

Facilitator Guide

ICD Patient Group Meeting in a Box



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THE ESSENCE OF AN ICD PATIENT GROUP

Patient feedback tells us that many patients who have received an implanted cardiac device want a place to tell their stories and share their experiences leading up to and after a device implant. Talking with others who have been through similar experiences helps many device patients feel less alone.

Family members of device patients also may find it helpful to talk with other caregivers who been through similar experiences. Often, family members have provided support throughout the process of deciding to have an implant, undergoing surgery, and learning to live with a device.

For clinicians, a patient group can be a place to learn more about patient concerns, and provide information and advice that may lead to better compliance and better outcomes.

Patients have different needs depending on their disease process, sudden death survivor versus someone at risk of sudden cardiac arrest (SCA) that may enable different types of groups to exist. One hospital set up one group of ICD patients under the age to 40 and another group over the age of 40. You may have multiple groups – women heart health, pediatric, retired, survivor network, etc.

The type of experience patients expect is often associated with the name of the group. Twenty years ago when the therapy was new, hospitals saw ICD patients needing a very supportive environment; they called the groups ICD support groups. This name has persisted, while the type of patients getting ICD devices has evolved. Today, meetings with ICD patients take an identity of user group or club and even create an identity based on their group hobbies, ages or creative energy.



Invite the Experts

“When we started our ICD support group in 1998 (before MADIT II), the anxiety level of those patients and significant others was tremendous. Since MADIT II, the patients don't seem to have as much anxiety initially. However, once they begin getting therapy (shocks), the anxiety level again becomes a factor.

“We have a meeting once every three months; one hour is spent on a specific topic, and one hour is spent on sharing and explanation/questions. It is important to have one or more "experts" (nurses/technicians) walk around as they are sharing. You would be amazed at the many misconceptions that are shared; the "experts" can quell some of these.” EP manager, NY

HOW TO START A GROUP, WHERE NO GROUP EXISTS

Simply to post a meeting date for an "ICD patient group" does not communicate clearly what patients are joining and what obligations are involved. Before inviting anyone to join the group, make sure you know and can communicate clearly what the group will do and what is being asked of participants.

Get Ready – Get Set – Get Together!

Get ready!

1. **Determine the purpose of the group.** As the sponsor of the patient group meeting, you need to determine, for at least the initial meetings, what kind of experience you want patients to have in this group. Some questions may be used to get the thoughts rolling. Variations of these are also appropriate for patients to answer at the first meeting.
 - Why do you want to sponsor a patient group?
 - What type of membership will the group have (men, women, 40+, young and old, single and married, children, mixed)?
 - What will the group do? Will people bring food or will the hospital or industry provide it?
 - Will there be an assigned leader/facilitator?
 - What ingredients do you want included in the group (refreshments and who is responsible, speakers and how often, etc.)?
 - What will make this group "successful" or worth the time involved?
 - What level of commitment and work will the patient provide? (How hard do you, the clinician, want to work?)
2. **Recruit one or two partners from the clinic.** These people may be involved in education, device clinic or support services. They may be asked to help with only a few meetings. Discuss with them your ideas for a patient group. Ask them if they would like to be involved.
3. **Discuss your idea with the appropriate leaders in your organization.** Do this throughout the process. They will be able to give you suggestions and consider possible resources and materials. Ask if you can meet on a regular basis with the clinician for counsel and training. In addition, reach out to local industry reps to allow them to support your group efforts.
4. **Decide on a time and place for the first meeting.** Set the date several weeks in advance to give people time to plan.
 - Choose a room that is easily accessible, if possible, on a ground floor or near an elevator for patients with limited mobility. Keep in mind any special needs participants may have: for example, be sure to provide extra room between rows of chairs for those with wheelchairs or walkers; and large screens or captions on presentations for those who are hearing or vision impaired.
 - A recommended schedule for meetings ranges from once a month to once per year. Meetings should be long enough to allow people to meet one another and learn valuable information, but not so long that participants become uncomfortable. One to two hours is average.

Get set!

