

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

First published July 2006. This edition August 2019.

© Cancer Council Australia 2019. ISBN 978 1 925651 62 1

Cancer Support Groups is reviewed approximately every three years. Check the publication date above to ensure this copy is up to date.

Editor: Jenny Mothoneos. Designer: Emma Johnson. Printer: SOS Print + Media Group.

Acknowledgements

This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Cancer Information Subcommittee initiative.

We thank the reviewers of this booklet: Sally Carveth, Assistant Coordinator, Cancer Support Group Leader Program, Cancer Council NSW; Kate Aigner, Cancer Information Consultant, Cancer Council ACT; Megan Blake-Uren, Cancer Support Coordinator, Cancer Council Tasmania; Peter Casey, Central Coast Prostate Cancer Support Group Leader, NSW; Kristina Coomber, Regional Support Services Manager, Cancer Council WA; Kezia Griffin, Manager, Peer Support and Volunteering, Cancer Council Queensland; Marg Lavery, Manager, Support Services, Cancer Council NT; Kim Pearce, Coordinator, Cancer Support Group Leader and Telephone Support Group Programs, Cancer Council NSW; Briony Squibb, Coordinator Peer Support Programs, Cancer Council VIC; Jennifer Teece, Armidale Cancer Support Group Leader, NSW; David Young, Co-facilitator, Byron Bay and Ballina General Cancer Support Groups, NSW.

We also thank the support groups, consumers, editorial and design teams who have worked on previous editions of this title.

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 46–55). Full references are listed on page 68.

This booklet is funded through the generosity of the people of Australia.

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 or call your local Cancer Council.



Cancer Council Australia

Level 14, 477 Pitt Street, Sydney NSW 2000

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

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

ABN 91 130 793 725

Cancer Support Groups

Support groups bring together people affected by cancer to help them manage the challenges they may face. They provide a way 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.¹

How you set up and coordinate a support group is up to you. We hope this book provides useful information to help you:

- work out the need for a cancer support group among your community
- determine a group's purpose and format
- learn how to establish, run and maintain a support group
- promote a group to the community
- deal with challenges that may arise
- revive or close a flagging group.

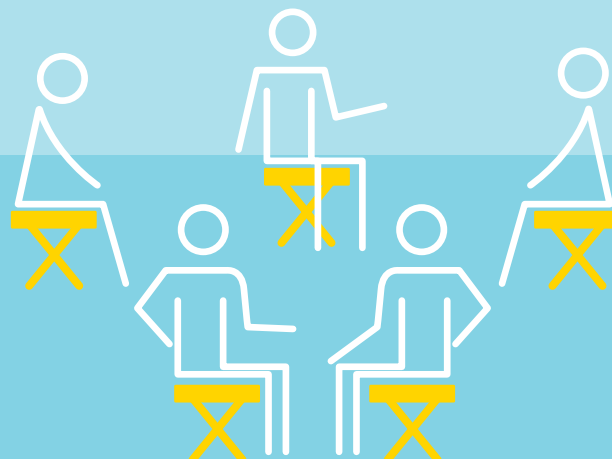
This publication has general information and guidance – it focuses primarily on face-to-face support groups, and not all the information will apply to your situation. For more specific details or to inquire about support group leader training, call your local Cancer Council on 13 11 20.

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 review their leadership and group practices. The information is relevant regardless of your previous experience with support groups, and your location in Australia.

How this book was developed

This national guide was developed through research¹⁻³ 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 covers a particular aspect of setting up and maintaining a cancer support group. You can choose to read the book from cover to cover or just read the parts that are useful to your situation – for example, if you already lead a cancer support group, you may choose to skip the *Forming a support group* chapter. Some people may also 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 specific types of content:



Tips



Personal story



Chapter summary

If you need help with a cancer-related issue, call Cancer Council 13 11 20 or see Chapter 10, *Where to find more information* at the end of the book.

How we help cancer support groups

Cancer Council is committed to ensuring that people affected by cancer have access to high-quality support groups.

Each state and territory Cancer Council may be able to help you in the following ways:

- give practical advice on how to start and promote a support group
- provide Cancer Support Group Leader Training workshops
- help with applications for funding through councils, state and federal government agencies, and private organisations
- provide links to information resources and professional guest speakers
- link you other support resources (e.g. online forum for leaders)
- offer public liability insurance for groups who meet in “party premises”.

Contents

1 Key questions.....	4
what support groups are why people join groups how groups are organised and run what keeps members coming back	
2 Forming a support group.....	10
researching support gaps considering the target membership defining the group's purpose finding a leader and working party recruiting members	
3 Administration issues	18
sorting out fundraising and tax issues opening a bank account purchasing insurance promoting the group	
4 Planning the first meeting.....	24
finding a venue working out the format of the first meeting creating a group agreement	
5 Maintaining a support group	30
keeping organised welcoming members finding guest speakers creating a resource library communicating with members ongoing promotion evaluation	
6 Being a group leader.....	38
the group leader's role establishing a regular format preventing and managing burnout rewards of being a leader troubleshooting issues	
7 Facing challenges.....	46
handling difficult situations discussing controversial topics when a group member dies	
8 The changing needs of a group	56
changing priorities fluctuating numbers leadership changes closing a support group	
9 Useful templates	60
promotional flyers radio and television announcements evaluation form media release	
10 Where to find more information.....	67
useful websites references	



1

Key questions

Support groups offer emotional support to people with cancer 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 to discuss their common experience. Cancer support groups are meetings for people with cancer and their carers.

Q: Why do people join support groups?

A: Having cancer can be stressful. Support groups provide a way for people to share their common experience in a safe and confidential environment. Even though people often receive support from family and friends, research¹ shows that the main reasons people join support groups are to:

- feel less alone and isolated
- feel understood by others affected by cancer
- give and receive support
- get information about current medical research from health professionals
- become informed about cancer treatments and side effects
- hear how other people cope with cancer
- share thoughts and ideas
- listen to one another in a non-judgemental and caring environment
- develop friendships.

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

Q: Do support groups work?

A: A survey of 184 groups in NSW¹ found that cancer support groups are a powerful way to improve wellbeing and help people with cancer and their families by:

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



Wayne's story

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.

Group administrator, online Facebook group (NSW)

Q: How are support groups organised?

A: Support groups vary in several ways, including how people meet, the type of support, whether the group is open or closed, and the purpose of the group.

