer support group include: researching existing support groups in the community; deciding who the group will be for; defining the group's purpose; establishing a working party; finding a group leader; and recruiting members.



### Ask around

Find out from local health professionals or people affected by cancer if they know of any existing support groups in the area. Cancer Council also has information on the location and types of established groups. Call **13 11 20**.

## Doing your research

It's important to find out about groups that already exist in your area. This will help to identify gaps and avoid duplication. For example, there may already be a general cancer support group in the community, so a group for people affected by a specific type of cancer may be beneficial. Or a health professional may be running a group that mainly provides information, so a group focusing on emotional support might be a useful addition to the local area.

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

## Considering who the group is for

Some questions need to be asked before a support group is established. The answers will form the basis of your group purpose (see page 12) by helping to clarify who the group is for and the type of support it will offer.

- Will the group be for people with any cancer or a specific cancer type?
- Will it be for newly diagnosed people, people with advanced cancer, or people at any stage?
- Is the group for people of a specific gender, all genders, or people who don't identify as a particular gender?
- Is it open to people with cancer, carers, or anyone affected by cancer?
- Is the group for a certain cultural, language or age group?

## Managing diversity within the group

Some members of the community may require a different level of support to help them feel included. Consider how the information in this book could be adapted so it is appropriate and relevant for their needs.

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

When people first join the group, ask them if they have 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.

Set aside a few chairs near the door for people who need to get to the bathroom frequently or urgently, and rearrange furniture to make room for wheelchairs or walking frames.

**Aboriginal and Torres Strait Islander people** – A culturally appropriate support group can provide a safe space for Aboriginal and Torres Strait Islander (ATSI) people affected by cancer to connect, share information and support one another. An effective and relevant way to provide cancer support might be to establish a Yarning Circle rather than a cancer support group. A Yarning Circle builds on the oral tradition of sharing stories, and it is an informal and relaxed way of gathering information.

It is important to consult and work in partnership with local Elders, community leaders, Aboriginal health professionals and the local Aboriginal health service. This will help to ensure that the needs of the local community are met, and cultural sensitivities are acknowledged and understood.

If you'd like to establish a more formal cancer support group for ATSI people, contact your local Aboriginal and Torres Strait Islander Registered Training Organisation or relevant training facility for information.

**People from CALD backgrounds** – People from CALD (culturally and linguistically diverse) backgrounds may not speak English or they may not speak it well. Some may understand English but feel uncomfortable speaking it, and they may be limited to listening to conversations without being able to actively participate. If the group is open to family and friends, ask that someone accompany the member to meetings to translate.

Be patient with people who have heavy accents or difficulty expressing themselves. Don't rush them or try to put words in their mouths. Speak clearly, and don't talk to them loudly.

Call Cancer Council 13 11 20 to find out if there is a support group in your area specifically for people from different cultural or linguistic backgrounds. The person may want to attend that group instead. Cancer Council may also be able to provide them with resources in their native language.

**“The meeting is open to all people with cancer and survivors, and 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 discuss their cancer journey with others in similar situations.”**

*Regional cancer support group*



### Examples of a group purpose

- “A monthly support and information evening for women aged 45–60 who have been diagnosed with gynaecological cancer.”
- “A group that provides support and friendship to people with breast cancer and their carers/partners.”
- “A monthly meeting that supports people affected by all cancers, including partners and carers.”

## Defining the group’s purpose

Every group needs a short, clearly written purpose. The purpose of the group may be to provide:

- up-to-date evidence-based information about cancer
- social support
- emotional support for people who are caring for someone with cancer.

A well-defined group purpose will make the group easier to plan and run, and provide a clear idea of what the group is trying to achieve. It will also help in the writing of a group agreement, which is a simple list of rules to help the group stay on track and be a safe place for members. For more information about group agreements, see page 28.

## Working together

It’s often better when a few people work together to establish a support group and share the responsibilities (working party). Even the most skilled and committed people can burn out quickly if they work alone.

Some people like to keep their roles very informal and take on various jobs as they come up. Others want to be more formal by assigning roles within a working party (see below for a list of suggested roles). This can help to match the right people to the right tasks.

## Working party roles and responsibilities



### Chairperson

Runs the working party meetings.



### Secretary

Manages paperwork and takes working party meeting minutes if required.



### Treasurer

Keeps track of incoming money, pays bills and keeps accurate books.



### Group Leader

Organises and/or leads each support group meeting.

If you opt for a working party, you should discuss the roles and agree on the best person for each role at the outset. If two people want the same role, they can share it or agree to switch later. It's a good idea to review roles regularly.

It's important to take minutes or notes of each working party meeting and write an action list. This ensures there is a record of each meeting, and it clearly provides direction and understanding for everyone who has a task to complete.

### Finding people to join a working party

Gathering a group of interested people will bring together a range of skills and talents, 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, and people from other interested community or professional groups. Where possible, it may be beneficial to include a staff member from your local health service or Cancer Council, or another cancer organisation.

If you're finding it difficult to form a working party or to encourage people to help you with the formation and subsequent running of a group, consider whether you'll be able to manage the responsibilities of setting up and running a group on your own in the long term.



#### Catering Officer

Organises food and drinks for each group meeting.



#### Resources Officer

Collects and manages printed and online cancer information.



#### Membership Officer

Helps to recruit members and maintains the membership database.



#### Promotions Officer

Promotes the group through the media, flyers, emails and newsletters.



### Good timing

Leading a support group can be demanding. Cancer Council recommends that potential leaders have recovered physically and emotionally from their own cancer experience and treatment. We suggest you wait at least 18 months to two years, when your energy levels have improved and you are more able to emotionally support others.

## 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.

Think about how leadership can be shared. It's often best to have two leaders to share the load. This also makes it less likely that leaders will burn out (see pages 41–43).

The leader provides a vital role in the group, so it's important to choose carefully and ensure the person is suitable for the role. For further information about characteristics of effective leaders, see the *Being a group leader* chapter on pages 37–44.

It's also important to consider how leadership can change over time. These changes can benefit the group in many ways. For more information, see *Changes in leadership* on page 56.

Group leaders will need to undertake Cancer Council training for the group to receive specific Cancer Council support. Call 13 11 20 for details.

## Finding people to join

One way to let people know about a new support group is to hold a public information session. You can advertise this session in various ways, such as with printed flyers – see the example on page 59.

Where possible, try to involve your local Cancer Council and/or a local health professional in organising and running the information session.

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 – for example, exercising after cancer treatment – and outline how joining the group might help to address that issue
- give an overview of how the group works – or will work – and its purpose (see page 12)
- ask for expressions of interest.

If someone is keen to join or help start the group, organise a convenient time to contact them within the following few days.





## Following up with people who are interested

When someone is interested in joining the group, it's important to chat briefly with them by phone before the first meeting to find out whether they are suitable. This will help to ensure that:

- the group's purpose meets the person's needs, expectations and interests
- it's the right time for the person to join a support group, e.g. it may not be appropriate for someone to join soon after diagnosis or during treatment.

Explain to the person how the group will operate (e.g. the first hour is for group discussion, and the second hour features a guest speaker), and the age range and experiences of other potential members.

Consider this conversation as a two-way process: the potential member also needs to find out what is expected of them, and they might need more information before making a final decision about joining.

If it sounds like the person is suitable, you can ask them if they would like to attend a meeting. Take down their contact details, such as their email address, postal address and phone number. It's important to keep all contact details private and confidential – see page 20 for information about storing people's personal details.

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 13 11 20 for information about other types of support they could access, such as counselling.

### Cancer Council support

Call **13 11 20** to ask whether your local Cancer Council is able to provide contacts, advice and support during the formation of a new support group.

### Questions to ask potential group members

- What is your name?
- How old are you? (optional)
- What is your experience of cancer, e.g. do you have cancer, are you a cancer survivor or are you a carer of someone with cancer?
- If you have cancer, what type do you have?
- Do you have any specific dietary or physical needs?
- Do you feel ready and comfortable to 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, emotional support, treatment information)?
- What are your main topics of interest? (Answers can provide ideas for guest speakers.)



