

ACPA

Facilitator

Guide

*The how-to book for those who want
to start a self help group for people
with pain.*



American Chronic Pain Association

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Introduction

How do individuals in a community start a self-help group for people with pain? More important, how do people with pain and limited energy start a support group that will provide support for all members, including themselves? For clarity, we will refer to the person or persons initiating a group as the facilitating member(s). This does not mean that they are more knowledgeable about pain management than others. It simply means that they took the incentive to get the ball rolling. This manual is designed to help a person or persons with pain organize, distribute, inform, and delegate responsibilities for the group.

When it comes to knowing how to manage pain, each of us who lives with pain is his or her own expert. We have designed this program to allow you to connect with your peers. It will allow you to share your ideas. You will learn new techniques that will help you and each group member to move from the patient role to that of a person.

It is our sincere hope that you will be able to implement this program with the help of the community you live in. We will show you how. It will be up to you to get things started. Know that you are not alone. There are hundreds of people just like you who have successfully managed to organize support groups for persons with pain.

Since 1980 the American Chronic Pain Association has worked with people who have chronic pain. Our mission is to help anyone who is willing to help themselves. We are here to support each and every one of our ACPA groups. All a facilitator has to do is ask for help.

Section 1

Getting the group off the ground

There are tasks which must be done before an ACPA group can get started. The following section will take you step-by-step through each phase of establishing the group and generating interest in the community.

Chapter 1 The ACPA and You

What is the American Chronic Pain Association?

The group must be facilitated by a person or persons with chronic pain.

The American Chronic Pain Association (ACPA) is an international association of self-help groups whose mission is twofold:

ACPA Mission:

- To facilitate peer support and education for individuals with chronic pain and their families so that these individuals may live more fully in spite of their pain.
- To raise awareness about issues of living with chronic pain among the health care community, policy makers, and the public at large.

The ACPA goal is that we might help members improve quality of life and reduce their sense of suffering by teaching coping skills whereby members can better manage their pain. The ACPA seeks to help members make the transition from the role of a patient to that of a person. Empowering members and providing skills to begin and maintain the transition is the main focus of the ACPA.

ACPA Guidelines:

The following guidelines are critical to group success. They

have been developed based on our past experiences, since 1980, working with group leaders and members of the ACPA. The guidelines help ACPA chapters to promote wellness and maintain a positive attitude among the members of their groups.

1. **The group must be facilitated by a person or persons with chronic pain.** Unless a person has experienced chronic pain, he or she cannot be effective with ACPA group members.
2. **No professionals are permitted to do therapy of any kind during group meetings. Professionals may attend group meetings** (for reasons other than their own pain problem) only on invitation, and all group members must approve. Invited speakers are, of course, welcome to attend a group meeting.
3. **Affiliation with any hospital or other health care institution is not permitted.** The ACPA is a self-sustaining nonprofit corporation. Local health care facilities may offer a local ACPA chapter help in the form of meeting space or making copies, however the group is still an affiliate of the ACPA and must abide by the ACPA guidelines and principles.
4. **Groups should be open to all people with chronic pain who are willing to help themselves, without regard to race, creed, age, sex or sexual orientation.**

The ACPA guidelines have been developed by the ACPA Board of Directors and are designed to provide each person with pain an equal opportunity to be an active part of an ACPA group. There will be no judgements placed on any member. Any person who attends ACPA meetings will be accepted as a person with pain, no questions asked.

Seven ACPA Principles:

The following principles form the foundation of the ACPA program. Understanding and learning them will help you to guide the group effectively and provide you with a framework with which to evaluate new ideas and solve problems, as they arise.

Groups are Confidential

- 1. ACPA meetings are strictly confidential.** It should be understood from the beginning that whatever is said in the group will go no further.
- 2. ACPA groups are self-help, mutual-aid groups and no therapy of any kind is provided in group.** All members of a group are lay people. The assumption is that members do not have the training to perform any type of therapy or medical advice in the context of the group. Even if members have this type of training, they should not be used in ACPA group settings. It is the personal experience with chronic pain that qualifies facilitating members to perform that role and for other members to attend group meetings.
- 3. The ACPA is not designed to take the place of medical treatment.** It is the intent of ACPA to work in a trusting relationship with the medical community and to be a resource to this community. It is the responsibility of all group members to suggest that other members seek professional help when indicated, rather than attempting to provide professional help within the context of the group. Remember, no one has all the answers to problems and saying, “I don’t know” or “you might need to seek professional help” is okay.
- 4. The ACPA encourages its group members to be well-informed consumers when it comes to medical care.** Knowing how to handle the doctor-patient relationship and how to choose a pain management unit, if necessary, can be the by-products of being well-informed consumers of medical care.
- 5. Groups belong to their members. Leadership and group tasks should be shared.** Groups may choose to circulate certain leadership tasks over time or have two or

three members share leadership tasks at all times. It matters less how leadership is shared; it matters more that no one or two people carry out leadership tasks for long periods of time.

Groups belong to their members.

6. **Utilizing skills taught at ACPA meetings will allow members to become actively involved in their own recovery. The support members receive at group meetings will enable them to continue to make progress.** It is in each individual accepting responsibility for oneself and investing time in the recovery process that the ACPA can help its members.

7. **ACPA groups are meant to offer a support system to members, as well as to teach skills which will enable members to cope with day-to-day situations.** There are no simple answers when it comes to chronic pain. It takes determination and perseverance on each member's part to improve the quality of his or her life.

Please feel free to make copies of these principles and give them to members. These principles are important to the ACPA and clearly outline what our mission is. Keep these in mind as the group begins to develop.

Chapter 2

How to Start an ACPA Support Group

An easy step by step guide to forming and conducting a support group.

ACPA meetings consist of a small group of about ten people or less with one thing in common—chronic pain. While pain is what brought each person to the group, it is clearly not the focus of the meetings. Our mission is to help members regain control by improving the quality of their life and by reducing his or her sense of suffering. ACPA groups are designed to be positive experiences for each person attending the meetings.

What is an ACPA Coordinating Member(s)?

ACPA groups often start as an effort by a single person. It is important, however, that once a person identifies another or several other interested people with chronic pain, that responsibility for facilitating the group be shared. Therefore, the first characteristic of ACPA group leadership is that this leadership is shared. We will call the core leadership group, “facilitating members.”