Support groups can bring people together in different ways. Although many groups meet face-to-face, some connect over the phone or online. See page opposite for more information.

Types of support groups

- all types of cancer
- one type of cancer, such as a group for women with breast cancer or one for men with prostate cancer
- people of a certain age, sex, sexuality or culture, for example, just for teenagers or young children
- carers – for children or family members. These groups focus on family concerns such as role changes, relationship changes, financial worries, and how to support the person with cancer. Some groups include both people with cancer and family members.

Groups offer support in two main ways:

Open groups – Many groups meet all year round, with members joining and leaving at any time. These open groups may be run by either health professionals or community peer leaders trained to be support group leaders.

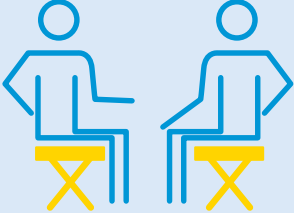


Closed groups – A closed group is when people begin together and meet for a certain period of time. This type of group is usually run by a trained health professional for an educational or therapeutic purpose. New members are unable to join the group after the first meeting.

The group purpose

Support groups work well when they have a clear sense of what they want to achieve. This is known as a group purpose. A group might bring together people who share the experience of cancer at the same stage in life – for example, parents of children or young people who have cancer. Other types of groups might be aimed at people who are interested in the benefits of exercise after cancer treatment.

For more information about developing a group purpose, see pages 12–13.

How people come together for group meetings

	Face-to-face	Telephone	Online
	 <p>People meet in person, often in a private room or meeting room</p>	 <p>People dial into a phone line that is linked together like a conference call</p>	 <p>People meet online or in a moderated chat room – for more details, see page 11</p>
Benefits	<p>Meet others in a similar situation; good for people who have difficulty expressing themselves in words; can pick up on tone, facial expression, body language and eye contact</p>	<p>Can access from wherever you live – useful for people too unwell to travel or people in rural or remote areas; can stay anonymous</p>	<p>Can access from wherever you live – useful for people in rural or remote areas and people who find it hard to travel to meetings or with mobility issues; may feel more private; can stay anonymous; available 24 hours a day, 7 days a week; flexible participation</p>
Drawbacks	<p>Need to live nearby or be well enough to travel</p>	<p>Not able to read body language and non-verbal cues; uncontrollable background noise at times; limited to English only</p>	<p>Difficult to convey tone online; unmoderated groups may lead to misinformation</p>
Facilitator	<p>Health professional or community peer leader</p>	<p>Health professional or community peer leader</p>	<p>Health professional or community peer leader</p>
Where to find	<p>Call 13 11 20 for details about a support group in your area</p>	<p>Cancer Council delivers a national telephone support group program – call 1300 755 632 for details</p>	<p>Social media sites such as Facebook or dedicated online communities – cancercouncil.com.au/OC</p>



Contact potential group members

To ensure potential members join a group that meets their needs, it is recommended the group leader contacts interested people before they attend their first meeting. See page 17 for more details.

Q: Who runs the group?

A: A group can be led by a health professional (such as a nurse, social worker or psychologist) or non-health professional (such as a community member with a personal experience of cancer known as a community peer leader). You need several different people to establish the support group, take care of administrative tasks and facilitate each meeting.

Group leader – The group leader attends and manages each meeting and is responsible for maintaining the group. Some groups have both a group leader and a group facilitator – sometimes these roles are held by the same person. Some support groups may have more than one leader.

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. See the *Being a group leader* chapter, pages 38–45, for more details on what a group leader does.

Group leaders who wish to have their group recognised by and included in their local Cancer Council's support groups directory or database will need to meet certain requirements, which may include training. For details, call 13 11 20 and ask to speak to cancer support group staff.

Working party – These group members are responsible for promotion and ongoing administration. The working party collaborates closely with the group leader. For more information, see pages 14–15.

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 through:

- word of mouth (from other people diagnosed with cancer, health professionals or Cancer Council 13 11 20)
- their local hospital – the social worker may be able to suggest a suitable group
- public information sessions (see page 16)
- promotional materials (see pages 22–23).

Some people actively look for a group to join, while others become interested after they learn a group is 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 36 for information.



Chapter summary

- ✓ A support group is a group of people who meet to discuss their similar experience.
- ✓ Groups can meet face-to-face, over the telephone or online.
- ✓ Support groups can be run by a volunteer who is a health professional or a community member with a personal experience of cancer (known as a community peer leader).

Q: Why do people stay in support groups?

A: Once people join a group, they stay for several reasons:

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 and relax. Using humour helps to build warmth in the group and helps members cope with confronting issues.

““ 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. ””

Wayne, online Facebook group



2

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.



Doing your research

Starting a support group takes planning. While this can be time-consuming, it will help ensure a successful start and a thriving group.

It's important to find out about support groups that already exist in your local area. This will help to identify gaps in available support 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 valuable. 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 to make establishing a tumour-specific group workable. Consider contacting your state or territory cancer registry for information about rates of cancer in your local area or check their website for statistics.

Ask around

Find out by asking local health professionals or people affected by cancer whether they know of any existing support groups in the area. Cancer Council also has information on the location and type of established groups, including details about groups for specific populations. Call **13 11 20**.

Establishing an online support group

Cancer support groups are increasingly being set-up online, particularly as closed Facebook groups. A closed group means that anyone with a Facebook account can see the group's page, but they're unable to read the content.

To join a closed Facebook group, you need to send a request to the group administrator (admin).

Online support groups need to consider the same issues as other types of support groups, such as:

Maintaining confidentiality

Online groups need to work out how they'll maintain the privacy and anonymity of members, and ensure their information is not revealed

to other members or people outside the group.

Developing a group purpose

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

Screening members

The group administrator may need to develop a screening process to ensure the group meets the needs of potential new members.

Sharing the workload

The 24 hours a day, 7 days a week nature of an online group means the administrator will need to work out how they share the responsibility of replying to members' posts.



Sally's story

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 unstable, 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.

Group leader, Maitland Women's Cancer Support Group (NSW)

Considering who the group is for

To develop your group purpose (see page opposite) and clarify who the group is for and the type of support it will offer, ask the following questions before a support group is established:

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

How to manage diversity within the group

Some people diagnosed with cancer or their carers may require a different level of support to help them feel included. Consider how the support you offer could be adapted so it is appropriate and relevant for their needs.

