



Australian Government

Cancer Australia

Cancer support groups: A guide to setting up peer facilitated supports



**Cancer support groups:
A guide to setting up peer facilitated supports**

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Preface

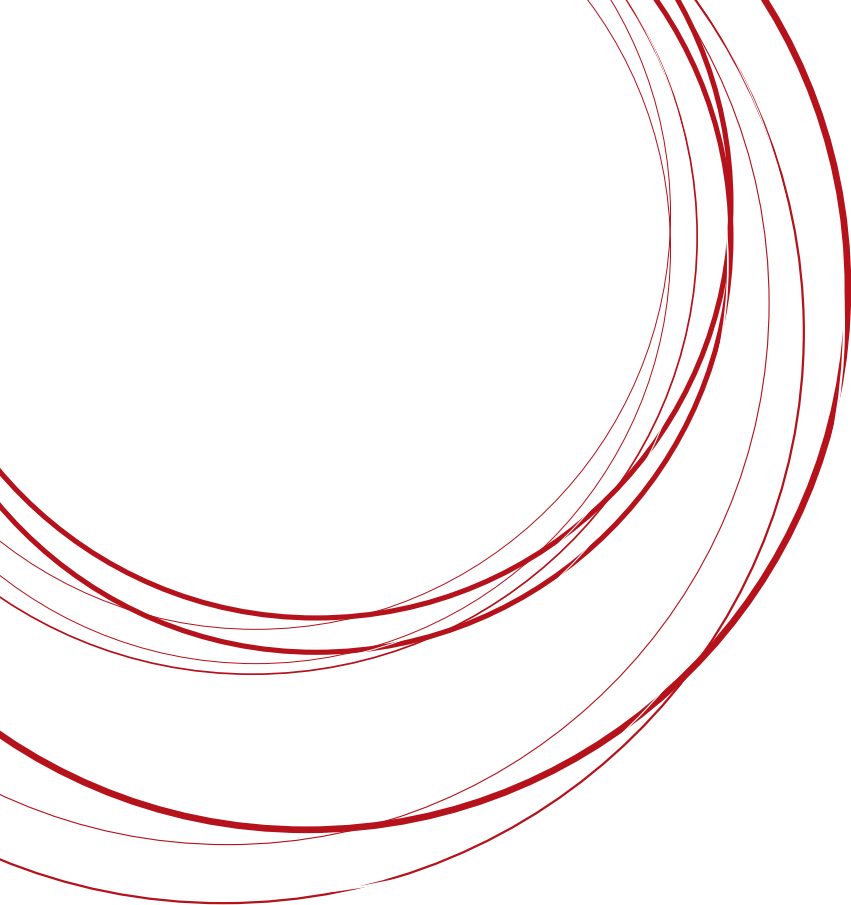
A key component of Cancer Australia's work is to enable consumers affected by cancer to support each other better.

This guide is one of three resources that have been developed in response to a need to ensure that community support networks meet essential quality and safety standards and that support networks are accessible, well coordinated and sustainable.

Cancer Australia does not want to duplicate existing resources. We therefore contracted the Health Issues Centre to work in collaboration with key stakeholders to identify the resources required to assist those who support people affected by cancer, and to develop resources to address those gaps.

Following consultation across Australia and an extensive literature search, the Health Issues Centre found that the Cancer Council NSW resource *Cancer support groups: A guide to setting up and maintaining a group* was an extensively used guide that should be promoted nationally as an excellent resource for people wanting to establish a cancer support group. The review and consultation process also showed that there were limited resources to guide peer facilitators to establish and manage cancer support groups. It was also identified that two further national resources would be useful to complement this resource—a resource describing the principles for people wanting to establish a quality peer support group and a resource designed to provide skills to peer facilitators involved in support groups or networks.

This guide has been developed by Cancer Australia to specifically address the needs of people affected by cancer who want to establish a peer support group for other people also affected by cancer. An accompanying booklet, *Cancer support groups: A guide for peer facilitators*, has also been produced by Cancer Australia to provide information about the skills required for people who are facilitating a peer support group. Both booklets are available from the Cancer Australia website at: www.canceraustralia.gov.au



Introduction

The principles outlined in this resource have been developed specifically for peer facilitators, but would also be useful for health and other professionals planning to establish support groups. The resource has been designed to apply to most situations and be useful to individuals and peer groups, as well as for organisations wishing to start a new cancer support group.

A peer facilitator is a person who has experienced cancer, either by being a cancer survivor, or a carer or family member of a person affected by cancer, who wants to facilitate a cancer support group for people with similar experiences.

Research has found that support groups for people with cancer are beneficial (Herron 2005). Research has also found that if they are not led effectively, they can be quite damaging (Cunningham 2000, Helgeson et al 2001). Cancer Australia recommends that anyone considering starting a support group, network or other option should do so with the assistance of experienced people or organisations, such as the Cancer Councils.

There is no simple way of setting up and running a cancer support group, network, or other option because the illness is so complex—physically and emotionally.

The literature that was reviewed and the consultations that were conducted to develop this guide showed that there are a variety of peer support options. These include:

- face-to-face groups
- online discussion groups
- online bulletin boards
- email groups
- online information and support
- peer-to-peer telephone contact
- video conferencing
- any combination of the above.

This guide refers collectively to the support options mentioned on the previous page. These groups are typically run by health or other professionals (eg nurses, social workers), but some can be and are run by people affected by cancer themselves (eg peer facilitators). Note that online discussions and telephone support are complex options, and require special skills and resources. Your local Cancer Council can provide you with the information and support you need if you decide to set up one of these groups.

How to use this resource

This resource is designed for anyone affected by cancer who is considering starting a cancer support group and who may not have access to professional or experienced support. It raises some key questions about the many issues to be considered in planning such groups. This document offers a set of principles rather than providing a series of guidelines, or a 'to do' list. Principles are the foundation or starting place that can be adapted to changing situations and circumstances.

A successful group will always have a clear purpose and be accessible. How these details are worked out will depend on the group or option being established. In this way the principles are meant to be used as a checklist in the establishment phase and to assist with the development of the aims and objectives of the support group.

Not every question listed under each principle will apply in every situation. The questions are only a guide; other questions can be developed, or existing questions removed according to specific needs.

This guide addresses the many factors that will impact upon the decision to start a cancer support group. The guide also outlines the main principles and other considerations for establishing and maintaining them.

The matrix presented in this section 'Before you start a support group' was designed to give you an overview to assess the possible complexity of starting and running your particular group. Before applying the principles offered in this resource, it is very important to decide who you are planning to work with, and how you will work with them.

The 'Principles for establishing a cancer support group' are presented as a set of questions. The list of questions aims to comprehensively review the main issues that a peer facilitator needs to consider.

After consideration of all of the above, you need to think about how to manage and maintain the support group. The three most important aspects to consider are addressed in the section 'Boundaries, management and seeking support for the management of support groups'. This section includes suggestions and practical examples about:

- boundaries (what is the group about and who is it for?)