1. **Get the word out.** Making patients aware that your group is available is a key component to success. Here are some suggestions for promoting the group.
 - Send a press release to local newspapers, radio and television stations. This is especially effective in smaller communities. In larger cities, many suburbs have smaller newspapers that can also be contacted.
 - Post flyers within your hospital or clinic that patients will see when they come in for appointments. If your hospital or clinic produces a patient newsletter, include an article or regular notices before each scheduled meeting.
 - Print a card or brochure with basic information about the group meetings to hand to patients when they come in for appointments. Information should include who is invited to attend, when and where the meetings are scheduled, and a phone number to call for more information or to register, if required.
 - If your hospital or clinic has a web site, be sure to post information there, as well. A web site is an ideal place to post the schedule, location, time, and presenter since this information can be easily updated as needed.
2. **Determine your leadership pattern.** Will a clinic member or patient be asked to lead the meetings? Will different people lead different parts of the meeting under the direction of an overall coordinator; or will a different person lead each week?
3. **Choose resources or the methods you will use.** What presentations will you use? What guest speakers may be available? What members may present? This is especially important for the early meetings, when the group is forming.

Get together!

1. **Plan and organize.** Determine the meeting room and resources you will have available for the first meeting. Refreshments, seating, tables, audio/visual resource, hand out materials, flipcharts – will be handy and appropriate to facilitate the first meeting.
2. **Conduct your first meeting.** Welcome patients as they arrive.
 - Ice-breakers may be a fun way to initiate the first meeting. (See the appendix for ideas.)
 - Once your group is established, it’s a good idea to ask members for feedback on the frequency, location, length, and time of day to learn what best fits their schedules and meets their needs.
3. **Evaluate the first meeting and decide on future direction.** Record your impressions. Allow patients to complete a brief survey – best take aways, what topics for a future meeting, etc. Below are questions to consider in your evaluation.
 - Did we achieve our purpose? (On a scale from 1 to 10)
 - What did we find most helpful about the group? Least helpful?
 - How did we function? (On a scale from 1 to 10)

Sample Meeting Agendas

The agenda for a typical 60 to 90-minute meeting might look something like this:

- Participants arrive, find seats – 15 minutes; refreshments may be served
- Greetings and announcements, housekeeping items (rest rooms, water, etc.) – 5 minutes
- Topical presentation or activity – 20-30 minutes
- Q&A/discussion – 15 to 20 minutes
- Opportunity to socialize – 15 to 30 minutes

Beginning and ending the meeting on time is most important to the group's success. When the group begins and ends late, people who have other commitments will tend to reconsider their involvement in it.

Although some groups choose to be casually structured and open to whoever shows up at a particular meeting, most discover that a commitment to regular attendance is absolutely essential.

SUGGESTED TOPICS AND DISCUSSIONS

Here’s a list of potential topics you may want to consider for the group meeting. Most focus on how to live with an implanted device, as well as heart health topic. Be sure to ask participants what kind of information they’re looking for, and plan ahead to have a knowledgeable source present the information and answer patients’ questions.

Discussion Topics

Therapy Awareness	Living with ICD Therapy
Heart Health Basics*	ICDs and how they work*
Heart Failure*	Living with your Device-FAQ**
Risk factors for Cardiovascular Disease*	Remote device monitoring*
Women’s Heart Health*	EMI (iPods, key fobs, security systems, etc)*
Understanding ICD Therapy-FAQ*	ICD checks
CPR for family and friends class	Relaxation techniques, stress management
Eating right - Does Diet Really Matter?	Hospice/end of life issues
Effective communications with medical staff, roles of various caregivers (cardiologist, HF doctor, EP, AHP)	
Exercise – What kinds, how much	
Financial planning resources	
Heart medications, what you need to know, managing medications	
Living will	
Volunteer opportunities	
Web topics – going online	

Activity Ideas

- Cookie exchange
- Game night
- Book club

** These topics are available in presentation format on www.bostonscientific.com in the Support Group Resource section for Cardiac Rhythm management.*

RESOURCES FROM BOSTON SCIENTIFIC

This facilitator guide and other resources are available online at www.lifebeatonline.com. Select the ICD Patient Group Meeting in a Box icon to select files for download. Included in meeting in a box are PowerPoint® presentations on topics that many clinics have requested (see the discussion topics above). Other topics will become available over time to expand the resources available to you

In addition, the following templates also available included to help you launch a patient group:

- Newspaper press release
- Invitation
- Flyer

We would appreciate feedback on the kit and suggestions for future topics. Please use the “Contact Us” button on www.lifebeatonline.com and indicate in the subject line – ICD Patient Meeting in a Box.