Members of this core should not accept complete responsibility for the group. They simply coordinate events leading up to meetings and act as contact persons for anyone seeking information about group meetings. Again, it may be one individual who coordinates the first meeting and acts as the

contact person. But, it should be the goal for this individual to eventually share the responsibility for future meetings. For the

ACPA Facilitating Members must be persons with pain who are willing to help him or herself as well as helping others.

sake of continuity, however, it is important to designate one person as “contact person” for group members to get in touch with for information and for communicating with the ACPA National Office about group activities.

Let’s take a closer look at some of the “qualifications” of individuals acting as Facilitating Members:

Person with pain: First and foremost, Facilitating Members must be persons with pain. It does not matter what other qualifications they may possess, he or she has to have a chronic pain problem. There is no way to understand the complex nature of chronic pain if he or she does not have first hand experience. This is the one requirement that is an absolute must.

Accepted his or her pain: This is the first step in making the transition from patient to person. It is a vital step to begin the long journey toward regaining control of his or her life. Once all attempts at completely alleviating the pain have been exhausted, the person with pain needs to understand that there may be a certain level of pain that he or she will have to live with. Additionally, he or she needs to realize that a portion of the responsibility for recovery is his or hers.

Needs support: A person who takes the responsibility as facilitating member is not someone who has discovered a means to relieve his or her pain completely. He or she is not someone

who has all the answers either. Rather, a person who begins an ACPA group is someone who may still be struggling in an effort to regain control. He or she may be a person who is just beginning to understand pain management and needs a support system of peers to make the most of each day, while at the same time trying to reduce his or her sense of suffering.

Willing to get involved: Clearly, if a person is not willing to get involved in his or her recovery, there will be no way to help others accomplish that either. The person with pain needs to be willing to get involved in the community by reaching out to others who need support.

What a Facilitating Member should know about running a self-help group:

People helping people

The word self-help is the key. Self-help means that each person must commit to make every attempt to improve the quality of his or her life. To the ACPA self-help means a number of people who gather together to learn how they can manage their pain while helping each other. The facilitating member is willing to work with others and share information germane to the situation. Simply put, it means people helping people.

Finding others to help get the group up and running.

From the very beginning, it is easier to have others involved in the development of the group. One way you might identify potential members is to contact local doctors, pain management programs and hospitals. The following is a form letter for your use.

Dear _____,

My name is (your name) and I am a person with chronic pain. Currently I am in the process of organizing an American Chronic Pain Association self-help group in our community and I need your help to identify potential members. Since 1980 the ACPA has looked to people with pain to establish self-help groups designed to support the efforts of individuals to become actively involved in his or her recovery by accepting some of the responsibility. This is accomplished with the use of ACPA workbooks which focus on a variety of coping skills. Chronic pain is a lifelong problem for many of us. We must take part of the responsibility for our well being if we hope to make the most of each day.

Can you help me to identify several people with pain in the community who might be interested in helping form the group? The only qualification they need is the desire to regain some control over his or her life. The ACPA does not take place of medical treatment, but rather works as a compliment to the treatment they are currently receiving.

If you have any questions, please contact me at (insert your phone number). Any help that you could provide would be greatly appreciated. Thank you for your time in this matter.

Sincerely,

Your name

Chapter 3

Sharing Group Responsibility

*Remember, the
responsibility of the group
belongs to
each member.*

Each member who attends a local ACPA group is responsible for the maintenance and welfare of the group. Group reliance solely on one person is not fair to him or her or the group members. ACPA groups are about peer support and mutual aid. Once you have several members who have attended at least three meetings, it is time to delegate. Remember, the responsibility of the group belongs to each member. The ultimate goal of ACPA groups is to provide on-going support to the community. To ensure the group remains active, sharing responsibility of the group is a must. A group dependent on one person will not survive the test of time.

Jobs to delegate:

- h group contact person
- h meeting reminder phone calls
- h sending out public service announcements (PSAs)
- h placing posters around the community
- h obtaining resource materials
- h inviting speakers
- h lead group discussions

- h community outreach
- h sponsor program (will be discussed in later chapter)
- h refreshments
- h visiting members in hospital/home

Ways to delegate responsibility

Once the group has established a core membership of three or more people, it is time to share ownership of the group. On the following page is a Group Task List which can be modified to meet the group's needs. Prepare these either once a month or quarterly, depending on how often the group meets.

Plan ahead and have members complete the form at least a month before the responsibilities are to be assumed. Explain that members are making a commitment to the group when they accept a task. The rest of the group is depending on them to fulfill their task. When each member takes his or her job seriously and completes it on time, the entire group benefits. Accepting responsibility and seeing it to its completion is a positive step toward wellness.

NOTE: On the list below you will notice “Key Contact Person.” The National Office must be notified of this person so that we can direct potential members to the group. To ensure that information about group meetings is accurate and consistent, the contact person should be willing to accept this job for longer periods of time.

Group Task List

Task for the Month (s) of: _____

Today's Date: _____

Please place your name beside the task(s) that you would be willing to do for the dates indicated above.

TASK	First Week	Second Week
Phone Calls		
Posters		
Refreshments		
Sponsors		
Speakers		
Resources		
Car Pool		
Discussions		
PSAs		
Visiting		
Outreach		
Key Contact Person		
Other		

Chapter 4

Responsibilities of the Facilitating Members

An ACPA group is meant to be a safe place to talk freely about personal feelings.

Be honest with members. Become an active member in the group and communicate your needs to all the members. Don't separate yourself from the group by not sharing your problems with them. When you need support, let the group know. If you think of yourself in terms other than a group member, your needs will not be met. Unless you gain something from your involvement in the group, burn-out as a "facilitator" is a strong possibility. Make sure that you and each member see you as simply another person in group.

Be at the meeting on time. Always be at the meeting on time. If the meeting is canceled, make sure all members are informed at least two hours before the meeting. In many areas weather will prevent safe travel to and from meetings. Make sure the person in charge of phone calls to members will contact each member in case a cancellation is necessary.

Be supportive of members and try to intercede if you feel there are value judgments being placed on a member. When

discussions progress to a point where a member is placing a value judgement on another member, it is appropriate for the facilitator to speak up and remind the members that the ACPA does not make judgements. It is important that members do not feel alienated by others. An ACPA group is meant to be a safe place to talk freely about personal feelings. It is vital that no member make judgement of others. Remember, there are no wrong feelings.

Understand that you are not responsible for the actions of other members. You cannot tell members what to do, nor are you responsible for any actions they may take. Actually you are not responsible for anyone else but yourself. There is no way that you can control another's actions.

Have new members fill out the new member introduction sheet.