## **Wayne's story:** Penile Cancer and Melanoma Awareness Facebook Group

*I'm a group administrator (admin), which means I respond to requests from people wanting to join the group.*

*The group is a place for people to chat, get support and ask questions. There are about 60 members from different countries, mostly the UK, the US, Canada and Australia.*

### **How did you find out about the group?**

*When I was first diagnosed with penile cancer, I was lost for a while. I searched online and there seemed to be no support, awareness or information about penile cancer. I came across this group by pure chance.*

### **How do people join the group?**

*It's a closed Facebook group, so people have to request to join.*

*As an admin, I'll receive a Facebook notification telling me that someone has requested to join the group. I'll message that person asking them why they have an interest in the group, and what they hope to get out of it.*

### **How and why did you become a group admin?**

*I stepped up to help run the group when the man who started it died. I stand out and I'm vocal. I want to get the subject of penile cancer out there. I want people to know about it.*

### **How does the group work?**

*We don't meet, we don't get together face to face, but we talk all the time online. We're universally linked by the group 24 hours a day, seven days a week, so if someone has a question or a concern, there'll always be one person around to offer that support.*

*Some members prefer to stay in the background. For them, the group's there in case they need it. They don't say a great deal, but they might post questions every now and again. There are other members who get stuck in and are pretty vocal.*

*Two of our members are nurses – one works with men with penile cancer, and the other guy is a lymphoedema nurse. They can answer the questions that other members can't answer. It's good to have them involved.*

### **What do you get out of the support group?**

*When I was first diagnosed, I felt like I was the only person with penile cancer. The main benefit of the group for me is knowing that I'm not alone. It's a place to get support and companionship.*



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# Administration issues

There are several practical business issues to sort out so the group can function efficiently and according to any relevant state or territory regulations. The information in this chapter is a general guide only. Cancer Council recommends that the group leader or a member of the working party seek financial and legal advice.



## Alternatives to fundraising

Some groups raise funds to support the running of the group. If you'd prefer not to fundraise, you can cut back on costs by:

- asking a local organisation to donate a venue (e.g. council, school, hospital or treatment centre)
- meeting informally (e.g. in a cafe) so group members pay for their own food and drinks
- charging members a small fee (e.g. a gold coin donation) to attend each meeting to cover venue hire and refreshments
- organising a roster for members to provide morning or afternoon tea
- asking local businesses to donate postage, printing, photocopying and so on to help you produce a newsletter or promotional materials for the group.

## Mailing address

A support group needs a mailing address for correspondence. Unless the group is affiliated with a hospital, treatment centre or cancer organisation, or has its own office, a private post office box or the address of a member is generally appropriate. A post office box is best for consistency and privacy, but the rental fee will need to be taken into account. A member of the working party may also like to create a shared email account for correspondence.

## Fundraising, ABN and tax

Running a support group can raise some complex issues around fundraising, registering as a business, and tax. It's important to consider whether the paperwork that might be required for these processes is worth the time and effort.

### Fundraising

Many groups want to raise money and seek donations from the community. Each state or territory has its own regulations about fundraising. You can visit [fundingcentre.com.au/help/fundraising-legislation](http://fundingcentre.com.au/help/fundraising-legislation) for information about fundraising legislation in your state or territory.

For support groups that wish to be recognised by their local Cancer Council, call 13 11 20 to check whether there is a policy relating to groups undertaking fundraising activities. There may be government grants or funding you could apply for instead.

### ABN and tax

It's advisable to talk to a solicitor and/or an accountant about whether you need to register as a business and what tax issues you should consider.

If a business making a donation to the group wants a tax-deductible receipt, the group may need to be registered as a deductible gift recipient with the Australian Taxation Office (ATO).

An ABN (Australian Business Number) may be required if the group applies for grants or funding, as some funding bodies only deal with organisations that have an ABN. Applying for an ABN is free – visit [abr.gov.au](http://abr.gov.au).

Most support groups don't need to register for Goods and Services Tax (GST). If the group is registered for GST, there is a requirement to charge GST on any payment received and report it to the ATO. This will involve the regular lodgement of a Business Activity Statement (BAS).



## Bank accounts

If the group receives and spends money, it should have a bank account. The account should be set up in the name of the group (business account) rather than as a personal account of a working party member, and it should have two or more signatories.

It's worth spending some time investigating banking options, as fees and benefits vary between financial institutions. 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 makes it easier to keep track of payments.

The working party should ensure that bank account details (bank name, branch, account name and number, interest rate, fees, signatories, where statements are sent) are carefully recorded, and members should 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. Types of resources include:

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

If the group is affiliated with a cancer organisation, hospital, local club or another service organisation, that organisation may cover some or all of these costs or provide access to some resources.

You may be able to attract donations (of money, equipment and resources) 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, e.g. in the group's newsletter.

### Questions to ask a financial institution

- What are the group's account options?
- Do you have fee-free accounts or can the fee be waived for a small community group? If there's an 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 below 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) on the account? If I want to change this later, how do I go about it?



### Insurance from Cancer Council

Your local Cancer Council may offer public liability insurance to recognised cancer support groups.

Public liability insurance usually covers a group only 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, social events or exercise classes.

Call Cancer Council on **13 11 20** to ask about public liability insurance.

## Insurance

Obtaining insurance cover is an important consideration for all support groups. The group's insurance needs depend on how the group is set up, where it meets, and whether it is affiliated with other organisations, such as a hospital or treatment centre.

This is general information only – you will need to obtain specific advice on insurance as it relates to your group from an insurance broker or solicitor.

### 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 or negligence. The mistake or negligence may be caused by the 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

Talk to an insurance broker about other types of insurance that could be relevant to your support groups. These include 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 members and people in the community. Keeping this data confidential and well organised will make it easier to get in touch with members and promote the group to people who have expressed interest.

- Only collect information that is necessary.
- Keep personal information secure. You may want to keep it in a locked filing cabinet or create a database saved on a password-protected external hard drive.
- Keep people's contact information up to date.
- Inform people how their personal details 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 it's stored in more than one place.



## Promotion

Publicising the group is particularly important when the group is new so that people know it's available. However, it's also something 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 promote the group, including posters, flyers, a media press release, newspapers, a short announcement for community radio and television stations, social media and newsletters. This book has some templates to help develop these materials – see pages 58–63.

## 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 distribute promotional materials in hospitals and cancer care centres.

Aim to promote the group widely in the community so you can attract large numbers of interested people. Suggested locations for distributing promotional materials include:

- hospitals, cancer care centres and community health centres
- GP surgeries
- supermarkets and shopping centres
- clubs, churches and libraries
- online directories, e.g. your local Cancer Council directory or database.

Always ask permission before displaying posters or leaving flyers.

## Approaching a local newspaper

A media release is a summary of a story idea that features facts and figures and comments from expert spokespeople. It tells the media about a topic to generate interest. See pages 62–63 for a media release template and sample.

Journalists receive many media releases each week, so give them a compelling reason to run a story about your support group. Consider the following:

- **Identify a new angle** – The support group could be new, celebrating an anniversary, or featuring a guest speaker at the next meeting.
- **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 and why they joined the group. Only approach a group member who is comfortable


## Naming the group

A clear name for the group can help to promote it to people who might be interested. If the group is for people who have been affected by a specific type of cancer include this in the group name, e.g. Strictly Speaking: A Laryngectomy Support Group is for people who have been treated for head and neck cancers.

talking to a journalist and having their photo taken. Their story will provide a local human interest angle to engage readers and 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** – '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, and the local case study they can feature. Send a follow-up email (see sample below) with your media release.
- **Arrange the interviews** – Let the journalist know the availability of the person for the case study and pass on the person's contact details, if they have given you 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 a journalist

 Send	To...
	Cc...
	Subject

Dear [insert name of journalist],

Many thanks for your time on the phone this morning. As discussed, we are launching a new cancer support group for local people affected by cancer and will be hosting our inaugural meeting on [insert date]. I have attached our media release.

Our group leader [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. We look forward to providing much needed cancer support to local residents affected by cancer.

Kind regards,  
[insert name]





4

# Planning the **first meeting**

Once the preliminary work has been done – that is, the group purpose has been defined and the necessary administrative and promotional tasks have been completed – it's time to plan the first meeting. This meeting is important because it will help set the tone and future goals of the support group.