People with physical disabilities – Some group members may have physical impairments, 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 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 providing support.

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 Aboriginal and Torres Strait Islander people, contact your local Aboriginal and Torres Strait Islander Registered Training Organisation or relevant training facility.

People from culturally and linguistically diverse backgrounds – People from culturally and linguistically diverse backgrounds may not speak English or they may not speak it well. Some people may speak English but feel safer or more comfortable discussing personal issues in their first language, or they may be limited to listening to conversations without being able to actively participate. If the group is open to family and friends, suggest 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.

Members of the lesbian, gay, bisexual, transgender and intersex (LGBTI) communities – Research suggests that sexual and gender minorities often have different treatment goals and experience unique emotional challenges such as higher rates of cancer-related distress and sexual concerns, lower levels of family support, difficulties accessing health care or cancer services and lower satisfaction with cancer care. In a support group, to make everyone feel respected, use gender neutral pronouns (e.g. partner or they). If there is a specific need, you may consider establishing an LGBTI group.

Speaking to new members before attending a group meeting (see page 17) is an opportunity for someone to confidentially ask questions and understand that the group is accepting of diversity.

Defining the group's purpose

Every group needs a short, clearly written purpose outlining what the group wants to accomplish. 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 it easier to plan and run the group, and provide a clear idea of what the group is trying to achieve. It can also be used to promote the group. The group purpose can help guide the 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, see page 29.

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 men with prostate cancer and their carers/partners.
- A monthly meeting that supports people affected by all cancers, including partners and carers.



Support from Cancer Council

Call **13 11 20** to ask whether your local Cancer Council is able to provide contacts, and offer advice and help with forming a new support group.

Working together

If several people are coming together to establish a support group, it is often better to form a working party. Sharing responsibilities will mean that people are less likely to burnout.

Establish roles

The type of roles needed in the working group will vary depending on the size and structure of the support group. If you establish a working party, 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 the roles and responsibilities regularly.

Some groups like to keep roles very informal and allow people to take on various jobs as they come up. Others prefer a more formal arrangement and assign roles within a working party (see opposite for a list of suggested roles). This can help to match the right people to the right task.

Record discussions

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

Find people to join a working party

Bringing together a group of interested people with different skills and talents will 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, consider including a staff member from your local health service or Cancer Council, or another cancer organisation.

If you're finding it difficult to encourage people to join a working party or to help you run 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.

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

Maria, metropolitan cancer support group

Working party roles and responsibilities



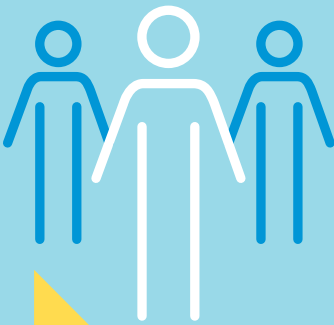
Chairperson
runs the working party meetings



Secretary
manages paperwork and takes notes or minutes at each meeting



Treasurer
keeps track of incoming money, pays bills and keeps accurate books



Group leader
organises and/or leads each support group meeting



Catering officer
organises food and drinks for each group meeting



Promotions officer
promotes the group through the media, flyers, emails and newsletters



Resources officer
collects and manages printed and online cancer information



Membership officer
helps to recruit members and maintains the membership database



Newsletter editor
writes and gathers news for the newsletter



Peter's story

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.

Group leader, Manning Valley Prostate Cancer Support Group (NSW)

Appointing a group leader

Every support group needs a leader. This may be you, another person with experience running support groups, or two people working together as co-leaders. Think about how this role can be shared. It's often best to have two leaders to share the load. This also makes it less likely that leaders will burnout (see pages 42–43).

The leader has a key role in the group, so it's important to ensure the person is suitable for the role. For further information about the qualities of effective leaders, see the *Being a group leader* chapter, pages 38–45.

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

It's important to consider how to renew leadership over time. For more information, see *Changes in leadership* on page 58.

To receive ongoing support from Cancer Council, group leaders will need to undertake Cancer Council training. 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 61.

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), outline the format of meetings, length of meetings, who leads the group, and its purpose (see page 13)
- ask for expressions of interest about joining the group.



Following up with people who are interested

When someone is interested in joining the group, it's important to chat briefly with them before their first meeting to help 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 the format of the meeting (e.g. the first hour is for group discussion and the second hour features a guest speaker), and outline the age range and experiences of other members or 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 to join the group.

If it sounds like the group is suitable for the person, invite them to attend a meeting. Ask whether you can have their contact details, such as phone number, email address and postal address. It's important to keep all contact details private and confidential – see page 21 for information about storing people's personal details.

A support group is not the right fit for everyone. 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, they may want to consider other support options, such as counselling. They can call Cancer Council 13 11 20 for more information.

Chapter summary

- ✓ Before you form a support group work out what type of support group you want and how many people could join.
- ✓ A support group needs a clear group purpose that clarifies who the group is for and the type of support it will offer.
- ✓ To help run the support group, get together a working party. This may include a chairperson, secretary, treasurer and group leader.
- ✓ Appoint a group leader who has had time to recover physically and emotionally from their own cancer experience.
- ✓ Promote the group through word of mouth, the local hospital and promotional materials.

Questions to ask potential group members

- 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?
- What do you hope to gain from the support group (e.g. meet people in the same situation, emotional support, treatment information, ways to manage side effects)?
- Do you feel ready and comfortable to give and receive support through this group?
- What are your main topics of interest? (Answers can provide ideas for guest speakers.)
- Do you feel ready to share your experience of cancer?
- Do you have any specific dietary or physical needs?



3

Administration issues

There are several practical business issues to sort out so the group can function efficiently and comply with any relevant legal requirements. 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 independent financial and legal advice when setting up a support group.



A support group needs an email address and a mailing address for correspondence. A member of the working party may also like to create a shared email account 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. If the group's funds can cover the rental fee, a post office box is best for consistency and privacy.

Fundraising, ABN and tax

When running a support group you'll need to think about 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. For information about fundraising legislation in your state or territory, visit fundingcentre.com.au/help/fundraising-legislation.

For support groups that wish to be recognised by their local Cancer Council, call 13 11 20 to check whether there is a policy about fundraising. You may be able to apply for government grants or funding 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 Australian Business Number (ABN) 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.