- management (how can the group be viable and accountable?)
- support (where can I go to start and what if things go wrong?)

This guide includes sections addressing the production of written material, principles for telephone and online supports, and some specific principles suggested by the literature and consultations to establish and manage cancer support groups for people affected by cancer in specific populations, such as culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander communities, people living in rural and remote communities, groups specifically for men and young people, and people affected by rare cancers.

If you decide to go ahead and establish a cancer support group, the following resources will also help you:

- *Cancer Support Groups: A guide for peer facilitators* (produced by Cancer Australia), which provides information about the skills required for people who are facilitating a peer support group. This resource is available from Cancer Australia's website at www.canceraustralia.gov.au
- *Cancer Support Groups: A guide to setting up and maintaining a group* (produced by the Cancer Council NSW), which is an easy-to-use and practical guide to setting up and maintaining a support group. It is mainly aimed at groups which focus on providing support and information. This resource is available from the Cancer Council New South Wales website at www.cancerCouncil.com.au A number of Cancer Councils in other states have also modified this resource to reflect their state or territory services.

Before you start a support group

Before you start a cancer support group, it would be worthwhile thinking about a number of very important issues.

Some key suggestions: first, if you have had cancer yourself, are you ready to take on this role with all its responsibilities? Are you well now? Was your experience positive or negative? All these factors can impact on the way you operate in the group.

Second, is there a demonstrated need for the group you are thinking about establishing? Have you spoken to your hospital, community health service or the Cancer Council to see if there is anything already established that you could link into? There are a number of peak cancer bodies that have groups for people with particular cancers. You can find a list of the Cancer Councils' contact details and cancer organisations at the end of this guide.

Third, have you consulted with the potential group members to find out what they want? The sooner you involve people in the planning, the more successful the group will be.

Finally, if you are still planning to go ahead, what kind of group will it be? Will it provide social and emotional support or will it concentrate mainly on education and information? What kind of cancer will people have? What stage will they be at in their cancer journey? Each one of these factors will affect the complexity of the group, and the complexity determines the extent to which you need to have support readily available for yourself and for the group members.

The matrix on page 9 gives you an 'at-a-glance' idea of the complexity of the group you want to start. This is only a guide to help you decide how to proceed. This matrix is intended for people thinking of starting a group, rather than for people who are already running groups.

How to use the matrix

To use the matrix, select whether you are going to start a group that will give support through sharing and interacting, or whether it will be a cancer information and education group. If you think the group may cover both, select 'social/emotional', as this is the more complex option. Next, think about the cancer that the members of the group will have and at what stage they will be in their journey. If you are not sure, choose 'mixed groups'; this is the most likely option, especially if you live in a small community.

Move across the matrix from the stage of cancer and down from the type of group to see what colour the square is. The key to the matrix tells you what the colours mean.

For instance, you may want to start a social and/or emotional group for people with any kind of cancer at any stage, including terminal. This kind of group is very challenging, even for experienced professionals. This square is coloured red to reflect that difficulty and complexity. Red squares mean a great deal of support will be needed by you and by the group, so it is recommended you work with a cancer agency or health professional. If you decide you only want to have information evenings for people successfully treated for their cancer, the square is green. You may not need any extra support but it would still be a good idea to collaborate with your local cancer agency in advance. At the very least, you need to think about having a cofacilitator so that you can share the load.

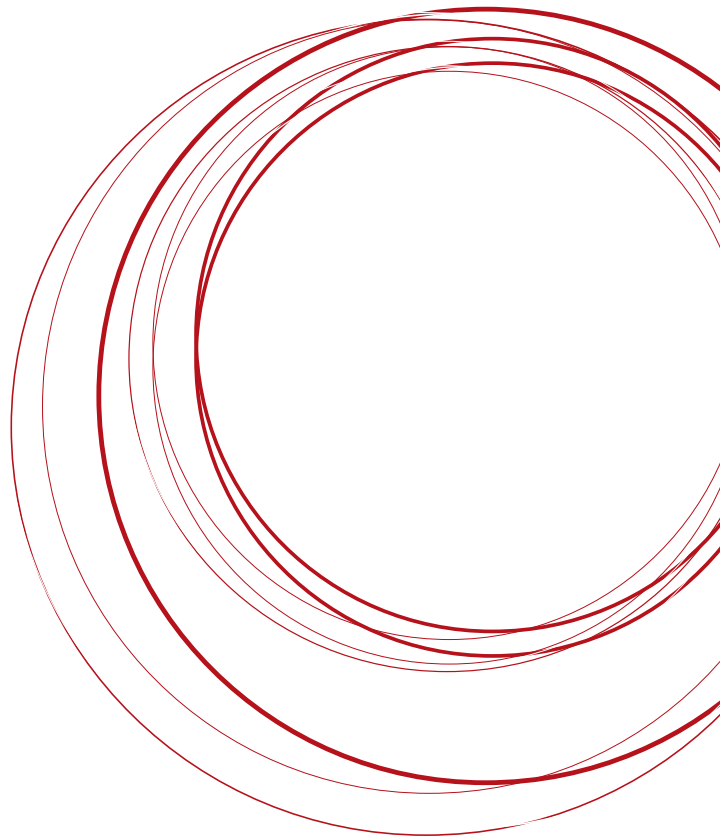
Social and/or emotional groups are those where people meet to share and support one another through their cancer journeys.

Education and information groups are those where people meet to learn more about their cancer and other related issues. These groups would engage the services of a professional to deliver the information.

Health and wellbeing groups provide information and advice on complementary therapies. These are run by professionals.

In reality, there will not be clear boundaries between types of groups or types and stages of cancer. It is most likely that you will encounter different levels of complexity at different times. There are factors that may occur during the life of the group that would change the ratings described above. People may join the group with different needs; for instance, people from different cultural groups, or with complex health issues, including mental health issues. In these cases you should seek advice or support from professionals or cancer organisations.

The most important factor in working with any kind of group is your access to support for yourself and for the group.



Matrix of cancer support group characteristics

GREEN Can be peer led, but support is recommended

'Green groups' are the least complex, because they concentrate on information and education for the members rather than more personal and emotional issues.

Peer facilitators are trained or already experienced in setting boundaries, managing a group and recognising when to seek support.

ORANGE Can be peer led, but only with readily available support

'Orange groups' are groups that are more complex than green groups because of the make-up of the group or the issues being addressed.

Peer facilitators are trained or experienced as for green groups but receive regular supervision (phone, online or face-to-face) to assist them with their group. They work with a cofacilitator, or leader, for regular support. Linking with the nearest Cancer Council or other professional organisation (eg hospital) is highly recommended.

RED These groups are not suitable for peer leaders or facilitators

'Red groups' are the most complex groups and should be facilitated by professionals with experience in dealing with the more complex issues that can arise. However, a peer cofacilitator can play a very important role in these groups, knowing that backup is available.

It is recommended that you consult with a Cancer Council, hospital or other health professional before starting a group in this category.

