

Lung Cancer Support Group

# Troubleshooting Guide

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**LUNG CANCER ALLIANCE**

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# Welcome to the Lung Cancer Alliance

# Lung Cancer Support Group Troubleshooting Guide

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We understand that starting and maintaining a lung cancer specific support group can be a challenge. There are great guides that provide advice and suggestions to start a group and some include a few ideas on how to manage a group that is struggling. However, practical, comprehensive assistance for troubleshooting a group that is struggling is virtually non-existent.

If you are reading this guide, it's likely your group can benefit from the experiences, guidance and lessons included here. By exploring the reasons groups struggle and offering creative solutions that have worked for other facilitators, our goal is to help you consider changes that may make your group more successful.

These ideas have been gathered through surveying and interviewing lung cancer support group facilitators in the United States, United Kingdom and Australia and a review of the literature. This is meant to be a living document, to be updated, revised and expanded as we continue to learn more ways to help lung cancer support groups thrive. Please send your ideas to [support@lungcanceralliance.org](mailto:support@lungcanceralliance.org).

In addition to this Troubleshooting Guide, we can help your group in other ways, including:

- Offering the assistance of our dedicated **Manager of Support Services** with support group expertise to provide:
  - » Consultation on educational topics of interest to people with lung cancer and their loved ones.
  - » Connection with support group facilitators whose groups are thriving for tips and support.
- Our toll-free **HelpLine (1-800-298-2436)**, which you or members of your group can call for specific information on lung cancer treatment options, educational resources and other information.
- Telephone-based one-to-one peer support through our **Phone Buddy** and **GUIDES** programs, which can be accessed by calling our HelpLine. The Phone Buddy Program matches lung cancer survivors, while the GUIDES Program matches loved ones of those at the end of life or who have died from lung cancer. Both programs offer information, hope and support.
- Our award-winning website, **[www.lungcanceralliance.org](http://www.lungcanceralliance.org)**, where you and your group members can find a wealth of information on lung cancer, its treatment, support options and ways to volunteer and get involved in the lung cancer movement.
- Our **Understanding Lung Cancer series**, a portfolio of educational materials to help your group members learn more about the disease. Find out more by going to our website, call our HelpLine or email [materials@lungcanceralliance.org](mailto:materials@lungcanceralliance.org).

# Table of Contents

<b>STARTING, MAINTAINING AND RUNNING A SUPPORT GROUP</b>	<b>5</b>
<b>CHALLENGE: GETTING THE WORD OUT</b>	
Think creatively	8
Think broadly	9
Think community	10
<b>CHALLENGE: INCREASING ATTENDANCE</b>	
Address emotional barriers	14
Address logistical barriers	15
Address physical barriers	17
<b>CHALLENGE: MAINTAINING ATTENDANCE</b>	
Remember the basics	20
Use the group to make the group	21
Consider the space	22
Set expectations	22
Provide refreshments	23
Offer alternatives	24
Follow up and keep in touch	25
<b>CHALLENGE: MANAGING GROUP ISSUES</b>	
Split the group	28
Address death	29

<b>CHALLENGE: ADDRESSING FACILITATOR ISSUES</b>	
Address burnout and capacity	32
Find a co-facilitator	33
Change the format	34
Be adaptable	35
<b>CHALLENGE: OVERCOMING INSTITUTIONAL BARRIERS</b>	
Use the evidence	38
Find a champion	38
<b>CHALLENGE: HITTING A WALL</b>	
Wait	42
Stop the group	42
<b>APPENDIX</b>	
Group aids	46
- Creating a flyer	46
- Welcome packet ideas	48
- Ground rules	49
- Dealing with challenging situations	50
- Commemorating the life of a group member	52
Guides to start support groups	54
Bibliography and other resources	55



# Starting, Maintaining and Running a Support Group

People attend support groups to learn more about their illness and for a sense of community, hope and sharing. Even those with a strong support system can benefit from joining a group where they can meet and interact with others who truly understand the lung cancer experience.

The main reason lung cancer specific support groups struggle and fail is due to attendance problems. Communication issues, logistical and emotional challenges and problems with group cohesion all affect the success of a group. Lung cancer stigma, symptoms, side effects and institutional barriers can also create persistent challenges in the group setting.

As a facilitator, you know when your group isn't where you want it to be but it can be hard to figure out *why*. Looking at the challenges groups face and learning creative solutions that have helped other facilitators may enable you to make your group more successful.





# Getting the Word Out

# CHALLENGE

Think creatively

8

Think broadly

9

Think community

10

Lack of attendance is the number one reason groups struggle and fail. Studies show that a doctor's recommendation of a group is significantly related to attendance. If people with lung cancer and their loved ones don't know about your group, they can't attend so getting the word out is critical.

## Think Creatively

Think about everyone, professionals and beyond, with whom people in lung cancer come in contact with on a regular basis and use as many as possible to get the word out. Meet with as many as possible in person and be sure to provide flyers for distribution.

- Thoracic oncology teams
- Medical and radiation oncologists
- Intervention radiologists/techs
- Thoracic surgeons
- Pulmonologists
- Nurses
- Social workers
- Patient navigators
- General practitioners
- Physician assistants/Nurse practitioners
- Respiratory therapists
- Palliative care specialists
- Hospitalists
- Other staff at:
  - » Infusion centers
  - » Registration desks
  - » Smoking cessation programs
  - » Cancer support organizations
  - » Community health clinics
  - » Senior centers

# Think Broadly

It is important that information about the group is posted on the website of your facility and to make sure it is included in their social media plan. Here are other things that will help your group be noticed.