### 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 return.
- People may feel nervous or unsure about attending a support group for the first time. Help people feel at ease as soon as they arrive by having someone greet them at the door.
- If people arrive early, asking them if they can help you to set up the room might help them feel more comfortable. Let them know it's okay if they'd prefer not to help.
- If people arrive late, don't make them feel embarrassed. Instead, remind them privately of the meeting start and finish times.

## Finding a venue

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

Try to find a place that:

- is free, private and pleasant (e.g. has heating and cooling)
- has plenty of accessible parking, is close to public transport and is convenient
- is accessible to people with disabilities and reduced mobility
- has coffee/tea facilities
- has audiovisual equipment, if required
- has toilet access (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 and hospitals often have rooms available. Be mindful that a hospital setting may have negative connotations for people if it's where they were treated. 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 group meetings in someone's home.

## Setting a time

Each support group meeting should be at the same time, preferably monthly or fortnightly, depending on the availability of the working party.

Consider the following issues when deciding a day and time:

- What are the circumstances of potential members? Are they likely to work during the week? Are they still in treatment? Will they want to travel at night?
- When are the leaders available?
- When is the meeting venue 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 weekends.

# Jobs for the first group meeting

## Before the meeting

- Call Cancer Council 13 11 20 to obtain relevant literature to display at the meeting.
- Confirm any guest speaker/s and send them the group agreement (see page 28).
- Plan the format for the meeting (see pages 26–27).
- Prepare an agenda.
- Organise pens, pencils and name tags.
- Draft a group agreement (see page 28), then photocopy it with the working party's contact information to hand out at the meeting.
- Create an attendance list.
- Make flyers advertising the next meeting.
- Put up signs directing people to the room.
- Set up the chairs in a circle or another suitable layout.
- Set out tissues, snacks, hot and cold water, coffee, tea, sugar, milk, cups, spoons and napkins.

## At the meeting

- Have one or more people greet members at the door.
- As people arrive, ask them to fill out their details on the attendance list and provide them with a name tag.
- Go through housekeeping issues, such as the location of the toilets, the emergency evacuation procedure, etc.
- Provide everyone with a copy of the draft group agreement and a list of key contacts.
- Finish on time.
- Remind everyone of the date of the next meeting verbally and/or by handing out a flyer.

## After the meeting

- Rearrange furniture if necessary.
- Collect the attendance list.
- Clean and lock up.
- If you are the group leader, take time to debrief (see page 41).





### Keeping on time

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

## Format of the first meeting

The group leader and working party need to plan the format of the first meeting. The group leader runs the meeting.

The following format might be useful:

### Start the meeting by welcoming everyone and introducing yourself and any guest speakers

You might like to explain your personal experience with cancer and what prompted you to become involved in the support group. Members may like to know what leadership experience you have, and what you believe you can bring to the role.

### Introduce the working party members who helped to start the support group

Each member of the working party should talk briefly about their cancer experience and why they are involved with the group. Not all working party members will be part of group meetings, but it is good for the group members to know a little about them anyway.

### Mention that the most important rule is confidentiality

Group members should feel comfortable enough to share their cancer experience with the knowledge that what's said in the room stays in the room. Emphasise the importance of confidentiality at every meeting.

### Introduce the group members to one another

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:

- their name
- their experience of cancer
- why they've joined the group
- what they hope to get out of the group.

Keep in mind that some people may not want to share, and acknowledge that this is okay.

### Briefly summarise the group's development and plans

For example:

- why the support group was formed
- how the group was formed
- who was involved in forming the group.



## Discuss the group agreement

- Distribute copies of the agreement.
- Ask whether anything has been left out or if anyone disagrees with any part of the agreement. Allow time for discussion.
- Plan to bring a laminated copy of the agreement to each meeting to put up on the wall or keep next to the attendance sheet.

## Discuss the group's format and content

- Determine how each meeting should be run (e.g. the meeting starts with a guest speaker, then there is a break followed by a group discussion).
- Plan and suggest topics/guest speakers as appropriate.
- Select dates for meetings in the next few months.
- Hand out flyers for the next meeting and encourage people to return to meetings.

## Have a tea and coffee break during the meeting

People may leave as soon as the structured part of the meeting is over, so having a break about halfway through the meeting means people won't miss out on an important chance to socialise and share.

## Closing question

Prepare people to move away from the group with a closing question, such as "What will you do when you leave this meeting?" or "Name one thing you are looking forward to in the coming week."

## Reflect and debrief

Once the meeting is over and group members have left, allow yourself time to reflect on how the meeting went and discuss any issues (debrief) with your co-leader or another member of the working party. It's important to do this after every group meeting, not just the first one. For a list of debriefing questions, see the box on page 41.

### Taking notes

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

However, you should take a written record of who attends each meeting so you can follow up with people who are not able to attend regularly or who have been absent for a while. This will also help you track how well the group is working, based on attendance.

It is also appropriate to take notes about decisions made by the group and any actions to follow up on, or to record what a guest speaker presents. Ask the speaker if they can provide a handout or copy of their presentation.

“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*

## 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 rules about communication and expected behaviour
- allow people to share responsibility and ownership for the meetings and discussion
- help to maintain a focus on the group purpose
- keep the leader 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.

### Sample 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 the 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 the 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 and inclusive of others' differences, e.g. people with a disability and those from a different cultural background.
- 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 one another 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 the meeting.



5

# Maintaining a **support group**

Once the support group is established and the first meeting has been held, good organisation and careful planning by the group leader and working party are vital to ensure the group thrives. This chapter includes information about: forward planning; organising guest speakers; creating a library; communicating with members; and promoting the group.



### A good guest

Always research potential guest speakers. It's preferable to book someone who is relatively well known or has been recommended.

## Planning ahead

The support group will operate smoothly if the people involved make an effort to be organised. Ways to do this include:

- writing down tasks that need to be completed
- leaving plenty of time to complete tasks
- sharing the workload through a working party.

For a list of jobs that need to be done before each meeting, refer to *Jobs for the first group meeting* on page 25.

Allow plenty of time to plan meetings. The working party should meet at least four times a year. This will allow enough time to complete tasks, such as booking speakers and producing flyers and other promotional material.

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

## Guest speakers

One of the key purposes of some support groups is to provide access to qualified guest 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 all guest speakers should have in common is a skill or a story to share that benefits group members. Having an oncologist talk about medical issues may be relevant, but it may be just as valuable to have a workshop about relaxation methods.

The working party and group members 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 64–65 for an evaluation template.

## Finding guest speakers

There are a few ways to source suitable speakers:

- Support group staff at your local Cancer Council can provide suggestions. Cancer Council also runs free webinars, which are live online seminars that can be accessed from a computer or mobile device anywhere in Australia. Webinars are recorded and can be viewed anytime after they stream live. For more information about guest speakers and webinars, call 13 11 20.





### 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 an issue, speakers may consider charging a lower fee. Be up-front about what the group can afford to pay when the speaker is invited.

Give a group member the responsibility of greeting the speaker, getting them a drink and showing them around the venue.

It's a good idea to give the speaker a small gift of appreciation or send them a thankyou note.

- The working party can request speakers from a cancer care centre or local hospital, a GP, or professional organisations, e.g. a lymphoedema association. The websites of many professional associations list accredited practitioners.
- Ask people involved in other local support groups for recommendations.

### Briefing the guest speaker

Give some guidance to guest speakers to help them feel comfortable and to ensure they present information that will benefit group members.

Send the speaker information about:

- how to find the venue
- how much time they have for their presentation and member questions
- the kind of information the group members would like (or wouldn't like)
- the group purpose
- the group culture (e.g. 'informal')
- whether they should attend the support part of the meeting (and whether this is at the beginning or end of the meeting)
- speakers and presentations that have been well received in the past.

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

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

### Groups in rural and remote areas

For groups in rural and remote areas, it may be hard to find a variety of guest speakers. There are 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 support groups.
- Work with cancer treatment centres and your local Cancer Council to find out if people will be visiting the area for other reasons, and ask if they will come to speak to the support group as well.
- Ask local hospitals or your local Cancer Council if they have any recordings of guest speaker presentations. Guest speakers don't have to be at meetings in person – you may be able to use a recording (such as a webinar) or a video clip instead.