Other Resources:

Expert Speakers

Dr. Sam Sears is director of health psychology and also holds an appointment to the Department of Cardiovascular Sciences at the Brody School of Medicine. A native of Florida, Sears worked and taught for more than 12 years at his alma mater, the University of Florida, before coming to Greenville. Sears researches and treats patients who become consumed with fear and worry about their devices.

Sears’ research focuses on implantable cardioverter defibrillators (ICD), which are used by cardiologists to treat annually more than 200,000 patients who have potentially life-threatening irregular heart beats. However, many of these patients have high levels of anxiety about receiving a significant shock, 750 volts, to restore a normal cardiac rhythm.

Contact: Dr. Sam Sears at (252) 328-6118 or searss@ecu.edu

APPENDIX A. SOLVING SMALL GROUP PROBLEMS

Adapted from *Serendipity Training Manual for Groups*, by Lyman Coleman. Serendipity House, Littleton, Colorado, 1989.

Common Problems of Small Groups

Problem #1: Aimlessness

Groups fail because they are not going anywhere; they have no purpose or clearly defined goals.

Observation—The leader has a key role at two times in the life of a beginner group: (1) at the beginning, to help the group clarify its purpose, and (2) at the close, to help the group evaluate its experience and decide if it wants to continue...and if so, what the new covenant will be for the next period.

The Meeting is Off, No On

One group tried a different phoning system use when membership waned. The leaders asked a respected member of the group to call each member to announce a meeting to dissolve the group because of low attendance. The next meeting there was 100 percent attendance of concerned and motivated members. This idea proved to be effective, but can't be used often because members will likely consider it a false alarm.

Problem #2: Varying Participation Levels

Some people clam up in groups and can't share, while others tend to talk too much or overwhelm the shy person.

The Quiet Ones: Two things could be going on:

- They are naturally quiet and need time to ponder an idea. They do not want to say anything that is silly or unimportant.
- The rest of the group is dominating.

Solutions—Involve them in a non- “spotlight’s-on-you” manner. Be attentive to their body language. Catching your eye, raising an eyebrow or leaning forward may be signals that a person has something to say. Remember to allow people the privilege of being silent

The Monopolizers: Monopolizers are often natural leaders. Appreciate their enthusiasm and involvement. At least the entire group is not consistently staring at you with blank looks and answering questions with the dreaded “I don’t know.”

Solutions—Give them a job. Often the talkative ones are those who love to jump in, help when needed, or lead when given a chance. Ask them to bring a story or quote about the topic you’re going to discuss. Put a time limit on responses by stating, “In one minute or less share a highlight of Christmas break.” Stick to it, if necessary, by assigning someone stopwatch duty.

The Argumentative Group Members: There may be deeper issues or simple unawareness taking place with an argumentative member.

Solutions—Validate, disagree kindly if necessary, and move on. For example, “I can see why you would feel that way.” Or, “I never have thought of it that way. What do the rest of you think?” Offer a place or opportunity where they can be heard by asking, “Would you like

to talk more about it with me or someone from industry?” This approach keeps the group safe for all members and validates the person with the issue.

Problem #3: Indiscretion

The opposite of being superficial is going too far into needs or problems that the group does not know how to handle.

CASE STUDY: Bob mumbles under his breath that he wishes he could get control of his temper, especially toward his teenage son who he "beat up" on last night. The host for the night has just rung the bell and asked all groups to return to the larger gathering area for the close.

CASE STUDY: Mary has sat in silence most of the night, silently crying. The meeting is ready to adjourn and she is still sitting there. Finally she says in front of the whole group, "This is the last time Bob and I will be coming to the group. Bob wants out of our marriage. Bob is furious for 'letting the cat out of the bag.'"