Stage of cancer	Social/emotional			Education/information			Health and wellbeing		
	Face-to-face	Online	Phone	Face-to-face	Online	Phone	Face-to-face	Online	Phone
1st diagnosis Pre-treatment	orange	orange	orange	green	green	green	red	red	red
During treatment	red	red	red	orange	orange	orange	red	red	red
Post-treatment Remission	orange	orange	orange	green	green	green	red	red	red
Recurrence	red	red	red	orange	orange	orange	red	red	red
Advanced Terminal	red	red	red	red	red	red	red	red	red
Mixed groups (no terminal)	orange	orange	orange	orange	orange	orange	red	red	red
Mixed groups (with terminal)	red	red	red	red	red	red	red	red	red

Principles for establishing a cancer support group

The principles outlined below were developed through the review of existing resources, a literature review, and consultations with key individuals and organisations. They are presented as a set of questions (with the principles implicit). They are the questions that a peer facilitator needs to be able to answer to establish a cancer support group (ie any of the different types of groups or networks or options listed on page 9). Remember that in this guide we use the term 'cancer support group' to refer to many diverse options. Also remember that telephone and online support are complex and it would be better if you seek support for you and the group from experienced people. Cancer Councils are the best resource for this.

Although the principles will not change, the questions presented here are seen only as a guide for reflection and an aid for decision making. Some questions may not be as applicable to your situation; others may be added or changed according to the needs of the person aiming to establish a cancer support group. The section that follows addresses the key issues of establishing a cancer support group.

Meets a need

- ▶ Is there another group with the same aim?
- ▶ Have you talked to or surveyed prospective members to establish their needs or ideas?
- ▶ Are there enough people to form a viable group?

Clear purpose (boundaries)

- ▶ Have the goals of the support option been clearly articulated with input from the people who are going to be part of it?
- ▶ Is the support option going to be for information, emotional support, social interaction or a combination of these?
- ▶ Is it for a particular type of cancer, stage of cancer, age of person, cultural group, etc?

- Have any requirements, policies or procedures been discussed and communicated?
- Will members have to pay to attend the group or will there be free access?
- What hidden costs are involved both for the person or group setting it up and for the participants (eg phone, computer, travel, parking, printing)?
- Will it be easy for people to find out about the group?
- Is the venue easy to find and access (consider parking, public transport accessibility)?
- How will you advertise the group or support option so that people hear about it?
- Is any written material available in a variety of formats (eg downloadable, hard copy, large print, CD, DVD)?
- Can any written material be translated into other languages?

Builds on strengths

- Will the group help members to use and build on existing knowledge, skills and networks?
- Can members participate in roles if they wish (eg chairperson, moderator, librarian, story-teller)?

Collaborative

- Has the group or support option been developed with the input of other relevant consumers and health professionals?
- Have partners and existing supports been identified or suggested?
- Can the group or support option adapt and respond as needs change?

Supportive

- ▶ What kind of agreements have you reached with members about giving and receiving support?
- ▶ Is there an easily accessible source of further information if needed?
- ▶ Have professional and reliable supports been identified?

Inclusive

- ▶ Is anyone welcome regardless of socioeconomic status, age, race, gender, sexuality, etc?
- ▶ Will you use culturally appropriate practice if members are from diverse ethnic groups? How will you find out about culturally appropriate practice (eg including family members, working with communities, talking about death and dying)?
- ▶ If some groups or people are not suitable members, have you considered sensitive ways of conveying this information?
- ▶ How will you maintain membership if numbers drop? (Bear in mind that some members may decide they no longer need what the group offers and some groups are only established for a set period of time).
- ▶ Do you have a process for following up with members who stop attending? Is this process non-intrusive and respectful?
- ▶ Do you have a process for welcoming new members?

Safe

- ▶ Are physical (easy access, comfort, access to toilets, etc) and emotional needs (strategies for dealing with members who are upset, etc) recognised and catered for?
- ▶ Have boundaries been defined and described?
- ▶ Will there be support for members who become distressed?
- ▶ What kind of confidentiality agreement will there be about what is shared in the group?

Comfortable

- What size will the group be? (If it is too big, it is impersonal; if it is too small, it can be too intense.)
- If going across state boundaries (eg phone or internet options), have different time zones been considered?
- If meeting face-to-face, is the room pleasant, the chairs comfortable and facilities readily available? (Aim to meet in a community facility like a Neighbourhood House, community centre, RSL or community health service. Meeting in private homes is not recommended).

Organised and structured (management)

- How is the group going to be organised?
- Will the group have structures or processes in place for its effective running?
- Will records (eg minutes) be kept?
- How do people apply to join or find out about the group?
- How will it advertise itself?
- If any money changes hands, have systems been implemented to account for it?
- Do you need to apply for permission or permits from any groups or agencies?

Skilled leadership

- Will the group be led by a peer, a health professional or other expert? A combination of the two (cofacilitating) is highly recommended.
- Will the leader be trained or be able to access training?
- Will the leader have access to adequate support?

Reflective practice

- ▶ How will reviews and evaluations be incorporated into the process?
- ▶ How will the group review the feedback and incorporate it into the group process?
- ▶ Will there be opportunities for members to share successes and learning?
- ▶ How will I seek feedback on my effectiveness as a facilitator?
- ▶ How can I build on my strengths?

Boundaries, management and seeking support

Outline

This section addresses the main issues related to managing a cancer support group. These three main issues—boundaries, management and seeking support—need to be considered after you have decided what type of cancer support group you will be working with (using the matrix), and after you have looked into the main principles for establishing a cancer support group. Fictional stories are provided to illustrate each issue. They are not to be interpreted as necessarily ‘the way to go’; rather, the stories illustrate some pitfalls and challenges, and ways of addressing them.

The text below the boxes expands on the stories.

Establishing and maintaining boundaries

Establishment

When establishing a support group, clearly defined boundaries are vital. Boundaries are a statement about what the group does and who it is for. Boundaries also define what is appropriate and what is not; for instance, whether leaders can be contacted at any time, even when it’s not convenient. If you don’t want this to happen, then boundaries around when you can be contacted will need to be set.

CASE STUDY

Angela decides to set up a lung cancer support group following her own successful surgery and treatment. She advertises within her community and says that everyone is welcome. At the first meeting, ten people turn up, including Ernest, who is in the terminal stages of his lung cancer; Tom, who has just finished chemo and is still looking and feeling very unwell; and Maureen, who is attending to get support following the death of her husband Chas two months ago. Angela is quite unprepared for dealing with the needs of Ernest, Tom and Maureen and the rest of the group is looking to Angela for guidance.

Angela started her group without establishing any boundaries. Having said everyone was welcome, each person who attended took the invitation seriously and expected to have their individual needs met. She did not say who the group was for or what the group would be doing, which meant that people reading the information interpreted it in their own way. She also did not give people a chance to participate in the formation of the aims of the group before they attended the first meeting, therefore she had no idea what their needs and interests were.

