

What we know about cancer support groups



This fact sheet is one in a series developed about cancer support groups in NSW. Studies show that support groups can enhance participants' self-esteem, improve their relationships, and reduce depression and anxiety.

In NSW, about 36,600 people are diagnosed with cancer every year. Many people who have been diagnosed with cancer say it's one of the most stressful experiences they have been through.

Several studies have documented the psychological distress associated with a cancer diagnosis, and found that peer support can reduce this distress.

The information in this fact sheet is based on a Cancer Council NSW study⁽¹⁾ showing that peer support has a positive impact on quality of life and emotional wellbeing. Attending a cancer support group is one way to access peer support.

What is a cancer support group?

A support group is two or more people who come together regularly and voluntarily to discuss shared experiences. Most groups are face-to-face, but they can also be over the phone or online.

Venues for face-to-face meetings fall into two broad categories: those held in community settings and those held in hospital or health care settings. Groups can be led by health professionals or non-health professionals (such as a community member with a personal experience of cancer).

What happens in a typical support group meeting?

Support groups provide an opportunity for people to share their experiences and feelings with others who are 'in the same boat'. The group leader or facilitator may lead a discussion about particular topics or experiences, such as what it's like to talk to your children about cancer.

A meeting could involve laughter, tears, empathy, love, acceptance and/or learning something new.

Groups can also help participants become more informed about cancer-related topics, such as treatments, side effects, exercise and nutrition, relationships and life after cancer. Most groups regularly invite speakers to present topics of interest at meetings. Guest speakers may include doctors, nurses, psychologists, dietitians, naturopaths and pharmacists.

How do people find out about cancer support groups?

The Cancer Council NSW study⁽¹⁾ showed that people usually find out about support groups through a friend or the newspaper.

A quarter of respondents were referred by a health professional. It's not necessary to be referred by a health professional, but their opinion about the value of support groups may be an important factor in a patient's decision about whether to join.



Health professionals can play an important role in recommending support groups and encouraging patients to investigate them. Many survey respondents said that they wished they had known about support groups early in their cancer experience, but their health professionals didn't recommend attending one.

What makes a 'good' support group?

Participants say a 'good' group is one where there is a feeling of a unique bond with other people in a similar situation.

A 'good' group can also be influenced by the personal attributes of its leader. Group leaders are valued for their caring, dedication and availability.



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Why do people join a support group?

The main reason people seek support is because they are feeling anxious about the cancer and its 'social burden'.

A cancer diagnosis can also be a very isolating and lonely experience, especially if a person has little experience with cancer or doesn't know about support available. Isolation can lead to distress, fear and feelings of abnormality.

Reasons people join a group⁽¹⁾

Participants say they expect to receive:

- encouragement
- optimism and inspiration
- relief from fear, depression and stigmatisation
- hope for improved survival and quality of life
- advice about improving their outcome and maintaining a positive attitude.

What do participants get out of it?

Support group members say that they get a sense of belonging from being in the group, and a feeling that they aren't alone.

Members describe the group as a supportive and caring environment where individuals feel accepted for themselves, and where they feel safe to express their true feelings without having to protect family or close friends.

This sense of community results in a feeling of being cared for and 'held' by the group. Relationships between group members can be reassuring, and the group members can give them a sense of family.

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

Why do people stay? What is it that they value so much about their cancer support group?

People stay in the group because they feel a sense of empathy, caring, safety and humour.

Empathy

Everyone involved in a cancer support group has an experience of cancer. This creates powerful empathy within the group.

People outside the support group may dismiss a person's feelings or have difficulty understanding their experiences. In the support group, participants are not patronised or told to be optimistic. Instead, they are heard and understood.

Group members are accepting and tolerant of emotion – without asking for an explanation or offering a solution for it.

“The family don't really understand what it's like to have it thrown at you and then to have to learn to cope, but here you don't have to explain.”

Being cared for

Participants in Cancer Council's support group study all said that they felt cared for in their group.

This caring given and received within the group is contrasted with relationships outside the group. For instance, in a family setting, a person may believe that their feelings must be contained to protect others.

“I wanted a place where I could really talk about how I felt and I didn't have to worry about hurting someone or protecting them. That's really important.”