Be a good listener. Not everyone is able to get right to the point. Give members a reasonable amount of time to tell their story. When it is not clear what the person is saying you can say, "What I hear you saying is . . ." and repeat back to them what you believe they said. This will prevent misunderstanding as well as let members know you are listening to what they say and that what they say is important.

Prevent prolonged pain talk. Members need to share their reasons for coming to group. However, you must not let them spend all their time talking about pain. The best way to welcome a new member, allowing them to tell their story, is to have members fill out the new member introduction sheet found on page 34.

Introduce new materials in group whenever possible. The role of the ACPA is to provide support and coping skills to those with chronic pain. As a Facilitating Member you will receive information about new materials available through the ACPA National Office. Make sure you share that information with members.

Be open to suggestions from members about new ideas

which might help the group. ACPA members are bright and have insight into what coping mechanisms are helpful in given situations. To ensure that all the members of the group remain equal partners, always ask members for new ideas. Each member is a valuable resource to the group and the ACPA.

When you have a problem that you cannot solve, contact your Regional Resource Person or the ACPA National Office for help. You are not in this alone and should not have to struggle with questions or problems about the group. One of the advantages of being part of a national organization is having someone to talk to about problems that arise.

Return phone calls from members within a reasonable time. As a facilitating member, you may be the contact person for the group and must return phone calls. People with pain have been waiting far too long for help. The ACPA recognizes their need for immediate attention.

Delegating responsibilities for the group to group members is part of your role. Remember, the group is designed to provide support to each member . . . and facilitating members are members. If you are not benefitting from the meetings, then you need to call the Regional Resource Person or the ACPA National Office and talk about ways to enhance the group experience.

Allow for mistakes and failures. These may be opportunities to learn and to get all members to share responsibilities for failures as well as the successes of groups. Just as learning to live more fully with pain is a process, learning to support one another is a process. We all have the right to make mistakes. Those who move forward in spite of mistakes have the ability to use the mistake as a learning tool.

Accept each member as an equal. Accepting people “as is” can be difficult. It is important to remember that each person comes to group with one common bond—pain. Pain is the issue at hand. Lifestyle and personal values should not be a consideration for membership of the group.

Chapter 5

Responsibility of ACPA Members

Members should always call the contact member if they will not be attending.

The facilitating members are not the only people responsible for the group. Each member shares in the responsibility to ensure that the group provides the peer support which is the hallmark of the ACPA. Discuss the responsibilities below with members. The ACPA is designed to help a person with pain become an independent person who is willing to share the responsibility for their recovery and on-going wellness. The ACPA is not designed to become a caretaker for members. Facilitating members are not responsible for the actions of group members. Treat members with respect and dignity and you will give them the ability to accept some of the responsibility for their own recovery.

Members should be on time. Coming into group late is disruptive for everyone. If he or she cannot attend the meeting, make sure a call is made to the group contact person at least two hours ahead of time. Members may assume that it makes no difference if they attend or not, others will be there. What may happen is each member thinks the same way and the facilitating member makes the effort to attend group to find no other members. Remember, other members are also people with pain and it is as difficult for them to attend group as it is for you. Be considerate. **Don't judge your fellow members.** You do not always have a complete understanding of their circumstances. Unless you have "walked in their shoes" there are things that you do not understand. Making judgements of members is unfair and serves no purpose. **Be a good listener.** If a member

is talking, let him or her finish before you talk. *Make your needs known or they will*

not be met. Be honest with yourself and other members of the group. They are there to help. There is nothing to gain by dishonesty in an ACPA group. The most important thing in any ACPA group is trust among members. If you betray that trust, the entire group will suffer. **Make your needs known or they will not be met.** No one can read your mind so don't be afraid to share your feelings. The only way to have your needs met is to tell fellow members what those needs are. Your ACPA group is a safe place to be yourself. **Trust the other members of the group.** They are there to help. Treat them with dignity and respect and they will do the same for you. **Take responsibility for the group.** Offer assistance to the group members. Each group member freely gives his or her time and energy. Your help is needed in a variety of ways and would be appreciated. If you have a special talent, be willing to share it with the group. The more each member of the group contributes, the more the entire group will benefit. **Allow the meeting to end on time.** If you have something to say, make sure you do so during the course of the meeting and don't wait until the meeting is over. **Leave the group room the way you found it.** Also, be courteous to other groups meeting in the facility. The meeting facility is being donated and you should show your appreciation by leaving the room the way you found it. **Understand that your fellow ACPA members do not have all the answers.** Like you, others are involved for the same reasons as you— support and help. Work together as a group to resolve problems. Please feel free to make copies of this and share with members.

Section Two

The Meetings

Now that everything is in place for the meetings, there are other things that the group will need to know. Initially the facilitating

members will be the ones responsible for all the tasks of the group. But, as membership builds, the group can begin to delegate responsibilities to others. Remember, no one is alone in the ACPA. Each person who attends the group is equally responsible for keeping the group active.

Chapter 6

ACPA discourages from using a person's home.

How to Find a Meeting Place

One of the first responsibilities of getting an ACPA group off the ground is to identify a place where meetings will be held. There are a variety of possible location. The only locations that the ACPA discourages from using is a person's home. We do not know the people who will be attending group and would be more comfortable if you did not invite strangers into your home.

A public building, with easy accessibility to the meeting room, is ideal. Finding a place that will not charge rent is recommended. There will be plenty of work for the group to do without worrying about raising funds to cover rent. Available sites with meeting facilities may include:

- churches
- libraries
- banquet rooms of local restaurants
- government buildings
- health clubs

If you cannot find any free meeting space in your community, then we suggest that you try local health care facilities. We suggest that you inquire about health care facilities as a last resort. The ACPA believes that for many people with chronic pain, a health care facility represents a negative environment—a place the person with pain and the health care provider failed. However, the majority of health care facilities today have conference or educational rooms which lend themselves to an ACPA meeting. Contact the social service department of your local hospital to inquire about meeting space.

LETTER ASKING FOR A MEETING PLACE

Date

Name
Street
City

Dear _____,

The AMERICAN CHRONIC PAIN ASSOCIATION (ACPA) is a nonprofit self-help organization designed to help those suffering with chronic pain. Chronic pain is defined as any pain which intermittently continues longer than six months, but for many it persists for years.

Chronic pain is an affliction which has been misunderstood in the past. It is now being recognized as a problem not only for individuals and their families, but also for business and industry as well. The pain can become life threatening to many who suffer with overwhelming, all-controlling pain.