Most support groups won'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 lodging a Business Activity Statement (BAS) regularly.

Other ways to raise funds

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

- asking a local organisation to donate a venue (e.g. a council, local electorate office, 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, the local electorate office or the local Cancer Council office to donate postage, printing, photocopying, etc to help produce promotional materials or a 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?

Bank accounts

If the group receives and spends money, it will need a bank account. It is important for keeping track of the group's money and useful if you are applying for grants or fundraising. Spend some time researching banking options, as fees and benefits vary between financial institutions. Some banks have specific account types for not-for-profit groups or offer them fee-free community business accounts.

Set up the account in the name of the group (business account) rather than as a personal account of a working party member, and give two or more people the authority to operate the account (signatories).

If the group pays bills, it's generally best to use electronic funds transfer (EFT) rather than cash. This makes keeping track of payments easier.

The working party should record bank account details (bank name, branch, account name and number, interest rate, fees, signatories, where statements are sent) in a single and secure location.

Resources and expenses

Every support group needs some resources to run the group. Types of resources include:

- a post office box
- assistance designing flyers or newsletters
- printing or photocopying flyers or newsletters
- postage for mail-outs
- a computer, printer and external hard drive/USB drive
- internet access
- support managing the group's online presence (website, Facebook, etc)
- a TV, DVD player or laptop for presentations and video resources
- coffee, tea, snacks, cups, spoons and napkins
- access to a toilet and some private space.

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

You may receive 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 or website.



Insurance

All support groups need to consider getting insurance. The type of insurance will depend on how the group is set up, where it meets, and whether it is part of another organisation, such as a hospital or treatment centre.

This is general information only – you will need to get insurance advice specific 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 group. These include personal accident insurance, directors and officers liability insurance, and insurance through affiliated organisations.

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.

Managing personal details

Running a support group involves collecting personal information from members and people in the community. Keeping this data well organised will make it easier to contact members and promote the group to people who have expressed interest.

- Work out what information the group needs to collect.
- Store personal information securely. You can use a locked filing cabinet or create a database saved on a password-protected external hard drive.
- Keep people’s contact information up-to-date.
- Let people know 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.
- Record how to access database details or email accounts in case the person who manages this leaves or is unavailable.



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 – this group is for people who have been treated for head and neck cancers.

Promotion

Letting people know about the group is particularly important when the group is new. However, it's also useful to do on an ongoing basis (see page 36). You can promote the group using posters, flyers, a short announcement for community radio and television stations, and a media release for newspapers, social media and newsletters. See pages 61–66 for templates. Providing a phone number instead of an address on promotional material will encourage interested people to call before attending, which is an opportunity for the group leader to work out if the group meets their needs.

Reaching the target audience

Before distributing promotional materials, think about the target audience and where they are likely to see the notices. This will help you attract the maximum number of interested people.

Suggested locations for distributing promotional materials include:

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

Always ask permission before displaying posters or leaving flyers. It's a good idea to keep a track of where they are so you can remove them later if necessary.

Approaching local media

Many local newspapers and radio stations include information on community groups. Send them a media release to let them know of a story idea. See page 66 for a media release template.

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 – Ask a person from the support group to share an interesting story about their cancer experience and why they joined the group. Only approach a group member who is comfortable 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 the support group.



Chapter summary

- ✓ A group needs to organise several business issues such as email and mailing addresses, and an ABN.
- ✓ Groups may also need to consider opening a bank account and organising insurance.
- ✓ Work out how to store any personal information you collect about group members.
- ✓ Develop a promotions plan, which may include approaching the local media. Identify where you can distribute promotional materials.

Find a journalist to call – Look through the local newspaper to work out 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 identify 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), has a new angle, or there is a 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 helpful 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 your 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.



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. The size of the room may determine the size of the group.

Try to find a place that:

- is cost free, private and pleasant (e.g. has heating and cooling)
- has plenty of safe and convenient parking, and is close to public transport
- is accessible to people with disabilities and reduced mobility
- has coffee/tea facilities
- has toilet access (wheelchair accessible, preferably)
- has comfortable furniture that can be easily rearranged
- has audiovisual equipment, if required
- can be reserved for every meeting.

A member of the working party can look for possible meeting rooms. Community health centres, town halls, libraries, church halls and hospitals often have rooms available. Keep in mind that a hospital setting may have unpleasant associations 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. Most support groups meet for about two hours.

Consider the following issues when deciding a day, time and meeting length:

- 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 group leaders available?
- When is the meeting venue available?
- Will the meeting time 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 members to attend on Friday nights or weekends.

Ways to welcome 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 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.

Jobs for the first group meeting

Before the meeting

- Draft a group agreement (see page 29), then photocopy it with the working party's contact information to hand out at the meeting.
- Plan the format for the meeting (see pages 27–28).
- Call Cancer Council **13 11 20** to order booklets or other relevant information to display at the meeting.
- Prepare an agenda and attendance list.
- Confirm any guest speaker(s) and send them the group agreement (see page 29) and meeting agenda.
- Send out an email reminder.
- Organise pens, pencils and name tags.
- Make flyers advertising the next meeting.

On the day

- Put up signs directing people to the room.
- Arrange 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.
- Review how the meeting went and whether you need to change anything before the next meeting.
- If you are the group leader, take time to debrief (see page 42).





Format of the first meeting

The group leader and working party plan the format of the first meeting. The group leader or facilitator runs the meeting. A common format follows.

Welcome everyone and introduce yourself and any guest speakers

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

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

Ask each member of the working party to 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 did you have for breakfast?”, 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 more than their name, and acknowledge that this is okay.

Summarise how the group started and its purpose

Cover why and how the support group was formed, who was involved in forming the group and who it is for (group purpose).

Discuss the group agreement

Hand out copies of the agreement (see page 29) and ask whether anything has been left out or if anyone disagrees with any part of the agreement. Allow time for discussion.

Keeping on time

One of the basic rules about any type of meeting is that it should start and end on time. However, you may need to allow a little extra time for the first meeting.



Taking notes

It's okay to keep 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 important to take notes about decisions made by the group and any actions to follow up. You may also want a record of what a guest speaker talks about. Ask the speaker if they can provide a handout or copy of their presentation.

However, it's not appropriate to take notes of the things people share during group meetings because this information is confidential.

Bring a laminated copy of the agreement to each meeting to put up on the wall or keep next to the attendance sheet.