## 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 the emotional impact. Free CDs and DVDs are also available.

For more information about these resources, call Cancer Council 13 11 20, or visit your local Cancer Council website to download digital versions.

Resources may also be available from:

- other cancer charities or organisations
- your local hospital, cancer treatment centre or GP
- reliable websites (see page 67).

It's a good idea to nominate a member of the working party to become the Resources Officer. This involves collating reputable information and keeping track of resources that have been borrowed from other organisations. If the group maintains an updated list of resources, it will be easier to let people know what is available and to identify any gaps.

### 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 not-for-profit organisation with a solid reputation.
- The research was recently published and/or 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 in the topic.
- The information is old and/or the website hasn't been recently updated.
- The information involves the promotion of something.



## Staying in touch

It's important to maintain good communication with current support group members, potential members, local 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.

**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 attend meetings. Staying in touch with these people can give them support and make them feel welcome to attend in future.

**Local health professionals** – The support group is more likely to receive member referrals if local health professionals are familiar with the group and regularly updated about meetings.

**Donors** – Try to be involved with any donors year-round and not just when you need something from them. Acknowledge donors in newsletters or updates and send a thankyou note highlighting the benefits of their donation.

## Producing a newsletter

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

- summarise the agenda of the previous meeting
- advertise talks and events
- share new and reliable information, such as websites and research results
- stay in touch with people who can't attend meetings but still want to be informed and involved.

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.

There are many ways to produce a newsletter, ranging from photocopied sheets to professionally designed and printed publications. The design and style of the newsletter will depend on the group's budget and the skills of the people 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 – ask a local TAFE, design training school or high school whether its students would be willing to take on the newsletter as a design project.

## Creating a newsletter

- Look at other groups' newsletters for ideas about what might work well.
- Consider the target audience: current members of the group, potential members, health professionals, other support groups, the general public or all of these.
- Think about who will contribute to the newsletter, e.g. support group members or health professionals.
- Include a variety of stories (e.g. personal stories, interviews, evidence-based clinical articles).
- Consider distributing the newsletter by email to reduce printing and postage costs.
- Add a disclaimer to each 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. Always seek the advice of a qualified health professional."



### Creating a website

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

Basic websites shouldn't cost a lot to establish, or they may be free. Allocate someone to be responsible for keeping the website updated with the meeting schedule or a copy of the latest newsletter.

## Ongoing promotion

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

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

There are two issues worth revisiting every year or so:

### 1. 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 locations?
- Is the promotion generating any kind of response?
- Are there areas or ways to expand the promotion?
- Are there places where no-one is taking the information that's available?
- Does the working party have a media strategy?

Asking new and existing group members if they remember where they first heard about the support group may help determine the most effective promotional strategy.

### 2. Does the promotional material need updating?

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

## Welcoming new group members

Someone joining an existing group may feel anxious or uncertain. Similarly, current 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 that people have established.

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

- contact them before the first meeting to tell them about the group (e.g. how many people usually attend, how long the group has been established), and explain where they will be greeted when they arrive at the meeting

- provide them with a copy of the group agreement by email or post before their first meeting
- invite existing members to introduce themselves and share some of their story at the first meeting, then ask if the person is comfortable doing the same
- assure the person that they don't have to speak straightaway if they don't feel up to it.

Don't worry if the new member is not ready to share or contribute much at their first meeting – they may be shy or unsure how they fit in.

## The changing needs of a support group

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

A successful group responds to members' needs; if there are different needs within the group, the working party should try to find ways to meet them. People's different expectations and requirements may create lively and broad-ranging conversations during the life span of the group.

In some cases, there may be a feeling that not everyone's needs are being addressed. For example, there may be tension between the needs of a 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. Be mindful that if this is done in a face-to-face interaction, people may not feel comfortable being completely honest. An email might work better.
- Review attendance records to look for patterns in the number of people who have attended meetings and the popularity of discussion topics or guest speakers.
- Ask members to fill out a short, anonymous evaluation at least once a year – see the sample on pages 64–65. Be sure to inform members of the results and discuss ways any concerns could be addressed.

See *Changing priorities* on page 55 for more information.



## **Sally's story: Maitland Women's Cancer Support Group (NSW)**

*I'm a support group facilitator and also chairperson of the group's working committee.*

*The group's purpose is to support women who have felt the impact of cancer on their life, whether it's someone with cancer or who has had cancer, a carer, or even someone who may be at higher risk of cancer, such as women with a fault on the BRCA1 or BRCA2 gene.*

### **How did the group start?**

*I wasn't planning on setting up a support group; I wanted to attend a support group. I had just been diagnosed with cancer for the second time, and as well as feeling really unstable once again, I realised a lot of people around me were shattered. There were no formal groups in the area for cancer patients, so after a few false starts trying to get the local community health service to start a group, I decided to do it myself with the help of my local church, which provided the venue that we still use today.*

*It took several months and quite a bit of effort before we even had our first*

*meeting. We called for volunteers to help run the group, set up a committee, had lots of meetings and underwent Cancer Council training.*

*I'm really pleased we put in all that groundwork at the start because I think it's given us a solid basis to function from.*

### **What was the first meeting like?**

*Our first meeting was an Australia's Biggest Morning Tea event. Everyone brought a plate, we provided tea and coffee, and someone from the local Cancer Council office came and spoke to us about what Cancer Council does.*

*A lot of people came to the first meeting, including quite a few who were caring for people with cancer. Until then, we hadn't thought of carers as being part of the group, so we expanded our vision to include women who were carers as well as women who had a personal experience of cancer.*

### **Do you have guest speakers?**

*We go through phases of wanting guest speakers. Our last annual*

*survey indicated that people would like them more often. We've had all kinds of guest speakers, including an art therapist, an occupational therapist, a genetics counsellor and a mindfulness/yoga teacher. We invite speakers based on what our members are interested in.*

### **How do you promote the group?**

*We've got a pamphlet that we distribute to the local cancer nurses and that we encourage our members to give out when they meet someone who's interested. The pamphlet emphasises that we're about sharing and caring in a safe environment. We also have flyers in doctors' surgeries and we have a booth at the local Relay For Life each year to have a presence on the day. Occasionally, we'll get some time on the local radio station.*

### **What do you get out of the support group?**

*It gives me a great deal of satisfaction to see people getting something out of the group – seeing people supported and their experiences eased because of the interactions they have with other people.*



6

# Being a **group leader**

Leading a support group can be rewarding, but it is also challenging and carries a lot of responsibility. Cancer Council recommends that the group leader and working party share the load. Looking after your own wellbeing is also important. The information in this chapter might help you decide if you are the right person to lead a group.

## 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, whether its aim is information, support or both.

A leader needs the skills and ability to create a safe environment for group discussion and to keep the discussion focused. Group members should be encouraged to share their stories and feelings, and not made to feel uncomfortable if they'd prefer not to.

As a support group leader, you will also:

- take responsibility for keeping the group in line with its purpose so that discussions benefit everyone
- manage membership (people joining and leaving the group) and act as the first point of contact for questions from potential and current members
- plan the format of each meeting, including discussion topics, guest speakers, activities, evaluations and inquiries
- work together with a co-leader to review how the group is progressing and support each other through debriefing (see page 41)
- work on ongoing administration, planning and promotion (perhaps with the support of a working party)
- understand your own limitations and know how to ask for support if you need it
- avoid counselling group members.

### Responsibilities during group meetings

- Maintain confidentiality. Reinforce the rule of confidentiality at each meeting.
- Create a safe, friendly and warm environment within the group.
- Facilitate balanced discussion – lead the discussion, don't dominate it.
- Speak in the first person using 'I' statements.
- Be an active listener.
- Allow people to express strong emotions without being rushed.
- Don't offer health advice.
- Be comfortable with silence.
- Encourage each member to participate and to respect the views of others.
- Be honest – if you don't know the answer to a question, say so.
- Find information to answer members' questions.
- Keep a sense of perspective: don't let the group rule your life, and recognise your limitations.