- If your center has a general calendar of all support groups, the lung cancer group may be getting lost. Consider creating a separate flyer or reminder card to highlight your group.
  - » If each meeting addresses a different topic, try using a new flyer for each. Or create a flyer that lists the topics for the next few months so potential attendees can plan to attend those of interest.
- If your group is at a cancer treatment center and open to the public, try contacting your peers at other cancer treatment centers in the region to make sure they know about it.
- If your group is at an independent cancer support center, reach out to staff at local cancer centers and ask them to help get the word out.
- Make sure facilitators of general cancer support groups in your area know of your group and, if there are other lung cancer groups, contact those facilitators as well.

## Think About Your Community and Beyond

Think about all the places people in your community get information.

- Consider publicizing your group in support group sections of local newspapers and online calendars, on library, laundromat, grocery stores and coffee shop bulletin boards, through your local 2-1-1 service and in synagogue/ church bulletins. Some churches even have cancer ministries, groups whose mission is to reach out to people with cancer, that you can contact.
- Check Meetup.com and other online services for cancer-related groups in your area and contact them to let them know about your group. It costs money, but you can also try listing your support group as a Meet-up group.
- Try spreading information on the group beyond your immediate community or city. It might surprise you to learn just how far a motivated person is willing to travel to attend a lung cancer-specific group.

## Smart Tip

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Make sure we are aware of your group and that it is listed on our website:

**[www.lungcanceralliance.org](http://www.lungcanceralliance.org)**

Also be sure it is in the American Cancer Society's database.





# CHALLENGE

## Increasing Attendance

Address emotional barriers	14
Address logistical barriers	15
Address physical barriers	17

Even when you have fully marketed your group, barriers may prevent people from attending. They may think they don't need a support group or that they are negative places. They may not know enough about your group to understand why they should attend. Or they may perceive it as difficult to get to the group. Here are some ideas that may help overcome barriers.

## Address Emotional Barriers

Think about how you describe the group on your flyer, website and other postings. Communicating that it is a safe place to connect with others may encourage people to give it a try.

- Should you even call it a "support" group? Giving it a creative name may help those who don't like the idea of attending a support group consider attending. Names like *Bosom Buddies* breast cancer groups, *Glida's Club* *Networking Groups* and *The Living Room* lung cancer group convey the idea of a comfortable environment with minimal expectations and may draw people in.
- If you work at a cancer treatment center, it is convenient to hold the group there but some people have a negative association with where they receive their treatment. Consider having it in a more neutral setting such as a library, church or local cancer support center.

# Address Logistical Barriers

If possible, be flexible with when the group is held. It is helpful to survey the members about the time and day that is most convenient to the majority.

- **Schedule:** It might be easier for you to manage a monthly group and they can be very successful. However, strong groups can take time to form and meeting more often can help speed along the process. Also, if a monthly group is missed, the next may seem like a long time away and momentum may be lost for some participants. And the fact is, some people need more support than a monthly group can provide.
- **Day:** If your group is held at a treatment center with a lung cancer clinic day is it more convenient to hold the group that day or is that actually likely to interfere with attendance?
- **Time:** Most people diagnosed with lung cancer are older and may not want to drive at night. On the other hand, if your center sees a lot of younger people or people who are working through their treatment, a day groups is unlikely to work for them unless it's over lunch or they have a flexible work schedule.
- **Access:** If your group is at a cancer center but open to the public, is it clear that people who get their treatment elsewhere are welcome to attend?

## Smart Tips

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- One facilitator, a social worker, meets with every new lung cancer patient at her facility, which allows her to tell them about her group and to establish a relationship before they even attend.
- If transportation issues emerge, brainstorm with the group for ideas--there may be members who live close enough together to carpool or to provide rides.
- One group in our survey was held at a center where parking was not free. Donations were collected and a member was appointed treasurer to provide funds to members in need.
- If your group is monthly and you have survivors who need more regular support, consider suggesting they contact us for a match with a Phone Buddy volunteer.
- Even if your group is “drop in,” you can require people to register and engage them before they attend. You can also then send a welcome packet; see the Appendix for ideas on what to include.

# Address Physical Barriers

Where is your group held? Can people find it easily and navigate to the group setting?

- If your group is in a multi-site cancer treatment center, consider alternating meeting places. Offering it twice a month at different centers allows those in various areas of the city or region to attend. And it's likely some people will attend both groups.
- Try to hold the group in a location that is convenient to public transportation and is handicapped accessible.
- Is parking available? Well-lit? Easy to access? Free?
- If there are security measures that might be a barrier, can you come up with a way to make this easier for attendees?
- Make sure members have good directions and a contact number in case they get lost.





# Maintaining Attendance

# CHALLENGE

Remember the basics	20
Use the group to make the group	21
Consider the space	22
Set expectations	22
Provide refreshments	23
Offer Alternatives	24
Follow up and keep in touch	25

Some of the reasons people stop attending, such as the symptoms of lung cancer, treatment side effects and high mortality rate are outside your control. But, sometimes they weren't invested in the group or it didn't meet their needs. Here are some ways you can ensure a pleasant, inclusive experience for attendees.

## Remember the Basics

Providing some structure and information will help create a predictable experience for attendees.

- Start and end on time.
- If you haven't required people to pre-register, give them a welcome packet (see page 48 in the Appendix) when they arrive.
- Provide name tags, a sign-in sheet and discuss if attendee information, such as email addresses and phone numbers, will be shared.

- An opening (and/or closing) ritual or reading can set the tone for the group, encourage cohesion and provide continuity.

### Smart Tip

Including long-term survivors can provide hope and sustain the group.

# Use the Group to Make the Group

As much as possible, incorporate ideas and feedback from members to ensure the group is working for them. They can help decide:

- Where and when it meets
- Group rules
- How refreshments will be managed
- Group topics
- How to manage difficult situations, such as the death of a member

Ask the group what worked and what didn't so that you can adapt accordingly.