SOME DO'S AND DON'TS

- Don't leave a person stranded when he/she has gone "too far" in sharing something. Assure him/her that it was okay, and that you will keep what has been shared in strict confidence.
 - Don't give ANY advice. You can say something like, "I really appreciate what you have shared" or, "I will remember this thing in prayer" or, "Here's my phone number; I want you to call me the next time this happens..." etc. But advice is a "no-no."
 - Do make sure that you have a back-up system for deeper needs; refer this issue to a chaplain or psychologist on staff.
 - Do follow the discipline of confidentiality. The only exception to this rule would be if a person threatens to hurt himself/herself or someone else. (If this should happen, go to the person first and tell him/her that you cannot keep this information to yourself, but would be willing to help this person to find help.)
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Problem #4: Group Burnout

A lot of groups stay in "first gear" all the time, and end up consuming a lot of energy or burning up the motor.

Solution—Shift gears from time to time. There are typically three shifts over the life cycle of the group to prevent burnout.

- **First Gear:** Getting started, you need a lot of intensity and structure. The clinic may need to facilitate meetings until members step up to take on that responsibility. You may meet quarterly to ensure that the group identity is established and new members find their way to your event.

Second Gear: Gaining speed, you can shift gears to cut back on the energy consumption and go twice as far with the same amount of energy. For instance, you might cut back on your group meetings to twice a year, so that the group can break out into specific interest groups, such as by age or gender.

- **High Gear:** For the long haul, you shift one more time to a gear that economizes most of your energy while maintaining your speed. For instance, you might shift to an annual reunion meeting, so that you can concentrate on facilitating new groups that have been started to meet unique needs of the patients.

In the life cycle of a group, sometimes the longer it lasts, the lesser the intensity.

Tips for Group Conflict Resolution

Adapted from: Neal F. McBride, *How to Lead Small Groups*, (Nav Press, 1991).

Check to see how your meetings are run. Are the same people dominating group discussions? Are the meetings bogged down by continued discussions of problems with no mention of solutions? Are solutions repeatedly offered to patients who don't listen or try them? If you answered "yes," you may have a problem with facilitation.

Is anyone monitoring and guiding the meeting? If meetings are focused only on problems and seldom look at solutions or members ignore offered solutions, other members will feel trapped in an endless negative cycle.

Healthy groups try to resolve conflict either by openly seeking its source and planning a strategy for resolving it, or by bringing in an outside expert to help the group work through the problem. If you ignore conflict, you risk losing good people or the entire group.

- Attempt to define and describe the conflict in cooperative terms (as a common problem).
- Try to deal with issues rather than personalities.
- Deal with one issue at a time.
- Attempt to persuade one another rather than using threats, intimidation, and power plays.
- Focus on issues while they are small rather than permitting them to grow over time and become large ones.
- Opt for full disclosure of all facts rather than allowing "hidden agendas" (left-over feelings or old arguments not settled) to function.
- Encourage the validation of the other parties' interests or concerns. (Feelings are valid no matter what the facts are.)
- Emphasize what you still hold in common.
- Attempt to portray a trusting and friendly attitude.
- Opt for a "win-win" feeling (i.e., there is a piece of the pie for each one) rather than a "win-lose" feeling.
- Attempt to generate as many new ideas and as much new information as possible in order to broaden the perspective of all persons involved.
- Involve all principal parties in the conflict at a common meeting.
- Clarify whether you are dealing with one conflict or multiple conflicts.

APPENDIX B. REJUVENATING YOUR GROUP

Adapted from North American Council on Adoptable Children (NACAC), *Starting and Nourishing Adoptive Parent Groups, A Leaders Guide*. 2002.

A group is a living organism with a life of its own. Groups can become sick and die. They can heal and be renewed. They can even grow and mature to become something different than they started out to be. In order for a group to survive, the individuals within that group need to protect the life of the group. They need to listen to the rumblings within, pay attention to the outside forces, and take the necessary steps to keep the group healthy.

Not all groups have a long life. Some serve their purpose, and end quietly and gracefully. Some explode in discontent and scatter members in all directions. Some manage to continue to reinvent themselves, take in fresh ideas, attract new people, and remain energized. If a group has served its members and lived a good life, it may be okay to let it die. But what do members and leaders do when the group is floundering and no one wants it to die, but no one knows what to do?