CASE STUDY

Cheryl decides to set up a lung cancer support group following her own successful surgery and treatment. She thinks about what the group can do and who it could be for. She decides that if she works alone, she is only able to cope with an information and education group. Initially, she decides to start with such a group. She also thinks about who the group should be established for and decides to limit it to people who have recovered from surgery and treatment, but who may still want more information about rehabilitation. She talks to the local physiotherapist who helped her after her surgery and asks if she would be willing to run four sessions on exercise and strength building. These sessions will be conducted over a period of eight weeks.

The physiotherapist agrees and together they place advertisements that state clearly what the sessions are about and who they are for. Eight people turn up for the first session, which goes very well. Even more turn up for the next one. After the four sessions the people who attended decide to continue meeting as an information and education group.

Cheryl is very clear about what the group will do and who it is for. She limits who can come according to her own knowledge and information, and is therefore able to manage the group when it forms. She also seeks some professional help in the establishment phase. Once the group forms, she may or may not continue the help but she is clear about what she can do and what she needs others to do.

Maintenance

Boundaries have a way of getting stretched and successful facilitation of a support group means staying alert to this happening. It can happen quite gradually as agreements are relaxed and incidents are ignored rather than dealt with. Maintaining healthy boundaries involves being clear and at times assertive.

CASE STUDY

Cheryl's information and education group has been running successfully for six months. Jim is a regular attendee. One evening he brings his friend Ken with him to the meeting. Ken has recently been diagnosed with a recurrence of his cancer and he is very upset. Jim thinks that the group is a good place for Ken to get support because everyone is so friendly. Ken shares his story at the beginning with the group and Cheryl takes a deep breath. She knows that Ken won't get his needs met in the group and that some members will also be upset having Ken there. During the break she talks to Jim and Ken. She tells Ken that the group is not the best place for him to get the kind of support he needs, but that she knows of another group that meets nearby where he can get more appropriate support. She offers to introduce him to the leader of this group. Ken is relieved to get this information and Jim offers to attend the first session with him.

Cheryl noticed the boundaries being stretched. It would have been much easier and far less awkward for her to say nothing, but she knew this would not be in anyone's best interests. She had prepared herself for situations like this by having information readily available to give to someone like Ken, who may just turn up. She also offered to support him so that he did not feel he was being rejected by the group. She spoke about his needs rather than the group's needs and this helped as well.

When boundaries are clearly established, it is far easier to maintain them. Each group needs a clearly written and agreed statement about what the group does and who it is for. People who do not fit the criteria will not get their needs met and can be referred somewhere more appropriate. The criteria can be set around age, gender, location, ethnicity, type of cancer, stage of cancer, type of activity, and more.

Boundary statement

This is an example of a boundary statement:

This information and education group is for young women under 40 years of age living in the Greenacre region who have recently been diagnosed with breast cancer. The group meets on the first Monday evening of the month to listen to information about treatment options and the latest research.

A statement such as this makes it easy to maintain the boundaries if, for instance, a woman aged 50 applies to join the group. The group leader can say:

The group is best suited to young women because of their special needs. I can give you the number of the Cancer Council Helpline who will be able to put you in touch with other groups that may be better suited.

If someone in the group suggests inviting older women to join, the leader can say:

This group is especially for younger women who have very different needs to older women. Let's discuss whether we want to expand our guidelines. What do others think?

Confidentiality and disclosure

In establishing and maintaining a group, other issues where boundaries can become blurred or stretched are confidentiality and disclosure.

At the beginning of any new group, and as each new person joins, the issue of confidentiality should be raised. The group needs to be clear about what stays in the group and what can be shared. Confidentiality agreements

often state that any identifying or personal information remains confidential, but that more general information can be shared. However, some groups may decide that nothing that is said in the group can be shared. It is up to each individual group. The group also needs to discuss what will happen if confidentiality is breached.

Confidentiality also extends to group members' personal data, such as addresses, phone numbers and email addresses. This is discussed in the section 'Managing a group'.

Agreements around disclosure are also important. While self-disclosure can be very powerful for the person disclosing and for the people listening, it's not always appropriate in every situation. In education and information groups, disclosure is less appropriate than it is in emotional and support groups. The extent to which group members are encouraged to (or discouraged from) self-disclosure is another area for negotiation within the group. Disclosure can raise feelings in people that the group may not be able to handle; therefore, peer facilitators who do not have specific expertise will need to ensure that support is readily available. The Cancer Council Helpline is available during business hours, phone 13 11 20.

Managing a group

A clear structure for managing the group will help the current leader and any future leaders. It also gives the group a sense that they are part of something well organised and well thought through.

Some management issues to consider are listed below.

Finances

Will group members be paying any money for any reason? If so, how will the money be collected, held and accounted for? At a very minimum, if significant amounts of money are exchanged, a receipting system, a banking system and an invoicing system need to be in place. New groups may not want to start up a bank account as this requires properly constituting the group and electing office-bearers. They may opt for a locked money tin held by a member of the group, with all money given by members receipted and the details entered into a cash book. If this system is used, the amounts of money collected should be quite small—for instance, taking up a collection

to put towards catering or the fees for a guest speaker. If the amounts become regular or large, the group should consider becoming incorporated to protect individual members and set up a bank account. Groups that operate in partnership with other legally constituted bodies could enter into an arrangement with them to use their banking facilities.

No matter how close and trusting the members of a group are, it is important to have transparent financial systems in place.

Funding

You need to think about how you are going to fund the activities of the group. There are many ways of raising and attracting funds but they are time consuming and also require accountability. Most fundraising activities can only be conducted if you are an 'incorporated' body. Being incorporated makes your group a legal entity and offers some protection to individual members. To become incorporated you will need to write a constitution and hold a meeting to elect office-bearers. There are organisations and government departments that can help you, for example, with a model for a constitution. Government departments change names from time to time. You may need to look on the internet for 'becoming incorporated', to find the right department. Usually it's housed in consumer affairs or fair trading. Check with your local Cancer Council to see if they can advise or help you with raising funds.

Record keeping

Who will keep the members' details? People are quite rightly concerned that their private details remain private. Someone in the group needs to take responsibility for holding this information in a safe place. Your group will need to agree whether personal information (eg phone numbers and email addresses) are shared or kept private.

An easy way of inadvertently disclosing personal information is through sending group email messages. Each email address that appears in the 'To' section of the message can be seen by each recipient. To avoid this, the member sending the email message can send it to him or her self and include all the other members on the list in the 'Bcc' section. Email addresses in 'Bcc' cannot be seen by any recipient.

Other records can include meeting minutes, correspondence, accounts and statements. All these records need to be kept in a safe place and in an organised way.

Leadership issues

Some group members become very dependent on their founder or on a particular group member. Sometimes these people become very dependent on the group as well. Each person who takes a leading role in a group needs to plan to hand over at some point. That is why it's better to have roles rather than depend on individuals. When roles are clearly defined it makes it easier for others to step in and take over. When groups become dependent on a particular member, that person becomes indispensable, which is not healthy for the ongoing success of the group.