The ACPA provides a means for chronic pain sufferers to help themselves using well-designed and proven techniques. With the guidance of others who have experienced similar feelings and who understand their situation, group members can regain control of their lives and put pain into its proper perspective. As a self-help, nonprofit-agency the ACPA's services are free to the public. It has 501(c)(3) tax exempt status.

The ACPA has been providing service to people around the country since 1980. We are about to establish a group in the (city) area and would like to be able to use (facility) on the (days and time of the months). The group size is usually around ten persons and access without stairs may be required for some members. I will call you in a week and hope that you will agree to support us in this way.

Sincerely,

Your Name

Chapter 7

Publicizing the Group

The only way to attract members to ACPA meetings is to get the word out to the community.

The only way you are going to attract potential members to meetings is to get the word out to the community. There are several ways to let the community know about the ACPA meetings. The initial outreach to the community may take a little time, however, it will pay off as prospective members respond. Once the meetings begin, you should share this job with group members.

Posters: Place the poster—provided in the starter kit—in areas where people who might need the ACPA will see them. Pharmacies, doctor offices, hospital waiting rooms, church hallways, and health clubs are a few areas you might consider. Please remember to ask permission before displaying posters. Additional copies of the posters may be made by the group.

Pamphlets: Pamphlets are an excellent way to give a more in-depth explanation of ACPA meetings. Ask doctors and other health care providers in the community to offer the pamphlets to patients who would benefit from the ACPA. It has been our experience that health care providers are happy to provide the pamphlets to their patients. It provides the doctor with something to give to a patient as a means to help him or her deal with their pain problem.

Public Service Announcements: These are announcements about group meetings which are sent to the local newspapers

and radio and television stations. The ACPA is a 501(c)(3) nonprofit organization, which enables the group to qualify to have these announcement distributed free of charge. You will find the 30-second announcement for radio and television, as well as a brief newspaper release on the following pages. Simply retype them on the ACPA letterhead stationary provided in this kit, inserting personal group information where indicated.

To obtain mailing addresses of newspapers and broadcasting stations, refer to your phone book.

Television and Radio PSA

Date: FOR IMMEDIATE RELEASE
Contact: Your name
Your address
Your phone number

AMERICAN CHRONIC PAIN Association, Inc., Public
Service Announcement
30-second spot

Chronic pain is a pain that never goes away.

If you have it, you know that often doctors
and medicine can't help. But you can learn to

help yourself. The American Chronic Pain

Association

can teach you how through small group meetings in

the (your city) area. Call the American Chronic Pain

Association at (your phone number). They offer help

and hope. That's *(your phone number)*.

Make sure you double space this announcement.

SAMPLE MEETING ANNOUNCEMENT

Contact: *Your Name and Phone Number*
FOR IMMEDIATE RELEASE

The (area) Chapter of the American Chronic Pain Association will meet on (day, date) at (time) in (name of place), (address). The American Chronic Pain Association is a nonprofit, self-help group designed to teach people who suffer from chronic pain-- pain that continues longer than six months and is not completely relieved by medication or medical treatment-- to reduce the impact pain has on their working and personal lives. All prospective members are welcome to attend or to contact (name) at (phone number) for more information.

Things to know about sending out PSAs:

- Allow at least three weeks from the time you sent your PSA until you want it to appear
- Make follow-up calls to ensure the PSA was received
- Ask when they plan to issue the PSA
- Offer to answer any questions they might have when you call about the PSA
- Resubmit PSA at least every two months
- Always send a note of thanks when the PSA is used

Video PSA Through a grant from the Mayday Fund and with the generous help of Jamie Farr, the ACPA was able to produce a 30-second public service announcement about the American Chronic Pain Association. If you would like to obtain a copy, please send \$5 to P.O. Box 850, Rocklin, CA 95677. One will be sent you to for broadcasting in your community. The video is also a useful tool if you are asked to be a guest on a local talk show. You can use it as an introduction to the ACPA. Jamie Farr, well known for his role as Maxwell Klinger in the television series *MASH*, speaking on behalf of the ACPA will enhance the appearance of the ACPA.

The ACPA group certificate
is your way of showing members
that their group is
an official part of the ACPA.

Word of Mouth Good news travels quickly around a community. Encourage members, friends, family and health care providers to talk freely about the local ACPA chapter.

Group Certificate

Once the meeting time and place have been established for the first group meeting, call the ACPA National Office to obtain the group's ACPA certificate for the current year. The ACPA group certificate is a way of showing members that their group is an official part of the ACPA. The group will receive a new certificate each year by filling out the ACPA Annual Report. The Annual Report is to be filled out each January. The National Office will only refer potential members to groups with a current certificate. The certificate can be found on page 108 of this manual.

In Conclusion:

Creating an awareness in the community about the ACPA is the key to a successful group. Obviously, unless people know about the meeting, they will not attend. It is wise to invest time networking with people who work in the media in your community. The ACPA also recommends that you make every effort to inform the medical community about the ACPA meetings. A successful media campaign can get the group off to a great start. To keep the group strong, make sure that you continue to send out meeting announcements, check to ensure posters are up and pamphlet supplies are ample.

Chapter 8 *Get the callers name and phone number.* **First Contact**

Talking to Prospective Members

Now that you have successfully spread the word about the meeting, phone calls will begin. There are a few things that you need to know to help keep the phone calls short and to the point, but at the same time let callers know that you do care about him or her.

When taking any phone calls about the group, the first thing that needs to be done is to get the caller's name and phone number. Keep a small note pad by the phone just for ACPA calls. Sometimes we get so involved in the conversation that we forget to ask the callers name or to obtain his or her phone number. Always keep this information in a safe place.

You will be able to help them help him or herself.

You will receive a wide variety of callers. Most first-time callers really don't know what to expect. He or she heard about the group and the words "chronic pain" caught his or her eye. Rarely do we see those words boldly displayed in public.

Callers will probably fall into the following categories:

- Someone who has been looking for just such a group.

- Someone who thinks you are a medical facility and wants to see the doctor.

- Someone who has no idea what the group is about but just wants to talk to someone about chronic pain.

- Someone who has a family member or friend who

could use the group.

No matter what his or her reason for calling, each person has hope that you can help. Your job is to communicate that you will be able to help callers help themselves. Initially, it is important to acknowledge that you understand what pain can do to one's life. Try not to let him or her talk about physical symptoms for a prolonged period of time. After all, you cannot do anything about his or her pain. You can let them know you understand the control pain has over one's life and you would be happy to discuss this at his or her first group meeting.

Be careful not to spend too much time on the phone with the caller. If you do, you may take away his or her reason for attending group. The person on the phone has your undivided attention and, unless you keep the discussion brief, the prospective member may not attend the meeting.