- Try surveying them after each group or contacting them at a later time.
- Check in with them yourself or have a more neutral person such as an intern or volunteer ask for their input.

If you don't have a set agenda, ask what the group would like to discuss at the next meeting. That way they know what to expect and can prepare accordingly.

## Smart Tip

Understanding what members need from the group is critical - and it's important to ask. A study by Devitt (see Appendix) found facilitators don't always accurately anticipate group member's needs. Asking them how the group is going provides insight into their experiences and allows you to make adjustments accordingly.

## Consider the Space

Creating a space that is conducive to sharing will help members feel more comfortable with sharing.

- Comfortable chairs should be arranged so that all members can see and hear each other.
- If your group is in a large conference room, figure out a way to carve out a smaller, more intimate area.
- An environment with minimal noise and traffic will help members be able to focus, so make sure the area is free of distractions.

## Set Expectations

Establish ground rules so members know what to expect. Ideally, the group should be involved in this process.

- Rules should be simple and to the point but include whatever the group feels is important.
- It is helpful to use inclusive language, for instance, “We respect confidentiality.”

### Smart Tip

Posting the ground rules or reviewing them at the start of the group builds trust and predictability. See page 49 in the Appendix for a sample of group rules.

# Provide Refreshments

A tried and true way to encourage people to attend or return is to provide snacks or a meal. Especially if your group is held at a time when people normally eat, make sure they don't have to choose between your group and a meal.

If your facility is not able to help with food or to reimburse you, here are some free or low cost ways you might try:

- Bring in home-made cookies or treats.
- Seek outside funding or resources such as a local franchise that is willing to donate meals or snacks. Some groups have found regional pharmaceutical representatives able to provide financial assistance.

## Smart Tip

If nothing else, bring chocolate. One leader said, "If you have chocolate, they will come!"

- Ask members to contribute to a potluck.
- Collect donations for meals and assign a group member to manage the funds.
- Encourage members to bring their own snacks or meals. You can even advertise it as a "lunch and learn" or "dine and learn" group.

## Offer Alternatives

Lung cancer symptoms and side effects from treatment will affect member's ability to attend. If you are able to be flexible and your center is open to alternatives, issues such as fatigue or not feeling well don't have to deter attendance.

- Consider if there are logistical (see "Address Logistical Barriers," page 15) or physical (see "Address Physical Barriers," page 17) changes you can make to address those barriers.
- If your facility has the capacity, try offering a call-in option by telephone to those who can't attend. Or even host the group as a Google Hangout or Skype call for people who can't get to the group.

### Smart Tip

Sending out a personalized email rather than mass emails to the whole group has been found to be more effective and lets members know you care about them as individuals.

# Follow-Up and Keep in Touch

Keeping in touch between groups allows you to continue to build your relationships.

- Call or email a few days before to remind them of the group.
- Follow-up with those who missed the group to see how they are doing.
- Even if your group is drop-in, ask members to let you know if they'll be attending so you can prepare and let those who cannot make it know they will be missed.
- If your group is monthly, try checking in mid-month.
- Send personal notes through the mail.
- When new developments in lung cancer happen between groups, send email updates.
- Alert members to educational opportunities such as appropriate CancerCare Connect Education Workshops™ by telephone or online webcast ([www.cancercare.org](http://www.cancercare.org)).





# CHALLENGE

## Managing Group Issues

Split the group

28

Address death

29

The tone and tenor of the group can affect how members feel about it. Much has been written in the therapy and support group literature on how to manage challenging members but for some tips see page 50 in the Appendix. Other factors also affect the group dynamic. Here are ideas to help keep your group on the right track.

## Split the Group

Your group may be well attended but if it's hard to get full participation, it may have grown too large. Consider splitting the group in two, here are some ideas.

- If you have the time and resources, create two separate groups.
- You can also keep it as one group, starting and ending the session together but split in the middle according to:
  - » **Role:** Survivors and their caregivers/loved ones may have personal concerns they need to discuss and this can be a natural way to split.
  - » **Length of survivorship:** Long-term survivors and those who are newly diagnosed may welcome the chance to talk more intimately with others like them.

# Address Death

Even the most successful groups can falter or fail when members die so it is important to consider how you will manage these situations before they happen. It is natural for other members to want to know the details of the last days of the deceased. Give as much information as you have and are comfortable with sharing.

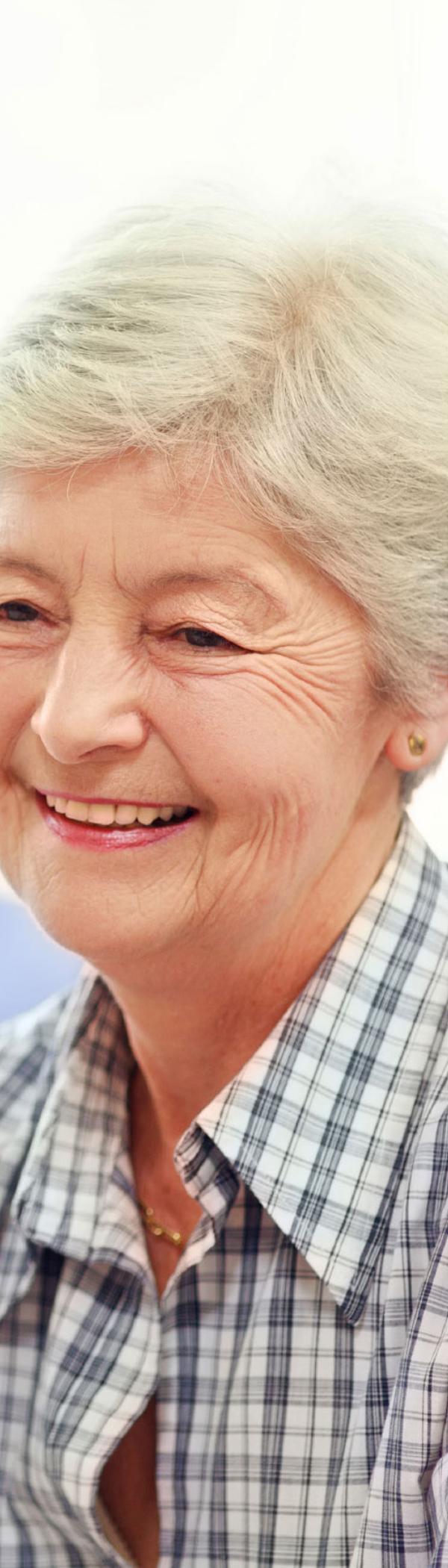
- When you learn a member has died, let the others know about it at once and give information about wakes, services or Shiva. If you have next of kin information, also provide it so condolences may be sent.
- Bring up the death at the next meeting. And the one after that, too. It can take time to process and members may be better able to discuss at a later date.