Groups that have a long, productive life:

- tap into their creativity
- work to build community among their members
- see the connectedness in all human beings

It doesn't matter at what level a group operates—if the group achieves any kind of longevity, there will come a time when members will need to consciously plan for ways to rebuild the organization from within, rejuvenate membership and leadership, and refocus mission and energy. It takes a lot of energy to develop a group and to provide services to patients. No matter how a group grows, it has to take care of its leadership and respond to its members' needs to remain effective and provide quality services to all.

Being Creative

Even if your group has found tried and true solutions to problems or has repeated efforts and events that are popular with group members, always look for ways to be creative. Put a new twist in something you have done for years, and by all means try something different. When people tap into their creativity, their energy can spread and sometimes spark creativity in others. When group members tap deeper into their creative selves, obstacles to difficult problems can disappear. When that happens, your group drops its problem-focused mentality and becomes a solution-oriented group.

Retaining Members

Over time, many groups struggle with attendance. You can try a variety of strategies to keep members interested and engaged.

- **Buddy System:** Leaders pair more experienced members with new members. The inexperienced member has someone to turn to for support and encouragement. Think about how you may facilitate member connections—geographic closeness, similar life experiences, etc.
- **Mentors:** Assigning a mentor to new members is similar to a buddy system, but mentors can be assigned on a need basis, upon request, or to everyone for the first year.
- **Phone Trees:** Phone trees are simple ways for members to remind each other about future meetings and events. Each member is assigned a person to call or a team of people is

assigned a list of people to call. Receiving a phone call from another member of the group can serve not only as a reminder of the meeting, but also as a reminder that each person is a valued member of the group.

- **Members' Talents:** While it can sometimes be difficult to find people to take on a long-term leadership position, it is often easy to recruit people to offer their specific expertise or talent. Maybe you have an excellent web designer, writer, accountant, trainer, speaker, lawyer, or chef. Learn about and assess the talents of each group member and think of ways to tap into those skills. This will help your members feel appreciated for their skills and give them a chance to help the group.
- **Remember to look for all of your members' talents.** Sometimes the last thing a chef wants to do is cook another meal after she leaves work, but maybe she is also a talented writer or speaker. Survey each member and keep updated records of their talents so that you benefit from the gifts each member has to offer.

Giving People Freedom to Change

- **Allow Others to Lead:** If the meetings are predominantly run by one person, encourage other group members to express their vision and offer their ideas and talents to the group.
- **Allow People to Leave:** Even though groups should try to retain members, they also need to know there are people who need to leave. Some people are ready to move on because their needs have been met, they need something different than what the group can provide, they are unwilling to work with others, or other reasons. Let them go. When any member leaves, however, you should document the reasons. A follow-up phone call may be appropriate to discuss their ideas about the group.

Newsworthy Members

A newsletter can give your group a built-in way to honor members and keep them connected. Patient groups have published:

- the names of group members with recent implants or replacement device
- a profile of a survivor and his/her anniversary, including names, favorite foods, activities, pets, successes, and barriers overcome
- the names of each new group member—parents and children

Laugh Together: Figure out what it will take to get your whole group laughing. Laugh about the silly things that have happened in your group, even the failures or mistakes. These are the funny stories that bind you together and forge a greater sense of community. The main perks of belonging to a patient support group are the sense of community that is earned through your relationships and the good work you do for each other.

Listen to Group Members: Groups exist for the group members and for the benefits they provide to the community, not for their leadership. If membership has dropped or people are unhappy, the leadership circle needs to take the time to find out why. Then they must respond to keep the group alive. Members will not stay if no one listens to them.

- Early on, you provided a questionnaire to your members so that you could get information about members' needs. You should continually gather information from your members, because people and needs change.
- If one faction of your membership seems uninvolved, maybe it is because their needs aren't being met. A member survey can be used during a phone interview where you record members' answers to specific questions. Or you can adapt it so that members can fill it out themselves. Phone interviews will probably be the most successful, because more people

may respond and you can get clarification to answers if needed. Analyze the responses you get. Make sure any changes you propose reflect the data gathered from your members.