## 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 workload. Try to ensure that 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, it can also 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. As a group leader, your focus will be on creating a safe space for members to share, rather than using group time to discuss the impact of cancer on your own life.

Leaders should have a boundary between what they know about group members within the 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. Privacy and confidentiality should always be respected.

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 a successful group

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

**“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*

### Cancer Council training

Your local Cancer Council support group staff may be able to help you decide if you are ready for the role of group leader.

Some Cancer Councils run group leader training. This training explains what leadership involves and helps people to reflect on boundaries. It is also necessary if you would like Cancer Council to recognise your support group in certain ways, for example, with promotion.

For information about support group leader training, call Cancer Council **13 11 20**.

## Establishing a regular format

Each meeting should follow a similar format. Consider the following steps:

### Welcome members and help people settle in

Invite people to say their name as a reminder to existing members and for the benefit of new members. It's a good idea to have name tags at every meeting. Ask new members if they would like to introduce themselves.

These icebreakers 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.”
- “What is something you are grateful for?”
- “Would you like to share something about your week?”

### Remind members of the group agreement

Briefly run through the group agreement, e.g. the importance of confidentiality and finishing on time. You can also discuss any housekeeping issues.

### Introduce the guest speaker or start a discussion

If a guest speaker is presenting, it's the group leader's job to introduce them.

If you don't have a guest speaker, you might start the group discussion by asking people to talk about something important that has happened to them since the last meeting. This process might introduce a broader theme to discuss (e.g. changes to relationships, fears about death and dying).

### Keep members engaged

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 will get everyone laughing
- have a break for refreshments and social interaction.

### Close the meeting

Although it may be tempting to wrap up the meeting quickly, it's important to have a definite close. This will let members' emotions settle and shift people's focus to daily life. As part of closing the meeting, 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 the meeting today/tonight?”

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



## Preventing and managing burnout

Leading 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, which is when you feel an intense level of exhaustion and stress.

The following signs may indicate burnout:

- feeling emotionally, physically and mentally tired
- the inability to concentrate on group members' stories
- a lack of satisfaction in completing tasks
- a reluctance about attending group meetings
- not 'switching off' after meetings
- a negative attitude to tasks
- questioning whether your work is valued
- a 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 in leaders because of the amount of work they do. It's important for everyone involved in running the group to look after themselves and have their own support systems. Turn the page for tips for managing burnout.

## Debriefing

Debriefing is thinking about what happened during the meeting. It will help you monitor your wellbeing and the group in general. It's an opportunity to process any concerns or questions that might have come up.

Schedule about 30 minutes after each meeting to debrief with your co-leader or another working party member. Debriefing can be done face to face, by phone or by email. You can also debrief on your own (self-reflection). It may not always be possible to debrief straightaway, but try to block out some time to do it during the week following the meeting. Once you get used to taking the time to talk to someone else or reflecting on your own, it often becomes a habit.

If the group has regular guest speakers, part of the debriefing should involve discussing how the speaker was received. You may also use this time to consider speakers that might be relevant for future meetings.

Your local Cancer Council may be able to link you with another support group leader so you can debrief with each other, or you can debrief with Cancer Council support group program staff. Call 13 11 20 for details.

## Debriefing prompts

If you are debriefing with someone, ask each other the following questions, or ask them of yourself if you are debriefing alone.

- Was the number of people who attended as expected?
- Did people seem to stay interested during the discussion?
- Did anything unexpected happen at the meeting?
- How did the group respond to me/us as the leader/s?
- What went well?
- What could be done differently next time?
- How do you feel after the meeting?
- Do you have concerns about a specific group member? If so, what needs to happen next (e.g. should someone contact them to check on them and/or suggest other support)?
- What do you need to do, if anything, before the next meeting?
- What are you going to do now to take some time for yourself?

## Self-care

Self-care involves taking time to look after your own wellbeing. Self-care can take some discipline – leading a support group is often 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’re less likely to be an effective leader. It can also be hard to support others while dealing with issues in your own life.

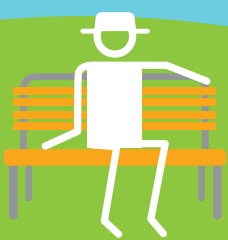
## Supervision

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 help steer the group in a meaningful way. However, not everyone is able to access a supervisor. In most cases, you have to pay for supervision, but if this is not possible, there may be other options:

- Ask a health professional in your area, such as a nurse, to meet with you. Although they might not be a professional supervisor, it may be helpful to talk to them about the group.
- Some Cancer Councils have programs that provide opportunities for professional development and support – call 13 11 20 for information.

# Managing the impact of burnout



Try to be aware of your feelings and realise your limitations.



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



Use relaxation, meditation and positive self-talk.



Debrief after every meeting.



## Rewards of leading a group

Although running a support group has the potential to be stressful, for many leaders, the rewards outweigh the demands that are placed on them.

Support group leaders say the many rewards include:

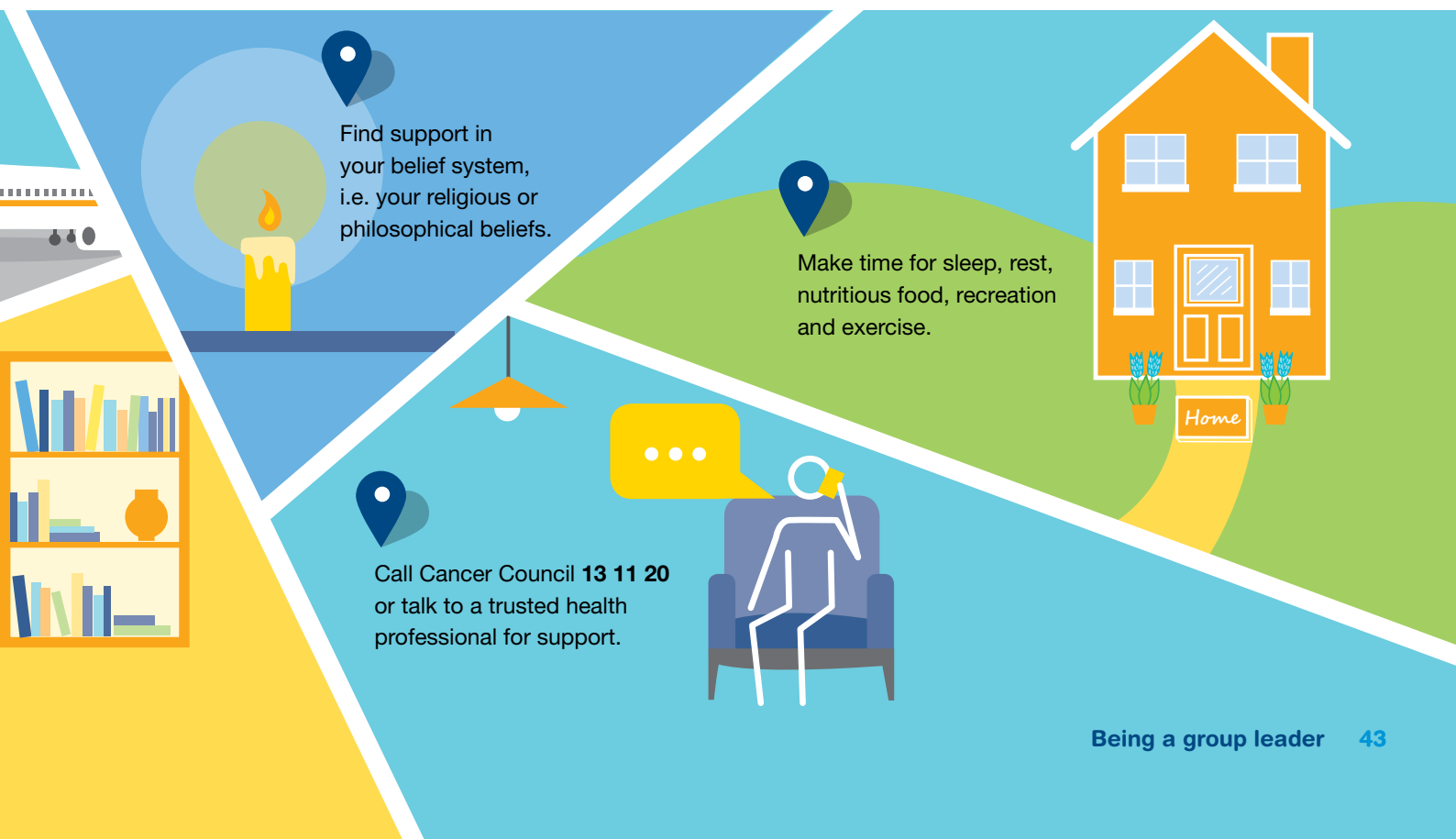
- seeing the change in people – from the initial shock and distress of diagnosis to becoming supported and feeling more in control of their lives
- learning more about themselves and developing new skills
- giving back to the community and providing awareness about health issues
- meeting new people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

## 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 some examples and ways to manage these issues.

Some group leaders find that they don't enjoy the planning, paperwork and record-keeping involved in running a group. Others find that the energy and focus required during meetings can be exhausting.