Ways around reducing the dependency include allocating tasks to other members rather than handing over the whole role. Some people can be resistant to taking responsibilities, but may for instance be willing to take over the banking or membership list. As individuals gain confidence performing the tasks, they can take over the role for periods of time as a trial. The member already in the role can support and coach them during that time. Having a cofacilitator from the start can overcome many of these issues.

Trusting others to perform a task or role that the currently responsible member knows (or believes) he or she is doing well can be challenging. It is, however, important to let go and allow others the opportunity to develop their skills. They may not do it as well as the incumbent, but there are many different ways of doing things.

Resolving conflict

There are many effective ways of resolving conflict. An internet search will provide you with many good sites offering great tips. Conflict Resolution Network is an Australian organisation that has been operating for over 20 years. For more information, see www.crnhq.org

Conflict is a group issue and everyone needs to play a part in resolving it, not just the facilitator. Many conflict resolution practitioners and theorists would suggest the following as strategies for dealing with conflict:

- ▶ Deal with it as it arises; leaving it doesn't solve it.

- ▶ Choose your battles. Let it go if it **really** doesn't matter; decide if it's a minor or major issue (this does not cancel out the point above).
- ▶ Say what you want, not what you don't want to say; suggesting possibilities and recommending ways forward is easier to hear and more effective than complaining and criticising.
- ▶ Speak for yourself; say how you feel and let others say how they feel.
- ▶ Deal with the problem first and the effects thereafter. For example, members arriving late is the problem, disruption is the effect; find ways to encourage members to arrive on time.
- ▶ Make problem solving a collaborative activity. Groups are far more likely to implement solutions if they had a part in shaping them.
- ▶ When you're angry, listen more than speak.
- ▶ Listen more than speak.

Be prepared—knowing when and where to seek help

The matrix on page 9 of this document gives an at-a-glance idea of the complexity of running a support group and the type of facilitator and backup needed for each type of group.

In an ideal world, these three group divisions (red, orange and green) would be clear cut and easy to organise, but it is not an ideal world. In some places, with a smaller population for instance, it may not be possible to separate people according to the stage in their cancer journey, and support may not be as readily available. In the same vein, straightforward information delivered to an education group could have the capacity to upset a person in the same way as hearing a personal story in an emotional or social group. Therefore, the lines between green, orange and red could, and possibly will, be blurred.

Many subsequent problems can be averted, or at least prepared for, by thinking about the following issues BEFORE the group is established:

- ▶ Who the group is for?
- ▶ What it will do?

- ▶ How it will do it?
- ▶ How it will be managed?
- ▶ Who is available for support?

Asking for help can sometimes feel like an admission of failure. In reality it is an admission of strength. Timely assistance can prevent issues from developing and will build stronger trust in the group.

CASE STUDY

During an education session on how cancer develops and spreads, Donna notices that Naomi is looking uncomfortable. A few minutes later Naomi starts to sob and is very distressed. Donna turns the focus away from the information and together with the group, listens to Naomi. Other members share how they are feeling as well. Naomi decides she needs to go home and talk to the Cancer Council Helpline.

Naomi calls her husband who collects her and takes her home. After the group session, Donna calls Sophie, a social worker who has offered to support her in her role as facilitator of the group. She talks about what happened and how she is feeling and is reassured by Sophie that she did well; she knew how to support herself and the group.

Being familiar with a variety of strategies to deal with predictable incidents increases the likelihood of being able to call on them when the need arises. In this case, Donna had a plan for dealing with upset people. She understood that a distressed member needs immediate support, no matter what was planned for the group. She also knew that after such an incident she needs to debrief, and had a strategy in place for this.

Not every possible problem can be predicted, but many of the more common ones can. Therefore, the more familiar the facilitator is with an approach to dealing with a problem, the easier it is to call on it when the time comes.

Contact your local Cancer Council to find out if there are any relevant or useful training courses available near you. Even if you are already an experienced facilitator, the extra information and the networking will add to your existing skills.

Principles for developing written materials

The following questions may help you produce written materials for your cancer support group or support option. They have been developed based on best practice principles for effective information management.

Accessible

- Is the material free?
- Can it be accessed easily?
- Is there a dissemination plan?
- Is it available in a variety of formats (eg downloadable, hard copy, large print, CD or DVD)?
- Can it be translated into other languages?

Readable (for written materials)

- Does it use plain language?
- Is the language inclusive? (Avoid using 'he' to describe males and females, include examples from other cultures, etc.)
- Has it been tested for readability and understandability with consumer input?
- Is the formatting attractive (plenty of white space)?
- Are illustrations and examples used to help describe concepts?
- Is there an index and table of contents for easy reference?
- Are there quick links if in a web-based format?
- Is there a glossary of terms?

Practical

- Are the concepts presented in an easy-to-understand format?
- Can the practical suggestions be implemented without extra information or training?
- Can it be used effectively without the need for previous experience or qualifications?

Informative

- Is there sufficient information?
- Is the information easy to process?
- Does the information cover contingencies?
- Are sources of further information mentioned?

Current

- Is the material based on the most recent evidence available?
- Can the information be easily and regularly updated?

Adaptable/transferable

- Is the material relevant to all support activities regardless of the type or location of the group?
- Will it work for different genders, ages, tumour groups?
- Will it work for different literacy and general ability levels?

Professional

- Are contributors named and acknowledged?
- Are references included?

Supported

- Is there an easily accessible source of further information or support provided?

Principles for telephone and online support

When considering establishing a telephone or online support option, we recommend that you seek advice from Cancer Councils and peak cancer organisations that have already established support systems.

For example:

- ▶ Cancer Council New South Wales—Telephone Support Groups
www.cancerCouncil.com.au
- ▶ Leukaemia Foundation of Australia—Talk Blood
www.leukaemia.org.au
- ▶ The Australian Lung Foundation—LungNET_Can Help
www.lungnet.org.au

Identifying management needs

- ▶ Have you considered the need for support from a professional organisation?
- ▶ Are you aware that this support group or support option needs to be run by professionals who know the risks and safety issues?
- ▶ Will you have structures outside the group where people can access counselling?
- ▶ Have you established a system by which members choose the topics of conversation?

Establishing boundaries and safety

- Are you familiar with the structure and procedures needed to conduct a telephone support option (eg procedures for dealing with people who are suicidal)?
- Are you familiar with the strict guidelines relating to the format of the group (eg privacy, anonymity, expectations, equal participation)?
- Have you considered that this option may not work for specific patients (eg people with communication problems)?

Principles for the establishment and management of specific cancer support groups

The following information is not meant to be used as a step-by-step guide. The population groups described below are highly complex and create challenges for even the most experienced leaders. If you are thinking about starting such a group, we recommend contacting the cancer organisations listed in each section, or your Cancer Council, and seeking their support and guidance.