Be careful not to spend too much time on the phone with the caller.

What you need to tell first-time callers is that you understand chronic pain because you are also a person with pain. Let them know there are ways to improve the quality of life and reduce his or her sense of suffering if the person with pain is willing to get involved. The ACPA group meetings will provide a means to accomplish this and receive peer support. This is the message you need to get across.

If you have a caller who is stuck on a problem, the best way to handle this might be to ask, "How can I help you bring this up in the group?" Let him or her know you realize how important it is, but your time on the phone is limited and you would be happy to help him or her discuss it in group. Remember, you do not want to take away his or her reason for attending the group.

Today many of us have answering machines to ensure that we do not miss important calls while we are away from home. If you have an answering machine, you might want to consider adding the comments below after your usual message:

If you are calling about the American Chronic Pain Association, please leave your name and phone number and I will return your call.

This allows callers to know he or she did, in fact, reach the correct person for the local ACPA groups.

Chapter 9 *Keep it short and to the point. Preparing for The First Meeting*

Why are you willingly volunteering your time and energy to facilitate this group? That will be the question many members will want to know. Like them, you are a person with pain and may have a limited amount of energy and resources. It is important that members have a clearer understanding of why you are volunteering for the ACPA.

Writing a brief overview about yourself, including information about family, hobbies, and other details will allow members to get to know you. Also, include a brief statement about your pain: what caused your pain, how long you have had it, and what changes it has created in your life. Every person who has chronic pain could easily write a book on the effect pain has had on his or her life, but you will be setting the example for discussing pain, so keep it short and to the point. If there are several facilitators working together, each one should prepare a brief statement.

While members come to the group because of pain, many personal issues arise during the course of the discussion. Members may hesitate to share these unless he or she feels comfortable with the group. Trust must be earned. Facilitating members, can promote the learning of trust by sharing their own personal experiences and feelings about his or her pain. This

helps members to feel less threatened and more willing to share his or her feelings. It will take several meetings or more to build trust among members.

New Member Introduction Sheets

Keep the New Member Introduction sheets on file.

The first few meetings you have will be focused around introductions. In order to keep the introduction informative, yet to the point, we have provided a **New Members Introduction sheet**. (*Please feel free to make additional copies as needed.*) This sheet is designed to provide all the information that members need to know about each other. It has been proven to be an excellent tool and prevent long-winded discussion about one person's pain.

Keep the New Member Introduction sheets on file. Do not send them to the National Office. They are for your records.

Welcome Kit

Providing sufficient information about the ACPA at the beginning of a member's group experience will help him or her to understand what the ACPA provides and what the ACPA expects from its members. All the materials below are available through the Nation Office. Please make sure that you keep your supplies replenished.

Other things that you may want to include in your welcome kit:

- ACPA Help and Hope* pamphlet
- ACPA Coping With Chronic Pain: Helpful Advice from the American Chronic Pain Association* pamphlet
- Guidelines for Selecting a Pain Management Program
- Your personal introduction to the group
- An ACPA membership order form
- Copies of reading list the group might have prepared
- Responsibilities of ACPA Facilitating Members and ACPA Members

The ACPA Do's and Don'ts
ACPA Chronicle

List of community resources such as health clubs, social service agencies, resources for providing services to those on fixed incomes, etc.

To learn how to obtain additional copies of ACPA materials, please check the chapter on ordering supplies.

New Member Introduction Part A: Please Print: My Name is

_____. I have had chronic pain for _____. (First name)

(Months-years) My pain is severe moderate

light variable and is caused by: (arthritis, effects of surgery, headaches, Rsd, FM, etc.)

I found out about the group from: I live in _____ with my

(City) (husband, wife, parents, children,

etc.) **Group Facilitator Information**

Part B:

Please Print Name _____ Birth date

__/__/__ Street Address City _____ State ____ Zip/Postal

Code Phone number: (_____) I was

_____ before my pain began.

(accountant, homemaker, customer service, etc.) My special talents are:

(computers, crafts, researcher, woodwork, etc.)

I most enjoy:

(reading, swimming, cooking, gardening, etc.) **Keep this form on file with other group information**



Chapter 10 *Design the meeting around the needs of the members.*

Meeting Format

Introduction Part A: Please Print: My Name is _____. I have had chronic pain for _____. (First name)
 (Months-years) My pain is [] severe [] moderate [] light [] variable and is caused by: (arthritis, effects of surgery, headaches, Rsd, FM, etc.) I found our about the group from: I live in _____ with my _____ (City)
 (husband, wife, parents, children, etc.)

Group Facilitator Information
 Part B: Please Print Name _____ Birth date __/__/__ Street _____
 Address City _____ State _____ Zip/Postal Code _____ Phone _____
 number: (_____) I was _____
 before my pain began. (accountant, homemaker, customer service, etc.) My special talents are: (computers, crafts, researcher, woodwork, etc.) I most enjoy: (reading, swimming, cooking, gardening, etc.)

Keep this form on file with other group information



Chapter 10 *Design the meeting around the needs of the members.* Meeting Format

New Member

Introduction

Part A:

Please Print:

My Name is _____ . I have had chronic pain for _____ .
(First name) (Months-years)

My pain is [] severe [] moderate [] light [] variable and is caused by:

(arthritis, effects of surgery, headaches, Rsd, FM, etc.)

I found our about the group from:

I live in _____ with my
(City) (husband, wife, parents, children, etc.)

Group Facilitator Information

Part B:

Please Print

Name _____ Birth date __/__/__

Street Address

City _____ State ____ Zip/Postal Code

Phone number: (_____) _____

I was _____ before my pain
began.

(accountant, homemaker, customer service, etc.)

My special talents are:

(computers, crafts, researcher, woodwork, etc.)

I most enjoy:

(reading, swimming, cooking, gardening, etc.)

Keep this form on file with other group information

Chapter 10

*Design the meeting
around the needs of the members.*

Meeting Format

Since 1980, when the ACPA first began, it has been clear that there is no secret formula for conducting an ACPA meeting. Each group is made up of individuals with different needs, different life styles, and different ideas about what they need. For that reason we tell all ACPA facilitating members to design meetings around the needs of the people attending the group.