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Safety

Although family and other social support networks are important, support groups are generally perceived as the safest place to express emotions about cancer. In particular, people say they feel safe to openly discuss ordinarily taboo subjects, like cancer or death. People encourage each other and give advice about how to cope with negative feelings or issues.

““ We’ve talked about death. You can’t talk about that anywhere else. ””

Humour

One of the most striking features of support groups is the level of warmth and humour between participants. Humour provides a positive way for people to relax and feel at ease. It’s also an effective coping mechanism for dealing with adversity. It creates a sense of solidarity amongst group members and reduces self doubt.

““ Sometime you’ve got to laugh or you’d collapse in a heap. ””

What is the impact of this?

Many support group participants describe positive changes in themselves, or changes in their lives, that occurred after being members of a group.

One of the major changes is an increase in empowerment and control over life. By attending the group, having permission to openly express feelings, and meeting and learning from others with similar experiences, participants report increased levels of control. They feel empowered within themselves and in their interactions with others, such as health professionals and family members.

This greater sense of control over life reduces anxiety, hopelessness and depression, and increases general wellbeing.

““ I was scared to ask my doctor or surgeon certain questions. I didn’t think I had the right. But I learnt through the group that I do have the right to ask. I then started asking my surgeon things, which was good for me because it settled me in many ways. ””

What makes it work?

There are three key ways that a support group facilitates a positive experience: leadership, modelling and information sharing.

Leadership

Group leaders vary in their training and experience with cancer, but consistently, it is their enthusiasm, caring and availability that underlies the unconditional support that group members receive.

Group leaders also have formal and informal educational roles. They may organise guest speakers, teach helpful coping strategies, develop information packs, create a support group newsletter, or provide updates about cancer research.

Effective facilitation of group meetings is a skill essential in any group setting. Research has identified facilitation skills such as inclusiveness, effective communication and organisational ability.

Modelling

Positive role models are a powerful force, and modelling is an important way that group members can learn. For example, someone else in the group may openly express their own emotions and vulnerability, which demonstrates that it’s okay to express feelings.

Interviews with group participants show that witnessing someone who has had a cancer



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diagnosis, and who is able to face their own mortality, helps participants to cope with cancer. It also normalises the experience.

Information sharing

Support groups provide a place where information is shared about treatment, side effects and complementary therapies. People who are yet to make a treatment choice are able to discuss what other people with a similar diagnosis have done.

Useful tips for communicating with health professionals are also shared. Many participants comment that a benefit of attending a support group is learning how to communicate with their health professional. A common tip is to write a list of questions to ask health professionals. People often bring the answers back to the group for discussion.

Reasons people do not attend a support group⁽¹⁾

- They do not want to revisit cancer experiences.
- They feel they have enough support.
- Their personality or coping style means they are fearful of exposure and have difficulty 'opening up'.
- They are avoiding contact with cancer.
- They aren't aware of any support groups.

Why do some people leave their group?

Attendance is voluntary, so members of support groups come and go as they wish. People may leave the group permanently for a variety of reasons. For example, their cancer may be in remission, they may not have wanted to attend many meetings, they don't want to talk about cancer anymore, or they may be dissatisfied with the group.

How can Cancer Council NSW help?

Cancer Council NSW can give you more information about support groups, and talk to you about giving and receiving support in a group.

There is also training for community members and health professionals who want to lead a group; support over the phone and through regional offices; and a book for support group leaders (*Cancer Support Groups: A guide to setting up and maintaining a group*). To learn more, call 13 11 20 or visit www.supporttalk.com.au.



Some health professionals worry that support groups are undermining medical treatment, but that's not the case. In fact, they are supporting and complementing medical treatment. Information sharing tends to offer clarity about medical treatment, and it also empowers patients to communicate better with their doctors.

Why doesn't everyone with cancer attend?

Although they can be very effective, cancer support groups may not be the most appropriate means of support for everyone. It's important for people to consider their own needs.

Supporttalk



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(1) Ussher, J., Butow, P., Wain, G., Hobbs, K., Smith, K., Stenlake, A., Kirsten, L., and Sandoval, M. *Research into the Relationship Between Type of Organisation and Effectiveness of Support Groups for People with Cancer and their Carers*, February 2005.