These principles were developed to fill a perceived gap in the support of people affected by cancer in specific population groups, such as culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander communities, people living in rural and remote communities, groups specifically for men and young people, and people affected by rare cancers.

These principles were developed for peer facilitators and organisations. They should be read in conjunction with the Cancer Council NSW's *Cancer support groups: A guide to setting up and maintaining a group* and the 'Principles for establishing a cancer support group' outlined in this guide. These principles are not exhaustive and it is important to bear in mind that more research and partnership work needs to be undertaken to produce tailored guidelines for working with specific communities.

These principles should also be used in conjunction with the processes to identify the type of support option to be established (based on the matrix offered in this guide), and the three main issues for maintaining cancer support groups (boundaries, management and seeking support).

These principles were developed following consultation with individuals working in this field and after a comprehensive review of available literature.

Aboriginal and Torres Strait Islander communities

The information contained below is a synthesis of discussions with individuals representing their own communities or projects. Each situation with Aboriginal and Torres Strait Islander peoples will differ across communities and states. Some key themes have emerged and are discussed below.

Honouring culture

- Before establishing any cancer support group for an Aboriginal or Torres Strait Islander community it is important to understand the cultural considerations that may exist within that particular community. Recognise that in some Aboriginal and Torres Strait Islander communities, particularly those in rural and remote areas, the cultural understanding of wellbeing and health may be quite different from the bio-medical model adopted by health services. This is particularly important in understanding an individual's perspective of cancer and the treatment process, and the community's acceptance of a particular medical approach. It is important not to go into a community with a preconceived view of what is required.
- Community Elders and other community leaders will be able to advise you on specific cultural considerations that you will need to acknowledge within the community. For example in some communities it is inappropriate to speak the name of someone who has died. If the intention of a support group is to include the support of family members, facilitators of groups need to be particularly aware of the cultural sensitivities and traditions associated with death and dying.

Consultation is essential

- It is essential that you carefully consult with Elders, relevant community leaders and community health workers and staff at the community medical clinic or Aboriginal Medical Service to ensure that the support you provide to people affected by cancer meets the needs of that particular community.
- Consultation must occur in a sensitive way that is mindful of the culture, values and historical perspective of the particular community. Do not assume that all communities are the same or that all individuals within a particular community have the same values or cultural needs.

Be Flexible

- ▶ Supporting Aboriginal and Torres Strait Islander peoples affected by cancer will be dependent on different individual and community circumstances. It is important to be flexible in your approach to providing support. Membership of a group may fluctuate depending on what is happening in a particular community. The support needs may also vary from community to community. In some communities there will be the need to provide child care during meetings as many participants will bring their children or grandchildren. Transport to and from meetings may also be required, and in some communities it is culturally appropriate to provide food to share when a group meets.
- ▶ Support processes can be provided through a number of approaches. Support may arise both formally and informally and these different approaches are discussed in the case studies on the following pages. Support may arise through already established community arrangements and this is highlighted by Roslyn's story below. In addition, support links may be established by organisations in response to emerging issues that impact on Aboriginal and Torres Strait Islander peoples receiving the best available cancer care and this is discussed in the subsequent case study provided by the Cancer Council Northern Territory.

CASE STUDY

It is a natural thing for women to come together. We share our culture, our experiences and our stories. We support each other in our daily lives. Our group started small and grew out of our need to share our stories about cancer. I am a cancer survivor; I understand this situation well. The emotional support we offer each other is part of what we already do as a community. We visit people in their homes and gather for Sunday lunches with family members in our homes. We found funding to help with transport to enable people with cancer and their families to go to the gatherings and so we can visit people at home. The groups are informal; the most important thing is the social support we give and receive.

Roslyn Weetra, Aboriginal survivor of cancer, South Australia

Communicating information about cancer to Aboriginal and Torres Strait Islander peoples

- ▶ When presenting material on cancer be aware that some of the material produced for 'consumers' may not be appropriate for an Aboriginal or Torres Strait Islander person affected by cancer.
- ▶ An individual's knowledge of cancer and acceptance of treatments and services may be affected by traditional views and treatments, and may be influenced by past experiences.
- ▶ Be mindful of the fact that English may not be the first language of many Aboriginal and Torres Strait Islander peoples. People providing information to Aboriginal and Torres Strait Islander peoples need to consider innovative ways of presenting health information about cancer treatment and support, that do not rely solely on the written language.

CASE STUDY

Polo Ralph Lauren is a designer and a philanthropist. Funding was sought from Polo Ralph Lauren Foundation by the Cancer Council NT for the training of Indigenous community leaders to act as peer support for people affected by cancer; mainly women with breast cancer.

Most people in remote Indigenous communities are shy and fearful about coming to Darwin for medical treatment. Many believe cancer to be fatal, “a death sentence” and often see it as “payback”. They often do not seek treatment and there are relatively low levels of compliance with medical treatments. These communities need someone they trust to deliver the message that cancer can be treated, etc. The project trains community leaders, who are trusted by the community.

The project trained six women from three communities over two days in Darwin in 2006. Each community sent two women so they could support each other after their return. These trainees have a relationship with the Cancer Council through the Breast Care support nurse who is employed by the Cancer Council. The nurse has visited all the trainee volunteers in their communities and calls them often to see how are they going.

The cancer journey for people in these communities is strongly influenced by their cultural responsibilities. They are committed to teaching others what they know. When they are diagnosed with cancer or ill, they often feel they must spend the time telling others their cultural knowledge. This leaves no time to attend treatment. The trained peer supporters talk with the communities about the importance of treatment and reinforce that cancer is not a death sentence.

The Cancer Council refers people they have identified as being affected by cancer to these peer volunteers and they talk with them in their communities.

Peer support people don't have to have cancer, but they know the community and the community trust them; they can speak with them because they share knowledge and culture.

Helen Smith, Chief Executive Officer,
Cancer Council Northern Territory

Culturally and linguistically diverse communities

These principles were developed after consultations with representatives of the Chinese community and do not apply to all culturally and linguistically diverse communities. However, they have general applications for other collectivist cultures.

Honouring the culture

- Have you identified migration history or length of community settlement in Australia?
- Do you understand historical social, political and economic factors affecting these communities?
- Have you considered cultural preferences for meeting places, times, gender mixes, etc?

Involving the community

- Have you integrated peers and volunteers to work alongside mainstream program workers?
- Will you involve family members and carers? And how?

Ease of access to information in first language

- Will you use interpreters when appropriate?
- If so, how will these be identified and funded?
- Do you have access to equipment for recording talks? (These can be either in a specific language or translated and then made available to the community.)
- Have you thought about accessing information from overseas (in the relevant language) and seeking permission to reproduce it?
- Is there someone who can act as a conduit between the community and sources of information (eg health services)?