ACPA Membership

Anyone is welcome to attend an ACPA meeting as long as he or she is a person with pain. They do not have to be a “card-carrying member” to be a part of an ACPA group. That means that you will have members who choose not to join the ACPA so they do not have the *ACPA Workbook Manual* or receive *The ACPA Chronicle*. We will talk about the benefits of membership in a later chapter. For now, know that if you plan on working from the workbook, there will be members who will have to find someone in group willing to share their book. **All ACPA materials are copyrighted and cannot be reproduced.**

Some groups prefer to use the workbook at every meeting. They feel the workbook provides both the format and the information necessary for members to gain the most from their group experience. Other groups like to have a mix of the ACPA workbooks and other books they found useful in their own study of pain management. Still, other groups like an open discussion the majority of the time. There are also groups that rely heavily on guest speakers to provide the bulk of information for members. Each of these style have advantages as well as disadvantages.

The following is a guide for sharing responsibility for the meeting with all the members.

Feel free to make copies of the form, Meeting Guidelines, on page 38 of this book. Each month a member should be appointed as the facilitator. The guidelines will provide them with the information they need to provide necessary components of an ACPA meeting. The guidelines allow the facilitator to touch on necessary skills important to all ACPA group

members. These guidelines make the job of facilitating a meeting easy-to-follow and non-threatening.

American Chronic Pain Association Meeting Guidelines

Month: _____
 Facilitator: _____
 Theme: _____
 Contact Person's Name and Phone Number: _____

MEETING FORMAT	PLAN
Introductory Statement/Purpose	<i>Mission statement</i> ~ read at the beginning of the meeting <i>ACPA Ten Steps</i> ~ Poster display at meeting <i>ACPA Do's and Don'ts</i> ~ Poster display at meeting
Relaxation Exercise	Read text found on page 38
Warm-up/ Stretching Exercise	There are some simple stretches on page 40. Members can also contribute to this portion.
Personal Goal Sheet Evaluation	This can be found on pages 22-30 of the ACPA Workbook Manual.
Members Self Introduction	Try to stay off of talk of physical symptoms.
Meeting Theme	Use ACPA Topic Calendar or ACPA workbooks and Kits.
Sharing Connection	Open communication between members.
Leadership Responsibility Assignment	Fill out Group Task Sheet found on page 16 of this manual.
Meeting Recap	Review what has taken place during the meeting.
Reflections	One resource for this would be the ACPA <i>Reflections of You</i> book. RELAXATION TEXT

¹Close your eyes gently, settle down comfortably. Begin by breathing out first. Then breathe in easily, just as much as you need. Now breathe out slowly with a slight sigh, and as you breathe out . . . feel the tension begin to drain away. Then go back to your ordinary breathing, even . . . quiet . . . and steady.

Now direct your thoughts to each part of your body, to the muscles and joints. Think first about your left foot. Your toes are relaxed and still. Your foot is resting easily on the floor. Now your right foot . . . toes . . . ankles.

Now think about your legs. Your thighs roll outward when they are relaxed, so let them go.

Your back muscles will relax when you hold yourself upright, and your spine is supported by the back of the chair.

Let your abdominal muscles become soft and relaxed. There is no need to hold your tummy in tightly. It rises and falls as you breath quietly.

Think about the fingers on your left hand. They are curved . . . limp . . . quiet . . . and still. Now the fingers on your right hand . . . relaxed . . . soft . . . and still. This feeling of relaxation spreads up your arms to your shoulders. Let your shoulders relax. Let them drop easily.

Your neck muscles will relax if your head is held upright . . . resting easily balanced on the top of your spine.

Let your face relax. Let the expression come off it. Make sure your teeth are not held tightly together and let your jaw rest in its relaxed position. Your cheeks are soft because there is no need to keep up an

¹ Madders Dip, Jane, Ped MCSP, *Stress and Relaxation*, Arco Publishing Company, Inc.,

New York, NY, 1979, p 68.

expression. Your lips are soft and hardly touching. Relax your forehead so that it feels a little wider and a little higher than before.

Now . . . instead of thinking of yourself in parts, become aware of the all over sensation of letting go . . . of quiet and rest. When your muscles are relaxed . . . you begin to feel peaceful . . . rested . . . and quiet. Stay like this, listening to your breathing for a moment . . . (two minutes) Now wiggle your hands and legs a little and open your eyes and sit quietly for a moment.

(Taken from *Stress and Relaxation* by Jane Madders Dip Ped MCSP. Reprinted with permission.)

**Suggested exercises for ACPA
group meetings are as follows:**

1. In a sitting position, hold your arms out in front of you, stretching as far out as possible. (Remind members that exercising should not be painful and to stretch only until they feel the pull in their muscles.) Hold for a count of five and return your arms to your side. Do this five times.
2. Next, place your arms over your head and reach up toward the ceiling until you can feel your muscles stretching. Hold for a count of five. Repeat three times.
3. Place your right arm across your chest and over your left shoulder and stretch your right arm as far as you can. Do this three times and repeat using left arm over the right shoulder. Have members say, "I like me," or, "I deserve a pat on the back," as they touch their backs.
4. Remain sitting while you bend forward and touch your toes; hold for a count of three and sit up. Repeat three times. Not all members will be able to do this one. Ask them to sit quietly through any exercise they choose not to do.
5. Turn your head slowly and evenly from side to side. Do this three times.

Remember, exercise is important, but it should meet the needs of the individual. Each member should take turns leading the exercise part of the group as long as their stretches are simple and easy. This will give members a sense that they are part of the group and they can contribute something to their group. Again remember, not all of the members will be able or willing to do these. That is okay.

**Always check with your doctor before
doing any exercise!**

Using the ACPA Workbooks

To provide a strong foundation the manuals are the best choice.

Providing the necessary tools to help ACPA members make the transition from patient to person is what the *ACPA Workbook Manual* and *Staying Well, Advanced Pain Management Manual* are designed for. Many of the basics of pain management are contained in these manual to help members make the transition from patient to person. To provide a strong foundation and an understanding of what is involved in regaining control of his or her life, these manual is the best choice.

Each member can have an opportunity to lead discussion groups based on any of the material in the manuals. The chapter on basic rights, for example, gives members a real sense of empowerment and ability. Discussion about the basic rights in the workbook will show members where they can begin to make positive changes in their lives.

Each chapter in the ACPA workbooks is designed to be a tool for helping a person with pain regain control of life by taking an active role in the recovery process. All members should be encouraged to use these manuals.

Using ACPA Kits

To help members understand the information in the ACPA workbooks you may want to consider the new ACPA Kits. Each kit is designed to provide information based on ACPA coping concepts with easy-to-follow instructions which can be completed in one group session.