Meet Group Members in Cyberspace

If, over time, attendance drops and more and more members are unable to attend meetings due to scheduling difficulties or geographical barriers, consider offering support on the Internet.

- Your group could do something as simple as creating an e-mail group or listserv for all group members. You could communicate with each other anytime day or night and not have to leave home for a meeting.
- Your group could also create a web site to function as an online support group.
- Consider using online chat rooms for more structured discussion times, or message boards where patients can post questions or ideas whenever it is convenient for them and check back later to see who has responded.
- You may find that you still want to meet in person and you could do this from time to time.

Support is Support

A group in Virginia realized the value of using the Internet to provide the benefits of a patient group without having to work within the limitations of the schedules and locations of the group's members. Offering help, hope, wholeness, and support, the group translated the goals of a traditional face-to-face support group to cyberspace. The group's motto, "support is support," captures the idea that the goal is to provide patients with the support they need, regardless of the strategy you use to connect patients to that support. Demonstrating the potential of an online group to break down geographic barriers to patients connecting for mutual support, this once-local group now attracts participants from other counties, states, and even countries.

APPENDIX C. ICE BREAKERS AND RELATIONSHIP BUILDERS

Adapted from Small Group Tools for Mentoring, <http://www.toolsformentoring.com/small-group/relationship-builders.html>, accessed 09/05/08.

Ice Breakers

1. Introduce yourself:
 - As your mother would introduce you to the group.
 - As your childhood babysitter would introduce you.
 - State your full name and the places you have lived.
 - How did you get your middle name?
2. Information gathering: Have people pair up and discover as much information as they can about each other in three minutes. The members then talk about their partner.
3. Nuts and bolts: Have nuts and bolts of different sizes making sure they match. Give each person a nut or bolt. The participants then have to find who has their match. Once they find their match, they tell each other about themselves. The members then talk about their partner.
4. Bag game – How are you different: Fill a bag with a cotton ball, stapler, scissors, paper cup, eyeglasses, paper clip, pencil and eraser, and wadded paper. One at a time each person grabs an object from the bag and names one way they are different from the item. (It should not be the obvious “this is metal, I am not”. Encourage creativity.
5. Key chain: everyone get out their key ring and, one at a time, tells the significant of everything hanging on it.
6. What’s in your wallet: Each member shows four different things from their wallets: 1) something valuable, 2) something worthless, 3) something memorable, 4) something revealing.

Relationship Builders

These questions are designed to allow people to tell their “stories”. They are not designed for simple “yes” and “no” answers. Try using these questions on retreats or to start meetings. Using “group openers” is a basic, yet essential, small group skill.

1. Name your favorite movie and explain why it is your favorite.
2. If money was no problem and you could choose one place in the world to travel for a week, where would that place be and why?
3. What is the most daring thing you have ever done? What made it so daring?
4. My favorite way to waste time is _____.
5. You have one minute to speak to the entire nation on national television. What one or two essential things would you like to tell them?
6. What is the story behind the longest time that you have gone without sleep?
7. If you could go to college (again), what would you study?
8. Describe the most boring day/event/period of time you can remember.

9. What is the smallest space you have lived in? What was it like?
10. I was (or would have been) voted “most likely to” _____ in high school?
11. As a time-traveler, I would most like to visit _____ because _____.
12. What has been one of the greatest adventures you have ever been on?
13. I am most like my mom in that I _____.
14. I am most like my dad in that I _____.
15. I wish that before I got married someone had told me _____.
16. If you were to describe yourself as a flavor, what flavor would you be?
17. What was the best gift you ever received as a child?
18. What is your favorite city? Why?
19. What is the best news you have heard this week? What was the worst news?
20. What was your first job? What do you remember most about it?
21. When you were a child, what did you want to be when you grew up? What did your parents want you to be?
22. If you could choose one different way to do your wedding (parachuting while reciting your wedding vows, holding the service underwater, etc.) What would you choose?
23. Using a fruit or vegetable as a metaphor, how would you describe your life this week (dried fig, ripe cantaloupe, smashed banana, etc.)?
24. You have been granted one hour with the President of the United States - what would you ask him? What would you tell him?
25. The most useless thing in my/our house is _____ but it is still there because _____.

