



Beyond the Visit: Providing Heartfelt Support

by Jon Caswell

“They are not there to hear about the upcoming picnic or how much money is in the bank. They want to know how to handle this life-changing event that’s happened to them.”

— Donnette Smith,
Southern Regional
Director on newcomers’
expectations at their
first meeting

Recovery requires support — that’s really a core principle of Mended Hearts. And that support is most effective when it comes from a peer, someone who has “been there and done that.” Mounting evidence shows that those who face recovery alone have the hardest time getting better, and those with the most social support have the best chance of recovery.

Mended Hearts’ peer support is offered in a variety of ways. Visits by trained and accredited visitors — whether in person, by phone or online — are the mainstays of how Mended Hearts supports cardiac patients. However, many people may need more than one-on-one visits. This article outlines ways that some chapters have handled the issue of emotional support.



Priscilla Soucy



Donnette Smith



Dotti Reiss

For background, we talked to three Mended Hearts members who have been innovators in this area:

- *Priscilla Soucy is Northeast Regional Director (RD) and a former president of Chapter 9 in Hartford, Connecticut.*
- *Donnette Smith is Southern RD and a former president of chapter 260 in Huntsville, Alabama.*
- *Dotti Reiss is an Assistant Regional Director (ARD) in northern California and a former president of Chapter 62 in San Diego.*

The approaches taken by their chapters are as different as the regions of the country they represent, and each has succeeded in its own way. Along with providing heart patients much-needed ongoing support, incorporating support mechanisms in chapter meetings also helps chapters by encouraging more interactive participation and increasing membership.

Support groups address three key areas: education, socializing, and

sharing stories and concerns. Mended Hearts chapters have solid ideas and resources on education and socializing, so here we’ll focus on sharing stories and concerns.

Most chapters are adept at recruiting knowledgeable speakers for monthly meetings, and good banquets, parties and picnics are a staple of Mended Hearts. However valuable they may be, hospital visits, informational meetings and good parties may not always be enough to meet the ongoing emotional needs of new heart patients going through recovery.

“There is interest in creating support groups as a response to growing patient requests for ongoing support,” says Dotti Reiss, who is co-presenting a workshop on this topic with Priscilla Soucy at the national convention in September. “As an added benefit, it is also another way to increase attendance and participation at chapter meetings.”

Dotti also notes that the phrase “support group” may suggest some disability or dependence that heart patients may not feel applies to them. She says, “If you feel like the members of your chapter would object to calling it a ‘support group,’ call it a ‘peer group’ or a ‘discussion group.’”



Three Ways of Doing It

Hartford, Connecticut

“We started hosting a support group for younger heart patients before our chapter’s traditional monthly meetings,” says Priscilla Soucy. “Their needs are different. I call it a ‘pre-retirement group.’ They have no understanding or interest in Medicare, Social Security, grandchildren or taking vacations of several weeks. Their everyday problems encompass work, relationships with co-workers, children and college. They need to talk to others who are dealing with the same issues.”

Chapter 9’s pre-retirement group started meeting in September 2001. They meet an hour before the regular monthly meeting. “The group dynamics are very different,” says Priscilla. “The group is very informal. We have snacks and beverages for them because they’re coming directly from work. We have to meet then because it’s unlikely they’ll get back out if they go home. And their weekends are full of family responsibilities.

“We sit in a circle. If there’s someone new, we do introductions, then we sit and listen to the new person share their personal story and experience, then every-



Members of the support group in San Diego gather to share experiences.