- Even skilled facilitators can struggle to talk about death. Consider asking a professional skilled in end-of-life issues, such as hospital clergy or hospice social worker, to guest facilitate after a death.
- Other members often want to recognize the life of the deceased. Having a culturally and socially appropriate ritual to do so can help the group cope and move on. See page 52 in the Appendix for ideas.

## Smart Tip

The best rituals are often those constructed with the open input of all the members. The worst are those imposed by a well-meaning facilitator.





# Addressing Facilitator Issues

# CHALLENGE

Address burnout and capacity  
Find a co-facilitator  
Change the format  
Be adaptable

32  
33  
34  
35

Successful groups don't happen overnight. They take care and attention and leading a support group can be emotionally demanding and time consuming. The group may need to take a different direction if you are feeling overwhelmed or burned out.

## Address Burnout and Capacity

It's hard to attend to your group if you are feeling overwhelmed or personally affected by the group. Here are some ways you can try to address those feelings.

- Post-group debriefing or supervision can help. If not available to you, see if you can form your own group and meet with other facilitators in the area or region periodically for support.
- Attending trainings on communication skills, group dynamics and the like may increase your confidence in managing the group.
- A reliable attendee may be able to help you with sending out reminders, completing follow-up calls and other tasks to take some of the burden off of you.
- Take time away if needed. This may mean suspending the group for a month or finding a colleague to run it for a time if you do not have a co-facilitator.

# Find a Co-Facilitator

You may be enthusiastic and an excellent marketer but are less confident of your facilitation skills. Or you may be a great facilitator but struggle with marketing. Finding just the right co-facilitator can help you out but also help your group to flourish.

- Seek out someone who complements you and rounds out your skills with their strengths.
- Consider finding someone with a degree in another discipline or of the opposite gender.
- Engage a peer at another treatment or support center in your region. This may also open up a new referral source.
- Using an intern or student to co-facilitate may be a great solution.

## Smart Tip

Consider asking an invested long term survivor with whom you work well to co-facilitate.

# Change the Format

If attendance is good but the level of engagement is not what you would like, consider changing the format. Or mix it up, meaning if your group is purely educational, try adding in time to share personal experiences. If it is only psychosocial, try adding occasional speakers on topics of interest.

Support groups can be:

- **Psychosocial:** These groups are interactive, emphasize participation and focus on providing emotional support. They may be facilitator or peer/group run.
- **Psych-educational:** These groups focus on teaching about lung cancer, treatment, coping skills, etc. They are facilitator-driven and often include speakers with expertise on topics of interest.

- **A combination of psychosocial and psycho-educational.** Some things to consider:
  - » Have speakers or educational content for part of each meeting and group sharing for the rest.
  - » Provide an education experience every other meeting (or every quarter or so) and group sharing in-between.

## Smart Tip

A review of psychosocial interventions found that psycho-educational groups are most effective, particularly for those newly diagnosed.

# Be Adaptable

It's important to be flexible and adjust to the group, whether session to session or over time.

- If you have mostly early stage members one month and those with metastatic disease the next, be prepared to change topics as needed.
- If the group is a mix of early and late stage, it can feel as though they don't have much in common. Acknowledge potential differences and work with the group to find topics that are relatable.
- If you've established a core group that seems to be getting sicker, recognize their changing needs and adjust topics if needed.
- Sometimes groups seem to run themselves and other times they need more active facilitating. Recognize these differences and adapt your style accordingly.

## Smart Tip

Try to be at the group site 10-15 minutes early to join in the pre-group chit-chat. The topics and thoughts discussed may inform the group's focus.



# CHALLENGE

## Overcoming Institutional Barriers

Use the evidence  
Find a champion

38  
38



It is surprising but not all treatment centers understand the benefits of offering cancer support groups. And unfortunately, the stigma associated with lung cancer may interfere with buy-in from the center. Sometimes centers have tried lung cancer groups and failed and aren't enthusiastic about trying again. Finding resistance to your group is disheartening but here are two ways you may be able to address it.