CASE STUDY

In the Chinese community and in some other culturally and linguistically diverse communities there is stigma attached to cancer, and people don't want to talk about the disease or about death and dying. Some people believe it's contagious or that it's a punishment. The support group helps them to accept that cancer is just like any other disease. In the group they feel comfortable with and respected by the other members. The relaxed environment offers an opportunity for them to share experiences in their own language and support each other in many ways. Occasionally, discussion of loss and grief among members at meetings helps each other acknowledge mortality and add meaning to the loss. The Chinese Cancer Society has been going since 1996 and support groups are held in three different locations: Box Hill, Footscray and Springvale (Victoria). We have some funding from the Victorian Department of Human Services through their Health Self-Help Grant, and we are able to get the meeting room for free in the Footscray Library.

At the beginning, people were recruited through nurses and social workers in the hospitals and also through the Cancer Council Victoria. Now, many cancer sufferers get to know us through word of mouth through the community. I speak both Mandarin and Cantonese and most group members speak both languages. If members speak either Mandarin or Cantonese, we will interpret for them at meetings. Sometimes we have two separate groups, one for Mandarin and another for Cantonese speakers. We offer home visits and phone support to people who cannot attend the meetings for various reasons. We train volunteers to help them do their work more effectively and safely. Most of the volunteers are cancer survivors or family members and carers.

Dorothy Yiu (Social Worker),
Founder and President of the
Chinese Cancer Society of Victoria

www.ccsv.org.au

People affected by rare cancers

Groups for people with rare cancers will be complex because of the nature of the cancer and because there may be insufficient numbers of people to maintain the viability of a support group. Innovative ways of supporting people with rare cancers need to be considered, such as over the phone support or via the internet.

We recommend, however, that you work with the Cancer Council or other cancer key specialist organisations when considering support options for rare cancers. For example:

- ▶ Cancer Council New South Wales, Telephone support group for people with pancreatic cancer and other rare cancers
www.cancerCouncil.com.au
- ▶ Leukaemia Foundation of Australia—Talk Blood Cancer
www.talkbloodcancer.com

Acknowledging psychosocial needs

- ▶ Have you considered the specific psychological needs of members? (Some cancers have a poor survival rate. Supporting people in these situations involves care and skill.)
- ▶ Will you seek professional support? From where or whom?
- ▶ Will you be able to provide follow-up support (eg after meetings or telephone calls)? How?

Engaging relevant others

- ▶ Will you involve family members and carers? How?
- ▶ Will the needs of carers be considered (eg meetings, support)?

CASE STUDY

Tumours of the brain are complex and impact greatly on the life of the person with the tumour and their families. Starting a support group for people with brain tumours takes a lot of planning. For instance, getting to meetings can be difficult for some people so transport, access and parking need to be attended to. The disease itself is very confronting and many people feel frightened and vulnerable when they first join the group. To meet the needs of the group members who attend, we need to make sure that the facilitator is very experienced and that members who become distressed have immediate support. It is sometimes desirable to encourage a buddy system for this.

When group members are too tired or sick to attend meetings, some phone-based support needs to be available. There is also online support. The facilitator needs to be alert to make sure members are not given false information or false hope. The facilitator also needs to take members offline from time to time if he or she notices their distress.

Clare Vivian, Victorian Chair,
Brain Tumour Australia

Young people

We recommend contacting and working with CanTeen if you are considering support groups for young people affected by cancer. CanTeen is the national organisation established specifically to meet the needs of young people aged 12–24, siblings and bereaved siblings. CanTeen has been operating since 1985 and has nine offices around Australia.

CanTeen's contact details are at www.canteen.org.au and are listed below:

ACT

Street: 2/45 Wentworth Ave,
Kingston ACT 2604
Post: PO Box 4591, Kingston ACT 2604
Phone: (02) 6262 8133
Fax: (02) 6262 8166
Email: act.admin@canteen.org.au

Victoria

Street: 161 Flemington Rd,
North Melbourne VIC 3052
Post: PO Box 63, Parkville VIC 3051
Phone: (03) 9329 5288
Fax: (03) 9329 3722
Email: vic.admin@canteen.org.au

Sydney and Central NSW

Street: Residence 2,
Prince of Wales Hospital,
Barker St, Randwick NSW 2031
Post: PO Box 1000, St Pauls NSW 2031
Phone: (02) 9382 1563
Fax: (02) 9382 1565
Email: nsw.admin@canteen.org.au

Tasmania

Street: 38 Cromwell Street,
Battery Point TAS 7004
Post: PO Box 63,
Battery Point TAS 7004
Phone: (03) 6223 7550
Fax: (03) 6223 7599
Email: tas.admin@canteen.org.au

Hunter and Northern NSW

Street: Suite 2, Ground Floor,
14 Albert St,
Wickham NSW 2293
Post: PO Box 2134, Dangar NSW 2309
Phone: (02) 4940 0330
Fax: (02) 4940 0608
Email: hunter.admin@canteen.org.au

Queensland

Street: 2/24 Light Street,
Fortitude Valley QLD 4006
Post: PO Box 2103,
Fortitude Valley BC QLD 4006
Phone: (07) 3252 9262
Fax: (07) 3852 5845
Email: qld.admin@canteen.org.au

North Queensland

Street: 15 Ingham Road,
Townsville QLD 4810

Post: PO Box 264,
Hyde Park Castletown QLD 4812

Phone: (07) 4729 9600

Fax: (07) 4724 3327

Email: nqld.admin@canteen.org.au

WA

Street: A H Crawford Lodge,
55 Monash Ave,
Nedlands WA 6009

Phone: (08) 6380 1884

Fax: (08) 6380 1885

Email: wa.admin@canteen.org.au

SA and NT

Street: Norwich Centre, Level 1,
77 King William Rd,
North Adelaide SA 5006

Post: PO Box 107,
North Adelaide SA 5006

Phone: (08) 8161 7488

Fax: (08) 8161 6435

Email: sa.admin@canteen.org.au

Rural and remote communities

Establishing groups or other support options in rural and remote areas may be complicated by insufficient numbers of people to sustain the viability of a group. In general, these groups will have members with different cancers and at different stages, creating competing needs. Working with a professional, or at least a cofacilitator, is recommended.

There are a number of other issues that relate to smaller communities:

- Confidentiality; people know one another in smaller communities and confidentiality can be more difficult to maintain.
- The closeness that usually exists within rural communities may affect group dynamics, particularly if a member dies.
- Consistency of attendance; people often go away for treatment and as such can't attend meetings during those times. This can lead to instability with numbers.