Each kit is designed to be used in ACPA meetings or by individuals. The kits will enable members to take responsibility for a meeting. The easy-to-follow instructions will enable a member to teach a valuable lesson in pain management in a way that each member can apply to daily life. There has never been an easier way to share responsibility for group meetings. And, the more responsibility members take for the group, the more confident they will feel about their own abilities.

Guest Speakers

Before inviting any person or health care provider to a meetings you must ask the members.

Having the ability to be a good consumer when it comes to one's medical care is important. Nowhere is this more pertinent than in pain management. It is important that ACPA members be kept abreast of the most current information on a variety of related topics. For this reason it is recommended that you invite experts to speak at your meetings.

Before inviting any person or health care provider to one of the group meetings you must ask the members. It will be a group decision to determine where their interests are, what they would like to know, and how often they would like to have speakers. It is recommended that there be no more than six speakers a year. Remember, the groups are designed primarily to provide peer support. If the majority of the meetings are open meetings with speakers, members will not have their needs met.

Book Study Groups

There are a wealth of books available on topics which are useful to ACPA members. The group might like to choose a book to read and discuss for two or three consecutive meetings. There is a recommended reading list at the end of this manual from which you can select. However, the list will quickly become outdated as new books become available. Spend some time in your local book store browsing through the self-help, psychology and personal growth sections. You may even be able to arrange a group discount with the store if each member purchases his or her book there.

Recreational Meetings

All work and no play can drain a group. One thing that the

ACPA has learned from years of ACPA Leadership Retreats is that many of us have forgotten how to play. We are so involved in life, illness and recovery, we forget to have fun. Life can be consumed by our pain. Providing a meeting focused around a non-pain topic will help members to see that they can still have a good time in spite of the pain. The Sectional Manual will have recreational activities for people with pain will be available by the end of 1999. Please contact the National Office for more details.

Craft night is also another way to help your members. Like the sewing circles of days gone by, people sitting around the table creating something from fabric, paint, or glue naturally puts them at ease. You might want to check with a local craft store to inquire if one of its employees would be willing to do a simple, inexpensive craft at one of your meetings. This activity can be very enjoyable as well as a means to build a bond between group members.

Social Meetings

A night out can also greatly reduce the pressure that life puts on us. Why not ask the group if members would like to meet at the local movie theater, pizza parlor, or community playhouse for an evening out? It is a great way to get to know each other better and enjoy a little of the life so many of us thought was no longer available. All ACPA members need to rediscover this aspect of their life. You might even consider inviting group member's significant others to these outings.

The holidays are a great time to show how much we care about the people who really matter in our lives. During the winter holiday season and the summer picnic season you might consider a group party in place of your regular meeting. A covered dish dinner, a back yard bar-b-que, or even a nice dinner at a local restaurant can provide a real sense of connection between ACPA members.

Family Meetings

This manual is designed to provide useful information to all ACPA groups, including family groups. However, if there is not a family group in your area for spouses without pain and

other family members, you might consider hosting a family meeting. Allow the families to talk with each other and see how much they really have in common. Hopefully it will be the beginning of a family group.

Chapter 11

Ongoing Communication Among Members

The success of the group depends a great deal on communication among members. There are ways to enhance communication. The most important thing to remember is that you have the right to make your needs known. You also have the right to be listened to and taken seriously. They are your basic rights. They are also the rights of every member of the group.

A majority of new ACPA members arrive at meetings feeling alone and isolated. They may have never met a person with pain before. It is what they hear at their first meeting that provides them with hope for the future. Knowing others understand all the problems that are created by pain can be reassuring. Each member needs to feel comfortable enough to express his or her feelings and feel that he or she is an equal part of the group. Establishing open communication from the beginning will ensure this is accomplished.

Below are some important points in obtaining open and honest communication in the group.

Establish an atmosphere for relaxed conversation by showing interest in what each member says. Let them know that what he or she has to say is important.

Be yourself. Let members know that you are comfortable talking with them.

Demonstrate respect and admiration to new members by

giving them credit for having the courage to attend their first group meeting.

Remember, no members is expected to have all the answers.

Show that you are listening by asking questions. In addition, the way in which you ask a question will determine whether you will get the information you desire.

Questions can provide a wealth of information. Ask questions that will provide more than a yes or no answer.

Observing and listening are very important to a conversation. Much of what the members are feeling will be evident not from what they say, but from the tone in which they say it or the way in which they move. If a member sits quietly off at the end of the room, legs tightly wrapped around the chair leg, arms pulled in close to his body, it usually means he has some real feelings that he can't seem to express. Facial expressions can often be a clue to what someone is feeling or thinking. Getting to know the members will involve observing them while others talk.

Providing support is the main purpose of the ACPA. You can show support to the members through your attention to them and what they say. Show empathy (identify with what the member is sharing), not sympathy, for the things they share. Make each member feel equal in the group.

Remember, no member is expected to have all the answers. Many questions you or someone in the group will be able to answer openly and honestly. However, there will be times when the only answer anyone can give is, "I don't know." There is nothing wrong with saying you don't know. At least the member will know

that you have acknowledged his or her question. If at all possible, you should offer to try to find out the answer.

Sharing phone numbers within the group

It is suggested that you set a policy at the beginning of the

New members need to attend three meetings before receiving phone numbers.

group. Explain to members that instead of sharing phone numbers that first night with any new group member, the new person must wait until he or she has attended three meetings. By that time it will be clear whether or not the individual is serious about helping himself or herself.

Ways to have positive phone calls between members

The phone can be a lifeline to members of the group. If the group only meets two times a month that leaves a lot of time in between meetings. Problems don't wait for meeting days to arrive. People with pain need on-going support. Below are some ways to help members make the most of the time they spend on the phone.

Members should be assertive on the phone when receiving calls from other group members. There must be an understanding right from the beginning that when a group member receives a call and it is an inconvenient time, they can tell the member, "It is not a good time to talk right now. I will get back to you in a day (or whenever they can)." Let members know that this does not mean the person doesn't care, but that it is truly not a good time to talk.

Limit phone calls to five minutes whenever possible. If

all the members understand this from the beginning, it will be easier for them to stay within the allotted time.

To make sure it is clear what the caller is saying, listen to him or her and then say, "This is what I think I heard you say. . . ." This will give the caller an opportunity to hear what he or she is saying and to make sure that you both understand the problem.

Never give the caller advice. Listen to what he or she has to say and then ask, "What do you want to do about it?" By giving advice you are indirectly taking responsibility for another's actions.

Chapter 12 Group Problems Group Solutions

Try to keep phone calls brief.