## Use the Evidence

In particular, people with lung cancer have greater unmet needs and experience higher levels of distress and depression compared with those diagnosed with other types of cancer. There is solid evidence of the benefits people with cancer gain from attending support groups, including:

- Improved quality of life
- Increased coping skills
- Decreased isolation
- Improved psychological well-being
- More positive attitudes toward treatment from educational groups

## Find a Champion

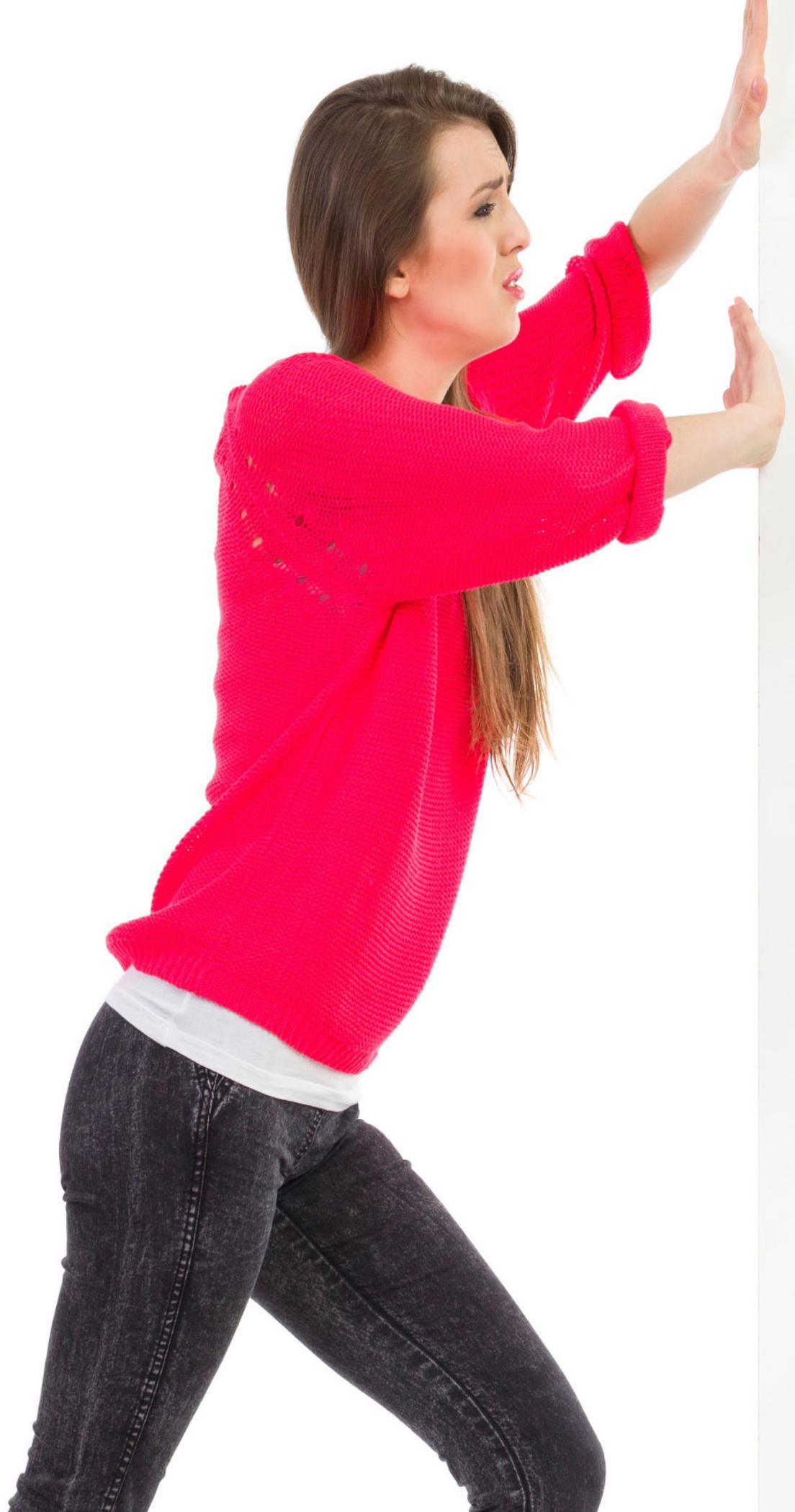
A physician's referral can be vital to the success of a group. Even if the center is not an obstacle to your group, one or more members of the treatment team may be. In any given setting, there is likely to

be at least one person of influence who will champion your group. Identify a leading administrator, oncologist, surgeon or radiologist who can reinforce the importance of your group and help to get referrals flowing.

## Smart Tip

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On pages 54 to 56 of the Appendix, you'll find examples of some of the research that supports your case and explores the unmet needs of people with lung cancer and the benefits that support groups provide. In particular, see Fobair (Part II, pages 141 to 143) for convincing evidence of the institutional benefits of support groups.



# CHALLENGE

## Hitting a Wall

Wait	42
Stop the group	42

The reality is that sometimes the timing is just off for the group. Maybe you found you don't have the time to devote to it. Or you've tried a number of things that haven't worked and feel discouraged. In any event, it may be time to consider putting the group on hold.

## Wait

Attendance may suffer if there are only a few people in the group each time. To adapt:

- Some groups close during the summer and over winter holidays when people may be too busy to attend.
- If your group is small but engagement seems to be working, consider waiting to hold the next group until you have a commitment from at least four people.

## Stop the Group

There are times when even the best facilitator with all the right tools can't get a group going. If you have done everything possible and you still can't get your group up and running, the timing just may not be right. Try suspending your group for the time being and restarting again in a few months.

## Smart Tip

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For a comprehensive list of potential educational topics, contact our HelpLine at

**1-800-298-2436** or email us at

**[support@lungcanceralliance.org](mailto:support@lungcanceralliance.org)**

and ask for a copy of our *Lung Cancer Support Group Facilitator's Guidelines*.

## Thank you!

Lung cancer support groups are an important way for those touched by the disease to get the psychosocial help they need. Thank you for your dedication to lung cancer patients and their loved ones and we hope these tips and suggestions will lead your group to success!