If your personal circumstances have changed, it may be time to consider leaving the leadership role. This is where succession planning is a good idea. See *Changes in leadership* on page 56 for information.





## **Peter's story:** Manning Valley Prostate Cancer Support Group (NSW)

*I'm a facilitator of the group. The purpose of the group is to provide information and support to men affected by prostate cancer and to their partners.*

### **How did the group start?**

*In May 2014, the coordinator of the prostate cancer support group in the nearby Great Lakes district organised a meeting in Taree to gauge interest in setting up a group to service the Taree area. The meeting was advertised in the local paper, and so many people turned up that some had to sit on the floor. There was a call-out for group leaders and I put my hand up.*

### **Do you share leadership responsibilities?**

*I share the running of the group with a treasurer, who has also been with the group from the start. We receive support from Cancer Council NSW and the Prostate Cancer Foundation of Australia. Representatives from these organisations usually attend one meeting a year.*

*Health professionals from the local hospitals and the community*

*health service also provide support by promoting the group to patients and presenting as guest speakers.*

### **What does your role involve?**

*A week before each meeting, I send out a reminder to our mailing list about the upcoming meeting. The list includes group members and interested health professionals.*

*I also organise the guest speakers, welcome new members to the group and organise the occasional fundraising event.*

*I try to keep the administration tasks as simple as possible because they have a tendency to take up a lot of time.*

### **How often do you have guest speakers?**

*Most of our meetings feature a guest speaker. It's a good way to provide information to the members and it takes some of the pressure off me as a facilitator, having someone else speak for the first half of the meeting. I try to invite a variety of people; in the past we've heard from a urologist, a continence nurse,*

*a cancer care coordinator and an exercise physiologist.*

### **How do you promote the group?**

*As well as including health professionals on our mailing list, we give flyers to hospitals, cancer treatment clinics and other therapists who request them. Occasionally, we advertise in the local paper. A lot of our members actively encourage new people to attend meetings; we seem to regularly attract new members.*

### **What do you get out of the support group?**

*Being a facilitator makes me feel valued. I'm retired, and in my working life I was involved in running meetings – I feel that running this group is something I can offer to the community.*

### **What qualities make a good facilitator or leader?**

*The main qualities are to be a good listener, to be patient, and to have empathy with people. On the practical side, it's important to make sure that one member doesn't do all the talking.*



7

# Facing **challenges**

As a support group develops, there can be difficulties dealing with a number of issues, such as personality clashes within the group, debate over controversial topics, and group members getting sicker and dying. This chapter outlines challenges that may arise within the group and suggests ways to manage them.



### A quiet word

If a group member is continually dominating meetings, talk to them privately. Acknowledge the contribution they make to the discussion, and emphasise that every group member deserves a chance to contribute and share.

## Someone who dominates the group

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

- always having the ‘worst’ problems or being in crisis
- constantly talking and filling silences
- being a know-it-all and ‘knowing’ the problems of another group member (e.g. “I’m like that too”) in a way that is not empathetic
- giving unsolicited advice and using ‘you should’ statements
- behaving aggressively.

People don’t always mean to act in these ways, and they might be unaware of how their behaviour affects the group. However, their behaviour may cause other group members to refrain from contributing.

### Actions

- At the start of each meeting, remind everyone about the group agreement (see page 28). For example, there may be a rule about not talking over one another and listening without judgement.
- Avoid pointedly discouraging someone who talks excessively; instead, encourage others to talk more and manage personal participation, e.g. you could ask, “What do other people think?”
- Pay attention to how other group members respond to the person who is dominating the conversation. If people aren’t given a chance to have their say, they will expect you to intervene.
- 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 person to summarise their partner’s comments.
- Acknowledge a comment, even if it’s not appropriate or helpful, then quickly involve others, e.g. “Jim, that was an interesting comment. Barbara, what are your views?”
- If someone is dominating too much of the discussion, limit eye contact and don’t respond to unhelpful comments. Politely move on to the next person.
- With difficult cases, change the group agreement (e.g. set a time limit on speaking).



## 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 and side effects, or 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-judgemental environment.

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, or becomes hostile or verbally abusive.

### Actions

- Clarify the issue. What exactly is the person angry about?
- Show empathy by focusing on the issue and not the behaviour, e.g.  
“John, I'm sorry to hear you believe your doctor isn't listening to you about your lethargy and expects you to exercise more. I wonder if others in the group have experienced this problem?”
- 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 for the person who is feeling angry.
- Keep the group discussion focused and allow people time to finish their statements.
- Encourage 'I' statements and active listening.
- Take a short break to allow the angry person time to cool off. Ensure they feel supported and ask if they'd like to speak with you privately.
- End the meeting with an open discussion. Wrapping up this way gives members a chance to have a 'last word' about the meeting.

“ There was a meeting when one of the members expressed a slight degree of anger towards me. I debriefed with another group member the next day because I took that issue home a little bit. ”

*Regional prostate cancer support group*

## Someone who annoys you

At times, 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 reflect on the personality traits and behaviours that irk you. Sometimes taking a step back and thinking about what triggers your reaction can help you calm down when you encounter these types of people.

### Actions

- Monitor your reactions to people who annoy you. Group leaders have to be understanding and polite to everyone and not just to people they like.
- If you work with a co-leader, ask them to deal with the person instead. Talk about it when you debrief and work on strategies together.
- Acknowledge that nobody is perfect. You may sometimes need to apologise for what you've said to a group member 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 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 meeting.
- Always have a box of tissues available.
- Acknowledge the emotion being expressed without singling out the person. Group members may offer 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 during the meeting or a break. Show them you care and ask if you can do anything to help them.
- If the person cries a lot or becomes disruptive, explore whether they might need other support outside the group, such as professional counselling.

## Someone who doesn't contribute

Members will contribute to the group discussion in different ways, and some members will talk more than others. Your group agreement might include a point on respecting people's right to participate as listeners, and not to speak if they don't want to.

People who don't or rarely contribute might be a problem if other group members start to feel resentful about sharing, or if there are several silent group members and not much conversation.

Members might not contribute because they don't like to interrupt, they may feel shy, or they may worry that they don't have anything worthwhile to say. It may be that English is not their first language (see page 11). Be aware of non-verbal cues that show the person is interested, such as nodding 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 to the wider group.
- Draw the person 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 member to gently draw the quiet person out of their shell during the meeting.
- Before a meeting or during a break, check in with the group member. Find out if they would like to talk more and how they can be supported. The person may be happy with their level of participation.
- If someone is usually chatty and then becomes quiet, it could be a concern. You may want to talk to them privately to find out 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*

## Discussing controversial topics

It is common for support groups to talk about controversial issues from time to time. Some topics can cause lively discussion or debate. These 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's job to keep their own opinions private and keep discussions on track.

### Actions

- If the discussion becomes too intense, or if it gets the group off track, remind members of the group agreement to maintain focus.
- 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 about a subject, refer them to the group's resources library – if there is one – or suggest they call Cancer Council 13 11 20. You may also be able to invite a health professional to speak about the topic.
- Keep up with your own self-care through debriefing and supervision (see pages 41–42) – it can be draining to facilitate controversial discussions.