Incorporating Support into Your Chapter Meeting (the San Diego example)

- Step 1** Before the meeting, choose your categories — CABG, Stents, Heart Attack, Caregivers, Valves — and secure a facilitator for each. Remind those people to start the discussion with an experienced member, then go to the newest participant or the person in the group who the facilitator senses might be most in need. Ask the facilitator to keep people on track, watch the time and squelch negativity.
- Step 2** Divide the room into groups of 5–6 people using the table tents or another method with a facilitator for each group.
- Step 3** Listen and talk, giving support by listening; 30–40 minutes should be sufficient.
- Step 4** Wrap-up can be as simple as giving a five-minute warning to the groups to finish their discussions. Another wrap-up might include reporting back from the groups on any significant insights, learnings or ideas.

body shares. For instance, recently we had a young woman who was afraid to fly after her surgery, but she had to for her job. She was really scared. She talked about her feelings, then several members who had had similar feelings shared their experiences. Hearing their stories helped this woman cope. She came for 2–3 months. After her first flight, she called me and said everything went just fine.

“If there’s no one new, I always bring a topic and we discuss that,” says Priscilla. “Many topics relate to work, families and feelings. These subjects are of the greatest interest to them. A speaker isn’t necessary, but we have one occasionally. After the meeting, they are invited to stay for the regular monthly meeting. Some do and some don’t. It’s not a requirement, nor is there a fee.” [See related story on Chapter 9 on page 11.]

Huntsville, Alabama

“We have focused on the emotional sharing aspect since Chapter 260 was started,” says Donnette Smith. Her chapter uses a different format. Rather than have a separate support group meeting, Chapter 260 integrates 15-minutes of sharing into each monthly meeting. They divide into groups of three; a topic is announced by the facilitator — for example, “How has your life changed since your heart event?” — then each person in the threesome has five minutes to share their thoughts. Caregivers are always grouped together.

“The facilitator always reminds the whole group that the point is to listen to the person speaking,” says Donnette. “The two listeners face the speaker and look that person right in the face and listen without replying. When everyone has shared, we come back into the big group, and people share their thoughts. We discovered early on that the chance to share their experience was what brought many people to our meetings.”

San Diego, California

Chapter 62 in San Diego combines these two formats: They have a meeting an hour before the regular monthly meeting, and they divide into smaller groups based on the kind of procedure they’ve had. Again, caregivers have their own group. “We put out table tents with the various procedures — CABG, Valve, Stents,” says Dotti. “As members sign in, they are directed to the appropriate table. We keep the groups small — six to eight people — and usually there is more than one bypass group.

“We purposely keep the groups small so people are more likely to share. In large groups, many people just won’t speak up. In a small group everyone feels freer to talk because it’s like talking to your friends. I think people listen better in small groups, too. It’s more per-

sonal, and people are willing to let their hair down because they trust these people will understand. I know education is important, but I think the education we give each other, that helpful advice, that real-life solution is the real education and support,” says Dotti.

Enhancing Membership and Attendance

All of the groups have seen increases in their attendance since implementing a support group element into their meetings. “The pre-retirement group is a revolving group,” says Priscilla. “Some come to just a few meetings, and others come for years, but all of them have joined Mended Hearts. I didn’t ask any of them; they did it on their own. Now Chapter 9’s president and vice president are members who came to Mended Hearts through that group. They are in their 50s.”

“I would say Chapter 62 has grown by a third since we instituted the discussion groups before the regular meeting,” says Dotti. “We have a lot more new people and lot of younger people. Most meetings are nearly one-half new people now. This solved a chronic problem for us because without new people, chapters just dwindle away.”

“Our membership has definitely increased, although that was never our main focus,” says Donnette. “Those newcomers who attend and have their needs met are much more likely to return and eventually join Mended Hearts.”

“I realize that over the years our stories have gotten pretty boring to our regular attendees,” says Donnette. “We may be tired of hearing the same story, but one of those stories just might be exactly what the newcomer needs to hear. They are not there to hear about the upcoming picnic or how much money is in the bank. They want to know how to handle this life-changing event that’s happened to them. Our success stories give them hope and encouragement.”

“The key benefit is that it allows newcomers to share their experience,” says Donnette. “They are comforted when they find someone who understands what it’s like to have nightmares or depression or be afraid to be left

alone. They open up and share feelings that they might hesitate to share with a family member, who might not understand anyway.”