# Appendix

Group aids	46
• Creating a flyer	46
• Welcome packet ideas	48
• Ground rules	49
• Dealing with challenging situations	50
• Commemorating the life of a group member	52
Guides to start support groups	54
Bibliography and other resources	55

# Group Aids

## Creating a Flyer

Many attendees will first learn of your group by seeing the flyer. Here are some ideas to maximize the appeal by creating a flyer that is both informative and eye catching.

- Consider the font--larger is better and don't use more than two types.
- Keep it simple and easy to read (think bullets rather than paragraphs of text).
- Maintain a lot of white space.
- Let potential members know why they should attend and keep the tone positive.
- Use appealing colors and include photographs, if possible.

See the next page for an example of a good flyer.



**YOU ARE  
NOT ALONE.**  
WE CAN HELP.

Join the newly diagnosed, survivors  
and loved ones for a

## LUNG CANCER SUPPORT GROUP

**JANUARY 19, 2015**  
**6:00PM-7:30PM**

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### LOCATION

Gilda's Club Nashville  
1707 Division Street  
Nashville TN 37203  
[www.gildasclubnashville.org](http://www.gildasclubnashville.org)

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### CONTACT

Felice at Gilda's Club Nashville  
(615) 329-1124  
[felice@gildasclubnashville.org](mailto:felice@gildasclubnashville.org)

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This event is brought to you by



# Welcome Packet Ideas

Here are some ideas for information to include in your packet:

- Welcome letter, introducing yourself and the group with your contact information for questions or to RSVP.
- Group schedule and topics list.
- Directions to the group
  - » Via public transportation or driving.
  - » To find the group room once at the location, if needed.
- Group rules.
- Confidentiality rules.
- Other services of interest at your center, the community or nationally.
- LCA information, including:
  - » Survivor bracelets.
  - » Information on LCA's Support Services.
  - » Phone Buddy Program brochures.
  - » Other LCA brochures, including those on non-small cell or small cell lung cancer, coping with lung cancer, stigma, information on our Give a Scan Program, upcoming events and ways to get involved.

# Group Rules

Here is an example of support group rules. You can use it as a template or guide, although your rules may be very different.

## Ground Rules for Support Groups\*

This is a mutual self-help group, not a therapy group. Hopefully, this group will provide emotional, psychological and moral support for its members. Each of us is encouraged to participate to whatever extent we feel comfortable. The following ground rules facilitate the development of trust in the group and enable us to share our thoughts and feelings with each other.

1. Because confidentiality is essential, we expect that each person will respect and maintain the confidentiality of the group. What is said in the group is not to be repeated or discussed at any other time or place.
2. We are here to share our own feelings and experiences; we try not to give advice.
3. We each share the responsibility for making this group work.
4. We try to accept people, just as they are, and we avoid making judgments.
5. We try to give everyone an opportunity to share.
6. We have the right to speak and the right to remain silent.
7. We give supportive attention to the person who is speaking and avoid side conversations.
8. We avoid interrupting. If we do break in, we return the conversation to the person who was speaking.
9. We have the right to ask questions and the right to refuse to answer.
10. We try to be aware of our own feelings and talk about what is present to us now, rather than what life was like for us in the past.
11. We do not discuss group members who are not present.
12. We begin and end our meetings on time.

Note: Even though our goal is to support each person, this particular group may not meet your needs. Before deciding this group is not for you, however, we hope you will attend at least two meetings.

\*Excerpted from Peer Support Group Facilitator Training – Student Manual, by Sharon Mahre. Available from the Catholic Charities' Counseling Services Support for Separated and Divorced, Archdiocese of St. Paul-Minneapolis, 1276 University Ave., Saint Paul, MN 55104. Telephone: 651-647-3126. Copyright © 1988 Sharon Mahre. All rights reserved. Any reproduction of "Ground Rules for Support Groups" must display credit to the author and © information.

# Dealing with Challenging Situations

Remember, your basic role as facilitator is to guide the discussion, ensure that everyone has the chance to participate and manage difficult participants. Evaluation of group members needs to be ongoing. Sometimes challenging participants will benefit from individual counseling, either instead of or in addition to the group. Here are recommendations for handling common attitudes, behaviors and situations that may prove difficult or require special sensitivity.

## Silent Members

Verbal participation is not a requirement. For some, listening to other's experiences is beneficial but you can try to ensure inclusion of silent members by:

- Acknowledging these members with eye contact from time to time.
- Not rushing them as it may take them more time to be comfortable sharing in the group setting.
- Chatting after group, as one-on-one conversation can give incentive for active group participation.

## Hostile/Angry Members

Displays of anger and hostility can make other members feel uncomfortable or frightened and need to be handled quickly and diplomatically by:

- Defusing the situation through understanding and empathy.
- Engaging the group in a discussion about anger and normalizing the emotion.
- Suggesting the member return to the group when these feelings are under better control.

# Dealing with Challenging Situations, cont.

## Distracting Members

Some group members may interrupt other, talk at length and be sensitive to criticism or correction. You can intervene by:

- Acknowledging relevant comments and soliciting input from other members.
- Actively cutting in if you notice tension and other group members appear restless.
- Breaking into smaller groups to encourage participation for everyone.

## Negative Members

Group members may express negative attitudes through body language and complaining. Negative members may be helped by:

- Modeling appropriate group behavior and communication for a group.
- Discussing in private the impact a negative attitude can have on other members.
- Focusing on strengths of the member and discuss, in private, how to channel these strengths into the group setting.

# Commemorating the Life of a Group Member

It is important to remember those who have died but you also don't want the topic of death to hang over your group. It may be helpful to provide an activity to use when needed but doesn't necessarily remain in each group session.