Outline the group's format and content

Let the group decide the order of meetings (e.g. the meeting starts with a guest speaker, then there is a break followed by a group discussion). You may also:

- plan and suggest topics/guest speakers
- select dates for upcoming meetings
- hand out flyers for the next meeting and encourage people to return to meetings.

Have a 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 the opportunity to socialise. You can offer tea and coffee during the break, or set out beverages for members to help themselves at any time throughout the meeting.

Close the meeting

Prepare people to leave 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 42.

“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.”

Meg, rural women's cancer support group



Creating a group agreement

One of the key tasks of the first meeting is to develop guidelines on how the group will work together. This is called a group agreement and it should:

- outline expectations about behaviour and keeping discussions confidential
- allow people to share responsibility for the running of the group
- help to maintain a focus on the group purpose
- keep the leader on track
- help the group work effectively and reduce conflict.

Ideally, the working party will already have drafted a group agreement for discussion at the first meeting. Refer to the agreement at each meeting, and review and update it from time to time.

Chapter summary

- ✓ Set a regular time and place for meetings.
- ✓ Plan the format of the first meeting.
- ✓ Develop a group agreement to guide how the group will work together.

Sample group agreement

- This is an open group for new and existing members, whatever their experience with cancer. The 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 insights, strengths and hopes, and to recognise that everyone in the group has expertise in dealing with cancer.
- Do not name or identify individual health professionals.
- Group members are respectful of each other's feelings, views and concerns at all times and inclusive of other's 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 when another person is speaking.
- Group members take responsibility for the success of this group by maintaining their focus on 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.



Planning ahead

To help the support group run smoothly it is important 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 tasks that need to be done before each meeting, see *Jobs for the first group meeting* on page 26.

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 or other promotional material.

Last-minute issues will come up from time to time, but if there's a crisis before every meeting, the working party needs to review the way the group operates.

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. Ways to help a new member feel at ease include:

Before the meeting

- contact them to tell them about the group (e.g. how many people usually attend, how long the group has been established), and explain where the meeting is held
- email or post a copy of the group agreement to them

At the meeting

- invite existing members to introduce themselves and share parts of their cancer experience at the first meeting, then ask if the new 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

After the meeting

- call or email members for feedback on their first meeting.

Peter's story

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.

Group leader, Manning Valley Prostate Cancer Support Group (NSW)



Finding a good guest speaker

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

Arranging guest speakers

One of the key purposes of some support groups is to provide access to guest speakers.

Although many speakers will often be health professionals, such as doctors, nurses, psychologists, dietitians, exercise physiologists and social workers, other experts can contribute to the group, such as artists, writers, yoga instructors, or massage therapists. All guest speakers need to have 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 suggest suitable topics and speakers. You can also use the group's annual evaluation 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 approach finding suitable speakers:

- ask support group staff at your local Cancer Council for suggestions
- request speakers from a cancer care centre or local hospital, a GP, or a professional organisation, e.g. a lymphoedema association. The websites of many professional associations list accredited practitioners
- get recommendations from people involved in other local support groups.

Working with guest speakers

There are several things to consider when inviting guest speakers:

Establish if they'll be paid – 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.

Ask for some background information – Use these details to promote the guest speaker's visit and for introductions.

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

Show your appreciation – Give the speaker a small gift or send them a thank you note.

Groups in rural and remote areas

For groups in rural and remote areas, it may be hard to find a variety of guest speakers. Ways around this include:

- Ask a local company or organisation to sponsor the speaker's trip and pay for their travel and accommodation expenses.
- 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.
- Share a speaker between several support groups.
- 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 webinar, podcast or video clip instead.

Briefing the guest speakers

Provide guest speakers with some details to help them feel comfortable and to ensure they present information that will benefit group members. Let the speaker know:

- the venue address and directions
- 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 and the group culture (e.g. "informal")
- whether they need to participate in the support part of the meeting (and whether this is at the beginning or end of the meeting)
- speakers and topics 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 support in the future.

“ We try to have guest speakers three times a year. We've had all kinds of guest speakers, including a lymphoedema therapist, counsellor, an occupational therapist and a mindfulness teacher. ”

Katrina, metropolitan breast cancer support group



Online resources

Cancer Council runs free webinars and produces free podcasts. These can be accessed from a computer or mobile device anywhere in Australia. You can participate in a webinar through live streaming or watch the recording later at a time that suits you. A podcast is an audio file that you can download later. For more information about guest speakers, webinars and podcasts, call **13 11 20**.

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. They cover all aspects of cancer, from medical information to how to deal with the emotional and practical impact. Free CDs are also available.

You can create a library for your group from these resources. To request copies, 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 68).

It's a good idea to nominate a member of the working party as the resources officer. This involves collating reputable information and keeping track of resources that have been borrowed from other organisations. Maintaining an up-to-date list of resources will make it easier for the group 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 has not 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 share their cancer experience. 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 referrals from local health professionals if they 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 thank you note highlighting the benefits of their donation.

Producing a newsletter

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

- summarise the agenda of the previous meeting
- advertise upcoming 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.

Start by deciding who will edit the newsletter. The editor is the person who works out the newsletter format and what to include. You also need to consider how you'll produce the newsletter. This could range from a photocopied sheet to a professionally designed and printed publication. The design 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. You could 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. Consider using email to distribute the newsletter to reduce printing and postage costs.

Newsletter content

- 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 can contribute to the newsletter, e.g. support group members or health professionals.
- Include a variety of stories (e.g. interviews with experts, personal stories, evidence-based clinical articles).
- Add a disclaimer to each newsletter to emphasise the importance of medical advice. For example: "This newsletter is not 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 don'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, regular promotion to attract new members will keep the group membership strong.

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

There are two issues worth revisiting annually.

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 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 you work out the most effective promotional strategy.

2. Does the promotional material need updating?

You may need to consider whether the design needs to be refreshed. There may be someone who could donate time and expertise to help with designing or printing promotional materials.

Look at the content and evaluate whether it accurately describes what happens in the support group. Consider whether the language or images are appropriate for the target audience.

“ We promote our group through the clinic's patient manager and we send out flyers. We've also listed the group with the Cancer Council and with the area's breast care nurses. Because our space comfortably holds a maximum of 10 people, we find the current level of promotion sufficient. ”

Katrina, metropolitan breast cancer support group



Evaluating the needs of your 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. Keep in mind that people may feel more comfortable being honest in an email rather than face-to-face.
- 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 complete a short, anonymous evaluation at least once a year – see the template on pages 64–65. Share the results with members and discuss ways to address any concerns.