Using community resources

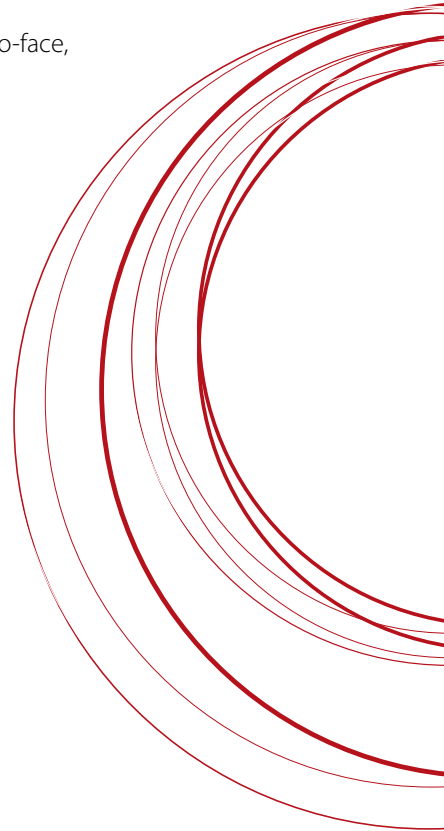
- Have key individuals in the community been identified?
- Can key individuals be trained to fulfil the role of facilitator or leader of the group in their community?
- Have other resources been identified (eg meeting space, facilities for video links, sources of free publicity, etc).
- Can you partner with other organisations? (Even if they are not related to health or cancer, eg Country Women's Association, agricultural society, service clubs).
- Can you partner with businesses in rural and remote areas? (These businesses could help with publicity, deliveries, funding, etc.)

Support

- ▶ Can individuals meet for training and support?
- ▶ Have sources of funding been identified to enable this to happen?
- ▶ Can support be via phone, internet, etc?

Flexibility

- ▶ Can speakers be funded to travel to remote areas?
- ▶ Can existing transport options be used to move people around (community buses, transport companies, car pooling, etc)?
- ▶ Can face-to-face groups meet in different places to optimise participation?
- ▶ Can the group mix support options; partly face-to-face, partly online or phone?



Men

Supporting men affected by cancer may require different approaches. Men with cancer have a range of support and information needs and yet, compared to women with cancer, men are very low users of cancer support groups. A number of studies have shown that men can find it difficult to talk openly about their condition and its implications, and yet they can feel very vulnerable and alone. Men appear to want specific information and practical advice about managing symptoms. If you are setting up a support group or option specifically for men you need to carefully take into account male values and be flexible in your approach.

CASE STUDY

A good way to target men is through sporting or service clubs such as Rotary or the Lions Club. Another good way is through their wives and their contacts. Speaking to or engaging guys through their wives and their meetings can be very effective. This worked really well for me in Albury where I was invited to speak to a breast cancer support network about men's health. Over 92 women and 103 blokes attended—some blokes brought their mates along as well!!!

John Stubbs, Cancer Voices Australia

Cancer Councils and organisations

The Cancer Council ACT

5 Richmond Avenue
Fairbairn ACT 2609

Tel: (02) 6257 9999

Fax: (02) 6257 5055

Email: reception@actcancer.org

Web: www.actcancer.org

The Cancer Council NSW

153 Dowling Street
Woolloomooloo NSW 2011

Tel: (02) 9334 1900

Fax: (02) 9358 1452

Email: feedback@nswcc.org.au

Web: www.cancerCouncil.com.au

The Cancer Council Northern Territory

Units 1–3, Casi House,
Vanderlin Drive
Casuarina NT 0810

Tel: (08) 8927 4888

Fax: (08) 8927 4990

Email: admin@cancernt.org.au

Web: www.cancerCouncilnt.com.au

The Cancer Council Queensland

553 Gregory Terrace
Fortitude Valley QLD 4006

Tel: (07) 3258 2200

Fax: (07) 3257 1306

Email: info@cancerqld.org.au

Web: www.cancerqld.org.au

The Cancer Council South Australia

202 Greenhill Road
Eastwood SA 5063

Tel: (08) 8291 4111

Fax: (08) 8291 4122

Email: tcc@cancersa.org.au

Web: www.cancersa.org.au

The Cancer Council Tasmania

180–184 Collins Street
Hobart TAS 7000

Tel: (03) 6233 2030

Fax: (03) 6233 2123

Email: infotas@cancertas.org.au

Web: www.cancertas.org.au

The Cancer Council Victoria

1 Rathdowne Street
Carlton VIC 3053

Tel: (03) 9635 5000

Fax: (03) 9635 5270

Email: enquiries@cancervic.org.au

Web: www.cancervic.org.au

The Cancer Council Western Australia

46 Ventnor Avenue
West Perth WA 6005

Tel: (08) 9212 4333

Fax: (08) 9212 4334

Email: inquiries@cancerwa.asn.au

Web: www.cancerwa.asn.au

The Cancer Council Australia
GPO Box 4708, Sydney NSW 2001
Level 1, 120 Chalmers St
Surry Hills NSW 2010
Tel: (02) 8063 4100
Fax: (02) 8063 4101
Email: info@cancer.org.au
Web: www.cancer.org.au

Australian Lung Foundation
www.lungnet.com.au

**Australian Council of
Stoma Associations**
www.australianstoma.com.au

Asthma Foundation of Australia
www.asthmaaustralia.org.au

Beyond Blue:
the national depression initiative
www.beyondblue.org.au

Brain Foundation
www.brainaustralia.org.au

Breast Cancer Action Group NSW
www.bcagnsw.org.au

Breast Cancer Network Australia
www.bcna.org.au

BreastScreen Australia Program
www.breastscreen.info.au

Cancer Voices Australia
www.cancervoicesaustralia.org.au

CanTeen
www.canteen.org.au

Guard Against Cervical Cancer
www.cervicalcancer.com.au

**Gynaecological Cancer Society
Queensland**
www.gcsau.org

Kids Cancer Support Group
www.kcsg.org.au

Kylie Johnston Lung Cancer Network
www.kjlcn.org.au

Leukaemia Foundation
www.leukaemia.org.au

**Lions Australian Prostate Cancer
Website**
www.prostatehealth.org.au

Myeloma Foundation of Australia
www.myeloma.org.au

My Parent's Cancer (Australia)
www.myparentscancer.com.au

**National Breast and Ovarian
Cancer Centre**
www.nbocc.org.au

National Ovarian Cancer Network
www.ovca.org.au

Ovarian Cancer Program

www.ovariancancerprogram.org.au

Prostate Cancer Foundation of Australia

www.prostate.org.au

Skin and Cancer Foundation Australia

www.scfa.edu.au

Sydney Cancer Centre Foundation

www.sydneycancer.com.au

The Lymphoma Research Foundation
of America

www.lymphoma.org

The Melanoma Foundation

www.melanomafoundation.com.au

Cancer Voices

Cancer Voices Australia

www.cancervoicesaustralia.org.au

Cancer Voices Australian Capital
Territory

(available via email through

[www.cancervoicesaustralia.org.au/
links.htm](http://www.cancervoicesaustralia.org.au/links.htm))

Cancer Voices New South Wales

www.cancervoices.org.au

Cancer Voices Victoria

www.cancervoicesvic.org.au

Cancer Voices Western Australia

www.cancerwa.asn.au

Cancer Voices South Australia

www.cancervoicessa.org

Cancer Voices Queensland

www.cancervoicesqld.org.au

Cancer Voices Tasmania

[www.cancertas.org.au/pages/
CancerVoices.php](http://www.cancertas.org.au/pages/CancerVoices.php)

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