Life commemorations may include a poem, music, ringing of a chime or bell or candles, if allowed in the facility. You and your group may come up with wildly creative ideas on how to recognize a member's life but if you could use some help, consider these ideas:

- Create a memory box with a slot and have each member write a note to the deceased.
- Plant or use rosemary, a symbol of remembrance, in some manner.
- Use an activity that allows group members to make and/or sign and/or inscribe a life celebration symbol such as:
  - » Cranes – The Greek and Roman symbol of the celebration of life. Buy origami paper and have group members learn to fold a crane, which they can either take with them or that the group uses to create a mobile or display.
  - » Butterflies – A universal symbol of change, resurrection, transformation, celebration and the soul.
  - » Doves – A universal symbol of peace, hope, love and faith and a symbol of the eternal spirit that lives on forever.
  - » Dragonflies – Symbolize change, transformation and adaptability.
  - » Remembrance flowers like forget-me-nots, pansies or poppies.

## Commemorating the Life of a Group Member, cont.

Or try the Stone Ritual, designed to remind us “of the continued presence of our loved one in our lives.”

All you need is a container and stones that you either pick up or buy. Have each member pick out a stone and say something to this effect:

*“The stone is a symbol of \_\_\_\_\_’s presence in your life. Keep the stone for a short or long while. Put it in a pocket, take it as you wander or bring it to a favorite spot. When you are ready, leave it and in that way the free spirit, the wanderer in \_\_\_\_\_ will go on. Who knows? Someone like \_\_\_\_\_ may come upon the stone in the future and find joy in it.”*

Adapted from: <http://www.sayingyourgoodbye.com/stone-ritual-celebration-of-life-ideas/>

# Select Guides to Start Cancer Support Groups

**Lung Cancer Alliance. (2012) *Lung Cancer Alliance's Lung Cancer Support Group/Family and Friends Support Group Facilitator's Guidelines*. Lung Cancer Alliance. Washington DC.** Unpublished, call 1-800-298-2436 or email support@lungcanceralliance.org to have a copy emailed or sent to you.

**Herron, L-M. (2005) *Building Effective Cancer Support Groups: Report to the Department of Health and Aging*. The Cancer Council Australia. Sydney.** Good review of the psychosocial impact of cancer, benefits of support, needs of people with cancer, evidenced-based advice on building groups and characteristics of effective support groups.

[http://canceraustralia.gov.au/sites/default/files/building\\_effective\\_cancer\\_support\\_groups.pdf](http://canceraustralia.gov.au/sites/default/files/building_effective_cancer_support_groups.pdf)

***Guidelines for Cancer Support Services in Ireland. (2011). Irish Cancer Society. Dublin.*** Extremely comprehensive guidelines and includes sections on managing change, evaluation, working with guest speakers, information on the types of groups and troubleshooting.

[http://www.cancer.ie/sites/default/files/content-attachments/ics\\_support\\_groups\\_guidelines\\_2011.pdf](http://www.cancer.ie/sites/default/files/content-attachments/ics_support_groups_guidelines_2011.pdf)

**Macmillan Cancer Support. *Handbook for Self-Help and Support Groups*. Macmillan Cancer Support. Undated.** For peer-facilitators. A good overview of how to set up a group, order from the UK.

<http://be.macmillan.org.uk/be/p-19960-handbook-for-self-help-and-support-groups.aspx>

**Cancer Council Australia. (2013) *Cancer Support Groups: A Guide to Setting Up and Maintaining a Group*. Cancer Council Australia.** Comprehensive assistance in setting up and maintaining a group including a sample evaluation template, tips on handling difficult situations, adapting to changes and closing a group.

<http://www.cancercouncil.com.au/wp-content/uploads/2013/07/CAN736-SupportGroups-Booklet-completeLR.pdf>

# Bibliography and Other Resources

## People with Cancer and Support Groups

Adamsen L. 'From victim to agent': The clinical and social significance of self-help group participation for people with life-threatening illness. *Scand J Caring Sci* 2002; 16:224-231.

Bell K, Lee J, Foran S, Kwong S, Christopherson J. Is there an "ideal cancer" support group? Key findings from a qualitative study of three groups. *J Psychosoc Oncol* 2010; 28(4):432-449.

Docherty, A. Experience, functions and benefits of a cancer support group. *Patient Edu Counseling* 2004; 55:87-93.

Fawzy FI. Psychosocial interventions for patients with cancer: What works and what doesn't. *Euro J of Cancer* 1999; 35(11):1559-1564.

Fawzy FI, Fawzy NW. Group therapy in the cancer setting. *J Psychosom Res* 1998; 45(3):191-200.

Fobair, P. Cancer support groups and group therapies: Part I. Historical and theoretical background and research on effectiveness. *J Psychosoc Oncol* 1997; 15(1):63-81.

Fobair, P. Cancer support groups and group therapies: Part II. Process, organization, leadership, and patient issues. *J Psychosoc Oncol* 1997; 15(3-4):123-147.

Glaser SR, Glassman R. Group work with individuals with chronic cancer. *Soc Work Health Care* 2014; 53(1):31-47.

Gottlieb BH, Wachala ED. Cancer support groups: a critical review of empirical studies. *Psycho-Oncology* 2007; 16:379-400.

Magen RH, Glajchen M. Cancer support groups: Client outcomes and the context of group process. *Res Social Work Prac* 1999; 9(5):541-554.

Morse KD, Gralla RJ, Petersen JA, Rosen LM. Preferences for cancer support group topics and group satisfaction among patients and caregivers. *J Psychosoc Oncol* 2014; 32:112-123.

Narsavage G, Romeo E. Education and support needs of younger and older cancer survivors. *Appl Nurs Res* 2003; 16(2):103-109.

Stanton AL. Psychosocial concerns and interventions for cancer survivors. *J Clin Oncol* 2006; 24(32):5132-5137.