### Complementary and alternative therapies

Complementary therapies are used along with conventional treatments such as chemotherapy. They tend to focus on the whole person, not just the cancer, and they may help people cope better with the symptoms of cancer and treatment side effects.

Alternative therapies are used instead of conventional treatment, and they can delay or stop the cancer being treated effectively.

Cancer Council supports evidence-based treatments, which may include some complementary therapies. Many alternative therapies have not been scientifically tested.

It can be an empowering decision to try a new therapy, so it's important that group members feel comfortable talking about their choices.

Cancer Council's *Understanding Complementary Therapies* booklet has further information.



## 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 taking their own life.

People who are feeling suicidal may hint at what they're feeling during a group discussion. For example, they may use phrases such as: "No-one can help me", "What's the point?" or "I can't take this anymore". Their appearance or behaviour may change over time – they may not be as well groomed as they once were, or they may be more prone to emotional or angry outbursts.

During a meeting, if someone says or does something that leads you to believe their life is at risk, it's important that you take the situation seriously and act straightaway. Taking action may be frightening, but it could save the person'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's okay to talk about suicide and that help is available.

## Actions

- If you have a co-leader, ask them to take over the meeting if you need to take a distressed member somewhere quiet and out of earshot. If you lead the group on your own, ask another group member to fill in for you.
- The best approach is to ask the person directly, "Are you thinking about suicide?" If the person answers yes, ask them if they have a plan to end their life, e.g. a stockpile of pills to take.
- Encourage the person to talk, and listen to them without judgement and without giving advice. Take them seriously and don't deny their feelings. People often feel relieved when they are able to talk about having suicidal thoughts.
- Don't attempt to counsel the person – refer the matter to appropriately qualified personnel as soon as possible.
- You or the distressed person can call Lifeline (13 11 14) for support. Lifeline is a national 24-hour suicide and crisis prevention service.
- When the crisis has passed and the person is safe, it's important to look after your own wellbeing through debriefing and/or supervision.

## Seeking help in an emergency

If a person is feeling suicidal during a meeting, make sure someone stays with them during the immediate crisis. Tell the distressed person that you need to make sure they are okay and that 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 **000** staff members are trained to deal with these types of situations.

## 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 next to someone whose cancer has come back (recurred) or is advanced. Their needs will probably be very different.

Members who have just been diagnosed may find it difficult to deal with the possibility of death and simply want basic information about 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 concerned about making others uncomfortable.

### Actions

- Acknowledge that people in the group have different needs and that everyone's 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 a range of situations, from diagnosis through to palliative care.
- Let people know they can talk to you privately 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 all group members.
- Organise a guest speaker to discuss 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*



## When a member dies

Many support groups have to deal with the death of a 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 group member is one of the hardest issues for group leaders to deal with, as they have to acknowledge the loss while minimising the impact on the rest of the group. At the same time, they are dealing with their own grief.

It can be helpful to talk about a death within the group before one occurs. Consider including a bereavement counsellor on the list of guest speakers when planning discussion topics for future meetings. This will show members that death is an important issue. The discussion will 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 the situation 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, don't push them to talk. The discussion may be a prompt for personal reflection.
- Some groups develop a ritual around the death of a group member, e.g. lighting a candle at the meeting when the news of the death is shared.
- After paying tribute to the person, take a break and come back together to continue the meeting. This ensures the topic of death doesn't dominate the entire meeting.
- Some leaders prefer to call group members when a person dies so no-one gets a shock at the next meeting. This also allows people to plan to attend the funeral or memorial service, if appropriate.
- Some Cancer Councils provide workshops for support group leaders on grief, loss and change. Contact your local office on 13 11 20 to ask about what's available.

### Memories and tributes

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

- Group funds can be used for sending flowers or a card to the family.
- You can write a note to the family. 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

# The **changing** needs of a group

Over time, there will be changes to the leadership and membership of the support group. If you no longer want to lead the group and no-one is available to take your place, the group may be forced to close. In other cases, the group may stop being viable, for example, if attendance drops or members feel they no longer need the support.



## Changing priorities

Over time, some members might think the group should move in a different direction. For example, they may want to shift the focus to advocacy or fundraising rather than information and support. Organising a yearly evaluation can help determine group members' needs – see the template on pages 64–65.

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 part of 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 members who are very keen or there may be a lot of interest from new people, while at other times membership may wane. At times, you may wonder whether the group can continue.

If numbers are low, it could be a sign of general dissatisfaction with the group. It may also mean that people can't attend because of the timing or location of meetings, or that people no longer need the support. 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 meetings.

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

In a situation where most people no longer need the support group, the group has done its job for the current membership. The working party may consider recruiting new members or closing the group (see page 57).

**“ Our numbers often seesaw 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*

## Changes in leadership

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

They may help to ensure that:

- no single person (e.g. the group leader) becomes overwhelmed with responsibilities or burns out
- other members become involved, especially those who might not otherwise volunteer their time or experience – e.g. another member of the working party may decide to take on the leadership role
- new ideas and energy keep the support group fresh.

## Planning a change

Preparing for succession is a healthy part of being a group leader. If you take on the role knowing that you will be handing over the reins at a particular time in the future, it can help you to set out and aim for goals that you'd like to achieve, both personally and within the support group. Having a definite finish date can also help to prevent burnout.

You might identify someone within the support group who displays leadership qualities or is keen to take on a leadership role in the future. You can offer them the opportunity to co-lead a few meetings to get an idea of what is involved. You may also be able to mentor them. This will help them transition to the leader role if they decide to take it on.

Although this kind of succession 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 find out whether they know someone who might be able to take on the role of leader.

“ I set up a succession plan early on, especially since I had a poor prognosis at the time. I'm just seeing the effects of that now. When I'm not available, people step up and take on my role. I get great satisfaction from seeing people upskilling and feeling comfortable taking on the responsibility. ”

*Rural cancer support group*

## Closing a support group

In some cases, support groups run their course and need to close. If people no longer need the group, think of it as a success and a job well done rather than as a failure. Leaders should feel a sense of satisfaction that they've been able to help people through a difficult time in their lives.

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

- If there are members who are still interested in being in a support group, help them find a new one, or refer them to Cancer Council 13 11 20. Some people might like to join Cancer Council's online community, [cancerconnections.com.au](http://cancerconnections.com.au), or a telephone support group.
- Write a letter or produce a final newsletter describing when and why the support group is closing and thanking people for their involvement. Ensure it is sent to members, local health professionals and anyone who has made donations to the group.
- Put up notices in treatment centres, and send one to the local newspaper announcing the group's closure so people don't show up for meetings.
- Arrange to collect old flyers and notices that have been distributed to locations such as hospitals and GPs and remove from online directories.
- Inform any partner agencies, such as Cancer Council or the local hospital, of the group's closure.
- Destroy all records and information except (in rare cases) if there is an obligation to securely store details for a period of time (i.e. to meet financial or legal obligations).
- Make sure all outstanding accounts have been paid before closing the group bank account. Any money left in the account can be donated to a cancer charity or another community group. An accountant can give you advice about anything else you need to do to finalise the group's financial affairs.
- Have a final meeting and farewell party. Celebrate the group's achievements and thank everyone who has been involved. Members can use this final gathering as a chance to reflect on how far they've come since they joined the group, and to thank one another for their ongoing support.



9

# Useful templates

This chapter includes examples of promotional materials such as flyers and media releases, and sample text for radio and television announcements. It also includes an example of an annual evaluation that you can photocopy and distribute to members.

## Flyer promoting an information session

### Cancer Information Evening

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- ▶ **Have you or your family been affected by a diagnosis of cancer?**
- ▶ **Are you currently having cancer treatment?**
- ▶ **Have you finished 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

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:

- Medical Oncologist Dr George Vardolos speak about the latest developments in cancer treatments
- Regional Oncology Nurse Karen Stewart present on the side effects of cancer treatments and ways to manage them
- Cancer Council staff member Jane Kelly talk about Cancer Council services that are available in the area
- the leader of the working party, Bryan Chung, present 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.

## Flyer promoting a support group

### The Sunbury Bowel Cancer Support Group

- ▶ Do you live in the Sunbury area?
- ▶ Have you recently 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 every month

**Time:** 2–4pm

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

**Cost:** Gold coin donation to cover refreshments

We regularly invite guest speakers to talk on topics such as diet and exercise, and relaxation and meditation, and we have group 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 find out whether the group is right for you, please contact chairperson Gavin Brown on 0400 000 000.