It's also a good practice to renew the membership of the working party on a yearly basis. Members may consider swapping roles or no longer being part of the working party.

For more information, see *Changing priorities* on page 57.

Chapter summary

- ✓ Maintaining a support group takes time and planning.
- ✓ Invite a variety of guest speakers to attend meetings.
- ✓ Create a library of resources for members to access, including printed and online information such as webinars and podcasts.
- ✓ Use email and/or a newsletter to stay in touch with members.
- ✓ Regularly promote the group to attract new members.
- ✓ Ask members how the group is going informally or conduct a short, anonymous evaluation.



6

Being a **group leader**

Leading a cancer 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. 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. You will also:

- keep 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 42)
- provide ongoing administration, planning and promotion (perhaps with the support of a working party).

Qualities of an effective group leader

It's helpful to understand what skills, knowledge and attributes you need to be an effective group leader.

Some general qualities include being open, objective and enthusiastic with good listening skills. Effective group leaders are well organised and can gently encourage people to participate in a group without being intrusive.

Group leaders with some administration, computer and promotional skills will be beneficial. An effective leader is able to separate their own needs from the group and maintain a balance between the group's needs and their own life. Taking time to look after yourself (see page 44) will help group leaders find the energy to keep running the group.

It's easier to be a good leader 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 (see pages 14–15). Not only does this reduce your workload, it can also help identify potential future leaders.

Katrina's story

I met my co-leader when we were both having radiation therapy for breast cancer. We communicate well and seem to be on a similar wavelength.

We both have a desire to help others and an ability to focus on members and not on our own needs.

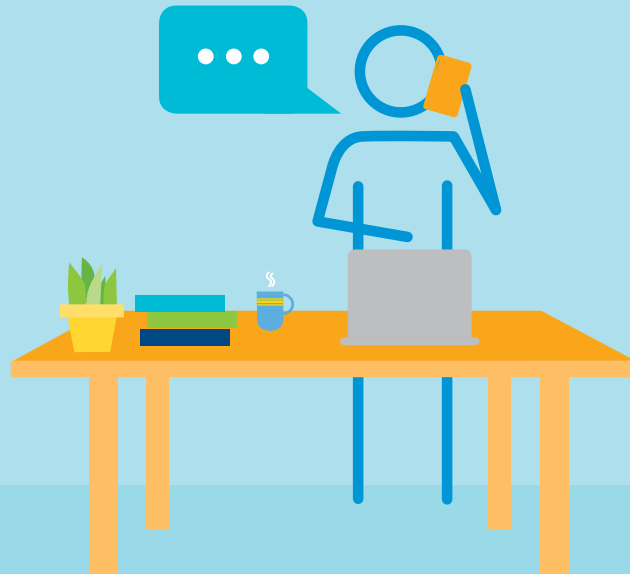
I think group leaders need to prioritise the importance of confidentiality amongst group members. It's also important group leaders feel comfortable and confident asking for help from appropriate people or organisations such as the Cancer Council.

Co-leader, Breast Cancer Support Group (NSW)

“ One of the biggest challenges of running a support group is having enough time and energy to sustain the group and yourself. ”

Katrina, metropolitan breast cancer support group

Responsibilities of a group leader

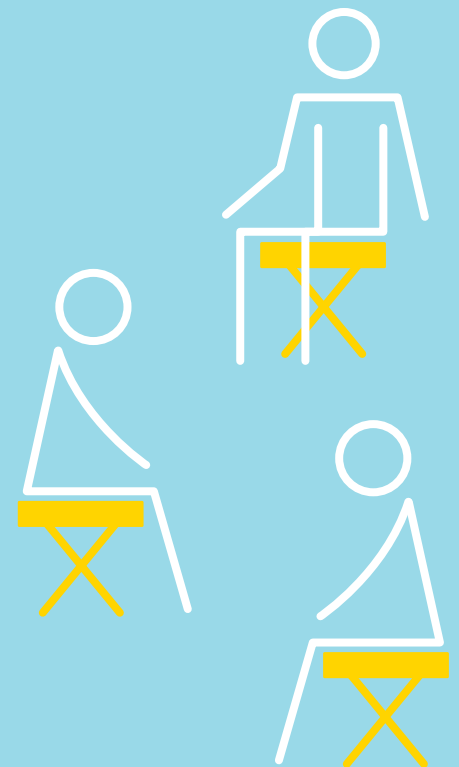


Before the meeting

- Prepare the agenda.
- Organise a guest speaker.
- See page 26 for more details.

During the meeting

- Keep meetings in line with the group purpose and agreement.
- Maintain confidentiality. Reinforce the importance of confidentiality at each meeting.
- Create a safe, friendly and warm environment within the group.
- Facilitate balanced and focused discussion – lead the discussion, don't dominate it.
- Speak in the first person using "I" statements.
- Be an active listener.
- Allow people to share their stories and express strong emotions without being rushed.
- Manage issues and any challenging members.
- Avoid making people feel uncomfortable if they'd prefer not to share their story.
- 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.
- Look for similarities between people's experiences.
- Stick to the start and finish times.
- Keep a sense of perspective: don't let the group rule your life, and recognise your limitations.



After the meeting

- Debrief with your co-leader or a working party member.
- Follow up with members.





Establishing a regular format

A similar format for meetings will help create familiarity. Features of a common format include:

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's the first thing you do on a Saturday?”

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 run through any housekeeping issues such as turning mobile phones to silent, pointing out the location of toilets, and what to do in case of an emergency.

Introduce the guest speaker or start a discussion

If a guest speaker is presenting, the group leader will need 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 socialising.

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 their 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.

How to improve your leadership skills

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



How to debrief

If you are debriefing with someone, ask each other the following questions. If you are debriefing on your own, ask them of yourself.

- 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?
- How are you going to take some time to look after yourself?

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. This is when you feel an intense level of emotional, physical and mental exhaustion.

Signs of burnout include:

- 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 prone to burnout, but it's most common in leaders because of the amount of work they do. It's important for everyone in the working group to look after themselves and have their own support systems. See page opposite for tips on 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.