Taylor SE, Falke RL, Shoptaw SJ, Lichtman RR. Social support, support groups, and the cancer patient. *J Consult Clin Psych* 1986; 54(5):608-615.

Ussher JM, Kirsten L, Butow P, Sandoval M. What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Soc Sci Med* 2006; 62:2565-2576.

Weis J. Support groups for cancer patients. *Support Care Cancer* 2003; 11:763-768.

## Psychosocial Needs and High Levels of Distress for those with Lung Cancer

Carlsen K, Jensen AB, Jacobsen E, Krasnick M, Johansen C. Psychosocial aspects of lung cancer. *Lung Cancer* 2005; 47:293-300.

Devitt B, Hatton A, Baravelli C, Schofield P, Jefford M, Mileskin L. What should a support program for people with lung cancer look like? Differing attitudes of patients

Hill KM, Amir Z, Muers MF, Connolly CK, Round CE. Do newly diagnosed lung cancer patients feel their concerns are being met? *Eur J of Cancer Care* 2003; 12:35-45.

Lehto RH. Identifying primary concerns in patients diagnosed with lung cancer. *Oncol Nurs Forum* 2011; 38(4):440-447.

McCarthy MM, Thompson A, Rivers S, Jahanzeb M. The benefits of support group participation to lung cancer survivors – An evaluation. *Clin Lung Cancer* 1999; 1(2):110-117.

Owen JE, Goldstein MS, Lee JH, Breen N, Rowland JH. Use of health-related and cancer-specific support groups among adult cancer survivors. *Cancer* 2007; 109(12):2580-2588.

Sanders, SL, Bantum EO, Owen JE, Thorton AA, Stanton AL. Supportive care needs in patients with lung cancer. *Psycho-Oncology* 2009; 19:480-489.

Xangmu S, Testerman LS, Owen JE, Bantum EO, Thorton AA, Stanton AL. Modeling intention to participate in face-to-face and online lung cancer support groups. *Psycho-Oncology* 2014; 23(5):555-61.

Zabora J, Brintzenhofeszoc K, Curbow B, Hooker C, Piantadosi S. 2001. The prevalence of psychological distress by cancer site. *Psycho-oncology* 10: 19-28.

## Who Uses Groups, Why People Don't and How They Fail

Eakin EG, Strycker LA. Awareness and barriers to use of cancer support and information resources by HMO patients with breast, prostate, or colon cancer: Patient and provider perspectives. *Psycho-Oncology* 2001; 10: 103-112.

Galinsky MJ, Schopler JH. Negative experiences in support groups. *Soc Work Health Care* 1994; 10 (1):77-95.

Grande GE, Myers LB, Sutton SR. How do patients who participate in cancer support groups differ from those who do not? *Psycho-Oncology* 2006; 15:321-334.

Lemberg R. Ten ways for a self-help group to fail. *Am J Orthopsychiat* 1984; 54(4):648-650.

Ussher JM, Kirsten L, Butow P, Sandoval M. A qualitative analysis of reasons for leaving, or not attending, a cancer support group. *Soc Work Health Care* 2008; 47(1):14-29.

# Facilitator Needs

Butow P, Ussher J, Kirsten L, et al. Sustaining leaders of cancer support groups. *Soc Work Health Care* 2005; 42(2):39-55.

Hoey LM, Sutherland G, Williams PA, White V. Comparing the needs of health professionals and peer cancer support group facilitators in an Australian context. *Eur J of Cancer Care* 2009; 20:87-92.

Kirsten L, Butow P, Price M, Hobbs K, Sunquist K. Who helps the leaders? Difficulties experienced by cancer support leaders. *Support Care Cancer* 2006; 14:770-778.

Lieberman MA, Golant M. Leader behaviors as perceived by cancer patients in professionally directed support groups and outcomes. 2002. *Group Dyn-Theor Res*; 6(4):267-276.

Price M, Butow P, Kirsten L. Support and training needs of cancer support group leaders: A review. *Psycho-Oncology* 2005; 15:651-663.

Vugia HD. Support groups in oncology: Building hope through the human bond. *J Psychosoc Oncol* 1991; 9(3):89-107. Move to other?

## Other Bibliography

Cain EN, Kohorn EI, Quinlan DM, Latimer K, Schwartz PE. Psychosocial benefits of a cancer support group. *Cancer* 1986; 57:183-189.

Campbell HS, Phaneuf MR, Deane K. Cancer peer support programs – do they work? *Patient Edu Couns* 2004; 55:3-15.

Cella DF, Sarfian B, Snider PR, Yellen SB, Winicour P. Evaluation of a community-based cancer support group. *Psycho-Oncology* 1993;2: 123-132.

Crothers MK, Tomter HD, Garske JP. The relationship between satisfaction with social support, affect balance, and hope in cancer survivors. *J Psychosoc Oncol* 2005; 23(4):103-118.

Davidson KP, Pennebaker JW, Dickerson SS. Who talks? The social psychology of illness support groups. *Am Psychol* 2000; 55(2):205-217.

Link LB, Robbins L, Mancusco CA, Charlson ME. How do cancer patients choose their coping strategies? A qualitative study. *Patient Edu Counseling* 2005; 58:96-103.

Rehse B, Pukrop R. Effects of psychosocial interventions on quality of life in adult cancer patients: meta analysis of 37 published controlled outcome studies. *Patient Edu Counseling* 2003; 50:179-186.

Slevin ML, Nichols SE, Downer SM, et al. Emotional support for cancer patients: What do patients really want? *Br J of Cancer* 1996; 74:1275-1279.

Zordan RD, Butow PN, Kirsten, JI et al. The development of novel interventions to assist the leaders of cancer support groups. 2012. *Support Care Cancer*; 20:445-454.

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