## Radio or television announcement

### Radio announcement

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The best way to promote a support group on the radio is to prepare a brief script that 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 your support group.

#### **Attention: Radio announcers**

Please share this message 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 face cancer 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 you may 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 support group leader Judi Martin on 02 0000 0000.

### Television announcement

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In some areas, there are opportunities for free announcements on community television. Contact the station manager for details.

## Media release

A media release will alert journalists to an important event or announcement involving the support group. It's a good way to get free publicity for the group. See pages 21–22 for tips on approaching local newspapers.

### 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.

### Media release date and timing (e.g. immediate release)

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

### Name

Mention the support group's name.

### Opening sentence

The first paragraph is the most important – it should 'grab' journalists' attention 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 first paragraph.

### Further details

Provide more information about the story, keeping the most important points at the top. You might want to include some quotes that journalists can use.

### Closing

Finish the copy off with 'Ends'.

### Contact details

Add a name and contact details for further reference.



## Local cancer support group provides support to 50 men with prostate cancer

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14 June 2016

Immediate release

### North Adelaide Prostate Cancer Support Group

Prostate cancer is the most common cancer in Australian men, with 17,000 men 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. It provides a safe, supportive place for men affected by prostate cancer. The group, established in March 2010, welcomed its 50th member in June 2016.

The support group was founded by Ken Lao, who was diagnosed with prostate 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 a 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 a month. It slowly and steadily grew, and there have now been 50 men who have attended one or more group meetings.

"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 the group."

For information about the North Adelaide Prostate Cancer Support Group, call Ken Lao on 08 0000 0000.

Ends

## 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. Please take a few minutes to answer these questions. This is an anonymous survey and your answers will be kept confidential.

### 1. When did you start attending the support group (month and year)?

---

### 2. Describe your circumstances when you joined the support group:

- I had been recently diagnosed with cancer (within the previous 6 months)
- a family member/friend had been recently diagnosed (within the previous 6 months)
- I was having treatment
- a family member/friend was having treatment
- I had finished treatment (within the previous year)
- a family member/friend had finished treatment (within the previous year)
- I had finished treatment more than a year earlier
- a family member/friend had finished treatment more than a year earlier
- other (please specify) \_\_\_\_\_

### 3. How did you find out about the group?

- health professional
- Cancer Council 13 11 20
- family member/friend
- other (please specify) \_\_\_\_\_

### 4. How old are you?

- 20–29 or younger
- 30–39
- 40–49
- 50–59
- 60–69
- 70–79
- 80 or older

### 5. How often do you attend support group meetings?

- every month
- a few times a year
- only one meeting

### 6. Which of these factors determine whether or not you attend a meeting?

(check all that apply)

- discussion topic
- timing
- guest 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?

---

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**9. How well do you feel the support group is meeting your needs?**

not well at all ◀ 

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

 ▶ extremely well

**10. Tell us how the group could better meet your needs. Be specific:**

---

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

extremely satisfied     satisfied     dissatisfied     extremely dissatisfied

**12. How would you rate the balance of time spent with speakers and time spent in group discussion?**

just right     prefer more time with speakers     prefer more time in discussion

**13. How often should we have guest speakers?**

monthly     every two months     a few times a year

**14. Which topics would you like speakers to address 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?**

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

extremely satisfied     satisfied     dissatisfied     extremely dissatisfied

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

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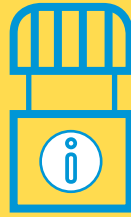
---

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

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



10

# Where to find more **information**

## Recommended reading

The following resources may be available from Cancer Council's library (available in some states and territories) or online.

- R Zordan et al., *Keeping Things on Track: A guide to managing challenging situations for leaders of cancer support groups*, Medical Psychology Research Unit, University of Sydney, Sydney, 2007.
- A Pomery et al., 'Skills, knowledge and attributes of support group leaders: A systematic review', *Patient Education and Counseling*, vol. 99, no. 5, 2016, pp. 672–88.

## Useful websites

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

Cancer Council Australia	<a href="http://cancer.org.au">cancer.org.au</a>
Cancer Australia	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Australian Taxation Office	<a href="http://ato.gov.au">ato.gov.au</a>
Bereavement Care Centre	<a href="http://bereavementcare.com.au">bereavementcare.com.au</a>
beyondblue	<a href="http://beyondblue.org.au">beyondblue.org.au</a>
Breast Cancer Network Australia	<a href="http://bcna.org.au">bcna.org.au</a>
Cancer Voices Australia	<a href="http://cancervoicesaustralia.org">cancervoicesaustralia.org</a>
CanTeen	<a href="http://canteen.org.au">canteen.org.au</a>
Gynaecological Cancer Society	<a href="http://gcsau.org">gcsau.org</a>
NALAG Centre for Loss and Grief (NSW)	<a href="http://nalag.org.au">nalag.org.au</a>
Not-for-profit Law Information Hub	<a href="http://nfplaw.org.au">nfplaw.org.au</a>
Our Community	<a href="http://ourcommunity.com.au">ourcommunity.com.au</a>
Palliative Care Australia	<a href="http://palliativecare.org.au">palliativecare.org.au</a>
Prostate Cancer Foundation of Australia	<a href="http://prostate.org.au">prostate.org.au</a>

## References

1. J Ussher et al, *Research into the relationship between type of organisation and effectiveness of support groups for people with cancer and their carers*, Cancer Council NSW, Sydney, 2005.





## Cancer Council 13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

Cancer Council services and programs vary in each area. 13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



If you need information in a language other than English, an interpreting service is available. Call 13 14 50.



If you are deaf, or have a hearing or speech impairment, contact us through the National Relay Service. [www.relayservice.gov.au](http://www.relayservice.gov.au)



## 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 supporting people with cancer and their families now and in the future.

**Buy Cancer Council sun protection products:**

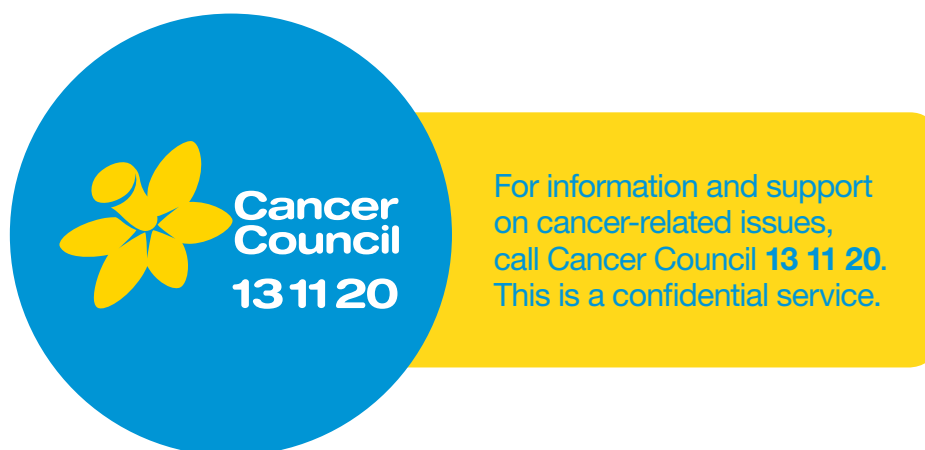
Every purchase helps you prevent cancer and contribute financially to our goals.

**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.



## Visit your local Cancer Council website

**Cancer Council ACT**  
actcancer.org

**Cancer Council NSW**  
cancercouncil.com.au

**Cancer Council NT**  
nt.cancer.org.au

**Cancer Council Queensland**  
cancerqld.org.au

**Cancer Council SA**  
cancersa.org.au

**Cancer Council Tasmania**  
cancertas.org.au

**Cancer Council Victoria**  
cancervic.org.au

**Cancer Council WA**  
cancerwa.asn.au

**Cancer Council Australia**  
cancer.org.au

*This booklet is funded through the generosity of the people of Australia.  
To support Cancer Council, call your local Cancer Council or visit your local website.*