Set aside some time after each meeting to debrief with your co-leader or another working party member. This can be done face-to-face, by phone or by email. You can also debrief on your own (self-reflection). 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.

If it's not possible to debrief straightaway, try to set aside some time to do it during the following week. Once you get used to taking the time to talk to someone else or reflect on your own, it often becomes a habit.

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

Ways to manage burnout



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



Let yourself enjoy life – take some time out from the group for a break.



Use relaxation, meditation and positive self-talk.



Debrief after every meeting.



Find support in your belief system, i.e. your religious or philosophical beliefs.



Make time for sleep, rest, nutritious food and exercise.



Call Cancer Council **13 11 20** or talk to a trusted health professional for support.





Ways to look after yourself

Taking time to look after yourself is known as self-care. It is not always easy to find time for self-care or you might think it's selfish to look after yourself. However, if you're feeling stressed or overwhelmed, you're less likely to be an effective group leader. Ways to look after yourself include:

- be active and eat well
- get enough rest
- limit the use of alcohol
- make time for your interests.

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 guide the group in a meaningful way. It can also improve and maintain wellbeing. 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.
- Keep a journal for self-reflection and note down responses to questions such as “How did the group go?”, “What would I do differently next time?”
- Some Cancer Councils have programs that provide opportunities for professional development and support – call 13 11 20 for information.

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 adjusting to the news, becoming supported and feeling more in control of their lives
- learning more about themselves and developing new skills
- giving back to the community
- providing awareness about health issues
- meeting new people and sharing their stories.

“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.”

Peter, regional cancer support group



Managing boundaries

Group leaders need to 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 need 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, avoid talking about group conversations while at the shops, at a dinner party, or on the sidelines of a football match. Privacy and confidentiality must 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.

Troubleshooting or stepping away

Leading a support group may mean dealing with challenging situations from time to time – 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, you may need to consider handing over the leadership role. See *Changes in leadership* on page 58 for further details.

Chapter summary

- ✓ A group leader keeps the group operating as smoothly as possible.
- ✓ Effective group leaders are well organised and have good listening skills. They need to be able to separate their own needs from the group.
- ✓ Group leaders are at risk of burnout.
- ✓ Making time to debrief will help group leaders monitor their own wellbeing and the group's progress.
- ✓ Practising self-care will help group leaders be more effective.
- ✓ Although running a group can be stressful, many group leaders find it rewarding.
- ✓ Sometimes, a group leader needs to plan for someone to take over the group.



7

Facing **challenges**

As a support group grows, there may be difficult issues to deal with, 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.



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 or “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.

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

- Remind everyone about the group agreement (see page 29) at the start of each meeting. For example, there may be a rule about listening without judgement and not talking over one another.
- 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, consider changing the group agreement (e.g. set a time limit on speaking).

Have 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.



Be respectful of health professionals

Sometimes people bring up their grievance with their doctor or treatment centre in support groups. To encourage a culture of respect with the medical community, remind people to not mention health professionals or treatment centres by name. It's a good idea to include this in your group agreement.

Someone who is angry or disruptive

Anger is a natural emotion when discussing a cancer experience, and it isn't always 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?
- Focus on the issue, 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.
- 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.
- Contact the member either immediately after the meeting or a day or two later to see how they're feeling.

“ 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. ”

Meg, 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". You need to be understanding and polite to everyone and not just to people you like.

Actions

- Monitor your reactions to people who annoy you. Thinking about what triggers your reaction can help you calm down.
- 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 so it's natural 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.

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 someone cries often or becomes disruptive, explore whether they might need other support outside the group, such as professional counselling.
- Contact the member either after the meeting or a day or two later to see how they're feeling.

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 13). Be aware of body language that shows 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 feel more comfortable to talk more.
- 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.”

June, rural cancer support group

Dealing with survivorship issues

When treatment ends, many people find it takes time to find a “new normal”. This process may take longer than expected, but there may be pressure from family and friends for life to return to how it was. It’s also natural for people to worry about the cancer coming back (recurrence). Most cancer survivors are likely to experience this fear to some degree, and it may come and go, particularly before check-ups. This fear may affect a person’s physical wellbeing, as well as their ability to enjoy life and make plans for the future.

Actions

- Ask people to reflect on their life priorities and what they can do if their goals have changed.
- Discuss ways they can take charge of their own health: maintain a healthy body weight, have a healthy, well-balanced diet, be more physically active, quit smoking, use sun protection, and limit or avoid alcohol.
- Arrange a guest speaker to talk about the risk of recurrence or what to consider when returning to work.

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 agree, 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 42–44) – facilitating controversial discussions can be draining.

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 feel empowering to try a new therapy, so it's important that group members feel comfortable talking about their decision. See Cancer Council's *Understanding Complementary Therapies* booklet for further information.

Dealing with disease progression

Support groups are likely to include people diagnosed with cancer at different stages. A member who has been newly diagnosed with stage I cancer may be sitting next to someone whose cancer is advanced when they are first diagnosed or has come back (recurred). Their support needs will probably be very different.

Members who have just been diagnosed may find it difficult to listen to discussions about advanced cancer or the possibility of death, and simply want basic information about cancer and support coping with the diagnosis. It can be particularly challenging in a group where most people are well and one member's cancer recurs.

Some people with advanced disease may feel that others don't want to hear about the experience of living when cancer has spread or face the possibility 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.
- Some groups separate people with advanced disease into smaller groups for discussion. People with advanced cancer may prefer to chat with others facing the same degree of uncertainty so they can work through issues of death, meaning and isolation together.
- 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 guest speakers to talk about topics that cover a range of situations, from diagnosis and fear of recurrence through to advanced disease and palliative care.
- Consider if there's a local group that would more appropriately meet the needs of a person with advanced cancer.
- Suggest the person join the Cancer Council NSW National Telephone Support Group program for people in any state and territory living with metastatic or advanced cancers. Call 1300 755 632 for more information. Some people might like to join Cancer Council's Online Community, cancercouncil.com.au/OC.
- Refer people to 13 11 20 to find out about programs supporting people living with advanced cancer.

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 you are going to seek some help. Ask them if there is someone you can call for them. 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.

“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.”

Max, rural cancer support group

Being aware of suicide

Although suicide is rarely an issue in a cancer support group, it's important to know what to 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 group discussions. 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 that the person feels heard and believed.