Facilitators – A Key to Success

A key to the success of these emotional support groups is having good facilitators to run them. “We’ve used volunteer counselors and psychologists to lead the pre-retirement group,” says Priscilla. “Those types of professionals can bring a lot to the table — they can do relaxation techniques and things like that, but a professional is not necessary for being a facilitator. A good listener who understands the feelings and issues will



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work fine. Nor do you need to be young to run a younger support group. The facilitator’s role is to coordinate the group and put the members at ease as well as to try to include everyone in the discussion.”

Says Dotti, “The president assigns the facilitators for each of the groups on the day of the meeting. A good facilitator is someone who’s been around awhile, who can lead and has good listening skills. It’s their job to get the discussion going and keep things flowing and focused.”

“Usually the facilitator calls on a more seasoned member to briefly tell their heart-event story as a model for the rest of the group. Then the newest person is asked to relate their experience. A sensitive facilitator can tell when some people need to ‘unload’ and can call on those people first. That way, if time runs out before everyone has shared, those with the most need have been heard.”



Enhancing, not Dividing

“When I’ve suggested the pre-retirement concept to group leaders in the past,” says Priscilla, “some of them have worried that it would split the chapter into younger and older groups. It hasn’t split our chapter; it’s energized it. Like I said, our new president and vice president came through the pre-retirement group. Any chapter that wants younger members should try this. Sure, it takes some effort, but most chapter leaders tell me it takes a lot of effort to recruit new officers from among the retiree age group.”

“New patients have the greatest need,” says Dotti, “and that’s when they’re most likely to seek support. By making it a formal part of the meeting, we can tell people who are interested that they will be sitting with people who have had the same experience they’ve had. That is exciting to them because, at that point, they really need to connect with someone. And our veteran members like it because it gives them an opportunity to support someone going through this for the first time.”

It Makes a Difference

Overcoming fear is a normal part of recovering from any life-threatening event. While it is possible to overcome fear alone, many people can’t. When she came home after three surgeries because of complications, Donnette Smith found herself alone. “My husband went back to work and my kids got on with their lives,” she says, “and I only had my dog, Penny, to talk to about my nightmares and depression. Now I know the value of this kind of support. When I was diagnosed with breast cancer, I started calling other survivors right away

because I knew I needed to talk about my feelings.”

“I know from observing the room that good things are happening,” says Dotti Reiss. “There are all kinds of emotions, and they’re all part of being a patient or caregiver. People get what they need from it, whether that means sharing something helpful or getting a question answered or just talking about their feelings without guilt.”

“This group is not intended to solve all the problems of younger people,” says Priscilla. “It is to share experiences, learn from each other and offer encouragement and hope for the future. These patients have many years that they must deal with their heart problems and need all the help they can get. Eventually they start attending the regular monthly meetings and participating in projects. They work into the roles of chairperson and officers. They are our future leaders.”

As you can see, support groups can have a variety of names and different formats. But whatever name they’re called or whichever format they use, they enhance the recovery of new patients while adding meaning to the lives of veteran members. It allows everyone involved to affirm the Mended Hearts’ motto: “It’s great to be alive — and to help others!” ❤️

Editor’s Note: *Mended Hearts, with support from GlaxoSmithKline, has recently developed a new tool to help chapters develop support groups. Chapter leaders will receive copies of “Heartfelt Support: A Support Group Guide” at the annual convention in Scottsdale and through the post-convention mailing in late September/early October.*

Language Matters

How we talk about heart disease and heart conditions is important in a support group setting. There is no place for negativity or victim-type comments.

Word choice suggestions:

Positive:	Negative:
Heart disease survivor	Heart disease victim
Experienced a heart attack	Suffered a heart attack
Challenges	Difficulties
Caregiver	Caretaker