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 an appropriately qualified person as soon as possible.
- Ask if there's someone they can call or you can call for them. You or the distressed person can contact the Suicide Call Back Service for free professional phone or online counselling. Call 1300 659 467 or visit suicidecallbackservice.org.au.
- When the crisis has passed and the person is safe, it's important to look after yourself through debriefing and/or supervision (see pages 42–44).



When a member dies

Many support groups have to deal with the death of a member at some stage. It is 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. 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.

Planning a memorial and tributes

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

- Use group funds to send flowers or a card to the family.
- Write a note to the family. Ask if anyone else in the group would like to include their thoughts or wishes.
- Include an article about the person in the next edition of your newsletter, if you have one.
- Plant a tree or a 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
- forming a subgroup that provides support about a specific issue, leaving the main group to focus on other topics.

Fluctuating numbers

Groups often go through cycles – sometimes attendance may be high with several members who are very keen or there may be a lot of interest from new people. At other times membership may be low, and you may wonder whether the group can continue.

If attendance is dropping off, it could be a sign of general dissatisfaction with the group. Or it may mean that the timing or location of meetings isn't right, or that people no longer need the support. Try to find the source of the problem: discuss with a few group members and take a close look at the evaluation results. It may be as simple as making a few format changes to bring people back to meetings.

If attendance remains low, it may be 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 59).

“ 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. ”

Pam, 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 someone to take over from you is a healthy part of being a group leader. This is known as succession planning. If you take on the role knowing that you can hand over the responsibility in the future, it can help you to plan what 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. Contact Cancer Council to find out if there is a Cancer Support Group Leader Training workshop coming up and encourage the prospective leader to register.

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

Lawrence, rural cancer support group



Closing a support group

In some cases, support groups need to close. If people no longer need the group, think of it as 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 little disruption to members and the community:

- Help members who are still interested in being in a support group find a new one. Some people might like to join Cancer Council's Online Community, cancercouncil.com.au/OC, or a telephone support group.
- Write a letter or produce a final newsletter outlining when and why the support group is closing and thanking people for their involvement. Send it to members, local health professionals and anyone who has made donations to the group.
- Put up notices in treatment centres announcing the group's closure, and send one to the local newspaper, so people don't show up for meetings.
- Collect old flyers and notices that have been distributed to locations such as hospitals and GPs, and remove entries 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 if there is an obligation to securely store details for a period of time (i.e. to meet any 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.

Chapter summary

- ✓ All support groups evolve over time.
- ✓ Plan for a change in the group leader and working party members. Look for someone in the group you can mentor.
- ✓ Changing priorities and a drop in attendance may mean a group has to close.
- ✓ If a group closes, think of it as a job well done rather than as a failure.
- ✓ Help people who would like to continue being part of a support group find a new group to join.
- ✓ Celebrate the achievements of the group with a farewell party.



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 form that you can photocopy and distribute to members.

Flyer promoting an information session

Cancer Information Evening

- ▶ **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
- 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 2019.

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 healthy eating, 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

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

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

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

5. How often do you attend support group meetings?

- every meeting 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?

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 22–23 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

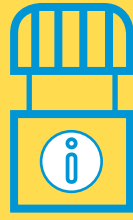
Provide more information about the story, keeping the most important points at the top. You might want to include some quotes that journalists can use.

Closing

Finish the copy off with “Ends”.

Contact details

Add a name and contact details for further information.



10

Where to find more **information**

Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian	
Cancer Council Australia	cancer.org.au
Cancer Australia	canceraustralia.gov.au
Australian Taxation Office	ato.gov.au
Bereavement Care Centre	bereavementcare.com.au
Beyond Blue	beyondblue.org.au
Breast Cancer Network Australia	bcna.org.au
Cancer Voices Australia	cancervoicesaustralia.org
CanTeen	canteen.org.au
NALAG Centre for Loss and Grief (NSW)	nalag.org.au
Not-for-profit Law	nfplaw.org.au
Our Community Group	ourcommunity.com.au
Palliative Care Australia	palliativecare.org.au
Prostate Cancer Foundation of Australia	prostate.org.au
QLife	QLife.org.au
<i>The Thing About Cancer</i> podcasts	cancercouncil.com.au/podcasts
International	
American Cancer Society	cancer.org
Cancer Research UK	cancerresearchuk.org
Macmillan Cancer Support (UK)	macmillan.org.uk

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.
2. A Pomery et al., "Skills, knowledge and attributes of support group leaders: A systematic review", *Patient Education and Counseling*, vol. 99, iss. 5, 2016, pp. 672–88.
3. R Zordan et al., *Keeping Things on Track: A guide to managing challenging situations for leaders of cancer support groups*, Medical Psychology Research Unit, The University of Sydney, Sydney, 2007.



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



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 other Pink events, or hold your own fundraiser or become a volunteer.

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

Buy Cancer Council sun protection products:

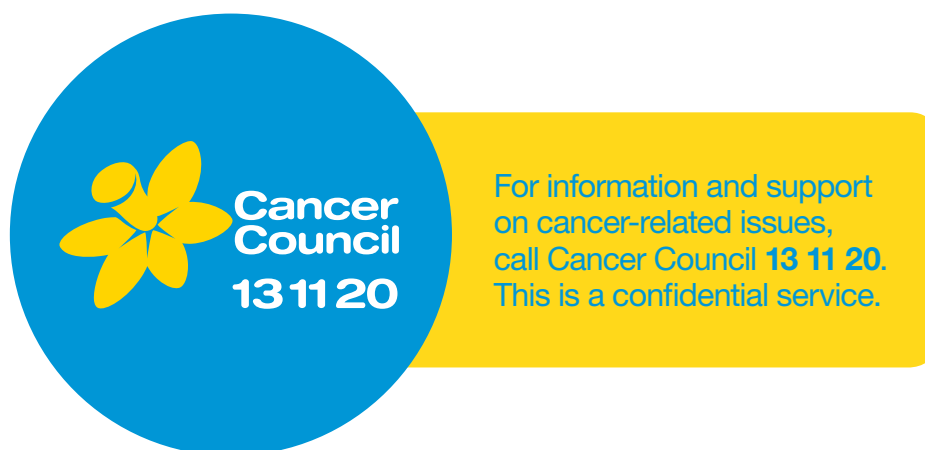
Every purchase helps you prevent cancer and contribute financially to our goals.

Help us speak out for a cancer-smart community:

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

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

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



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.*