Facilitating an ACPA chapter may present a few problems. In this chapter we are going to take a look at some of the most common problems which occur in ACPA groups. We will also look at some solutions which have been effective. The problems we look at are ones taken directly from ACPA groups annual reports. If you are struggling with a problem which is not address please call the National Office for help.

Problem: *"I can have three people call me, each one sounds very interested in attending the group. I spend a lot of time talking to each one of them, explaining what the ACPA is all about and answering all their questions. However, they never show up at the meetings. Why?"*

Solution: If you spend too much time answering each and every question on the phone, you are taking away the need for the person to attend group. It is important to keep the calls brief, letting the caller know that they will have the opportunity to ask their questions and discuss their concerns in group.

Problem: *“We can have four or five new members at one meeting, but most of the time they never come back. Why? Are we doing something wrong?”*

Solution: The group is not necessarily doing anything wrong. You have to realize that everyone has their own reasons for attending group. Some are looking for a magical cure. Others may believe that there are doctors involved in the group that will help them. Still others are looking for something other than what the ACPA offers and are not willing to accept their pain or get involved in their recovery. It is no reflection on the group when members do not return. Remember not everyone attending the group understands that they must accept some of the responsibility for their recovery.

Part of pain management is to distract your attentions away from your pain.

Problem: *“There is a member who talks about nothing but their pain. No matter what we say, they keep talking about their pain. What can the group do to help this person move forward?”*

Solution: There are a number of ways that the group might help this person. The first would be to explain to them the purpose of the ACPA. Have several members share their experiences of the group with the person. Help them to understand that if they focus on their pain they will indeed suffer much more. Part of pain management is to distract our attentions away from our pain.

Another solution might be to have a “penalty box.” When members talk for more than a few minutes about their pain, they must put in a nickel in the penalty box. This simply is a means to create an awareness about how often he or she talks about

pain. It can be a lighthearted way to manage the problem.

Explain to the person that the group understands they have pain, that is why they are attending the meeting. But, also explain that there is nothing anyone in the group can do to reduce their level of pain. All anyone can do is help by providing support. The ACPA cannot take away pain, we can simply help people manage that pain.

Have a “time out” for a member who spend more than three minutes talking about their pain. When a member gets into a prolonged discussion about their pain, ask them to take a “time out” and sit quietly in group for the next ten minutes. Have a member keep time.

Explain to the member that no one in the group questions their pain. They would not be attending group if they did not have pain. Let them know that in this group there is no reason to be defensive about pain, each person attending is immediately validated.

No medications will be exchanged, shared or sold in ACPA groups

Problem: *“There are members who don’t want to pay for the workbook. They like the information shared from other’s workbook during group. They don’t think it is necessary to buy one for themselves. They also expect other members to read his or her ACPA Chronicle to them. How can we get individuals to become members?”*

Solution: The cost of membership in the ACPA not only provides members with the workbooks and newsletter, it supports the work of the ACPA. If others had not become members and supported the organization, there would have been no one there to take their call or answer their letter. There would be no ACPA. How can the ACPA expect other outside sources to support the organization when the very people it serves are unwilling to support it? Membership is a statement

of support for the ACPA and all people who must live with pain. Each person attending group should support the ACPA in some way.

Problem: *“There is a member who asks other members what medications they are on. Then they want to “ borrow” one of their pills. The member continues to ask for the medication and often asks others in the group as well. What can we do to stop this person? It is making everyone uncomfortable and we have lost a few members because of this.”*

Solution: The solution is simple: ask them to stop immediately. If they continue to ask members for medications, then explain to them that it is against the law and the ACPA requires that the individual be asked to leave the group. You can also recommend that they talk to their own health care provider to help them get on the appropriate medications for their needs. No medications will be exchanged, shared or sold at ACPA groups. (Please refer to the drug statement in this manual on page 100.)

Problem: *“One member in our group is not happy with the way the group is operated. They think that we should do things differently. What should we do?”*

Solution: It is important to give that member the chance to present his or her idea to the entire group. Let the group discuss the idea. If the suggested changes are within the guidelines of the ACPA then take a vote. The way the group meetings are run is a choice that each member of the group has a voice in.

Problem: *“There have been a number of requests by the group to focus more on the medical side of their individual health problems. Three members have RSDS, one has fibromyalgia, and four have back pain. Can we talk about these problems in group?”*

. . . being a good listener means other must have an opportunity to share their

thoughts.

Solution: The ACPA is designed to teach coping skills and provide peer support. The coping skills that we teach are universal regardless of what the cause of the pain might be. However, people want to know as much as they can about their particular pain problem. There are a wide variety of organizations designed to do just that. In the last section in the manual, you will find a complete list of the most common causes of chronic pain. Share this with members.

Speakers can be invited to a meeting from other organizations to give an overview of health problems, what their organizations offer, and leading technology. Members can also do their own research and present a “report” of all the information they found about the condition to the group. Focusing on a particular problem for one meeting is appropriate. Each member needs to be well informed.

Problem: *“What do we do with a member who monopolizes the group? They always have something to say and even interrupt when others are talking.”*

Solution: It is important that each member feel comfortable sharing his or her thoughts. However, having one member dominate the conversation is taking away from the other members. There are several ways to alleviate the situation. One would be to present a problem to the group and ask them to talk about it for ten minutes and to write their answer. Then have each person read their answer. This will allow each member time to share their thoughts and keep the dominating member in check.

It may also be necessary to review the responsibilities of members with the group. Point out that being a good listener means others must have an opportunity to share their thoughts.

. . . show respect for each member.

If the person continues to dominate the conversation, you may have to ask them to stay a few minutes after group and explain the concern that other group members are not getting the opportunity to talk. Ask them to limit their discussion. They may need to be reminded from time to time.

The most important thing that you want to remember is to show respect for each member. Bring any concerns about a member directly to that member, not the entire group. Chronic pain bruises our egos enough, no one needs to feel any worse about himself or herself.

Problem: *“We have a member in our group who calls all the time. It doesn’t matter what time of the day or night it is. They call in the middle of the night and expect us to listen to their problem. It is difficult to do that and our families are not happy about the intrusion. We have asked them not to call, but they ignore our wishes.”*

***The group may not
be able to turn this member
around.***

Solution: Members should not be given a complete list of phone numbers at their first meeting. They should be required to attend at least three meetings before phone numbers are shared, and then it should be a partial list. That will give the group time to get to know the person better and prevent any problems down the road.

The member does, however, have the contact person’s phone number. It is necessary for that person to set a time for members to call. If you would prefer to have all group calls during daytime hours, then tell members to call only at that time. If you do not want calls after a certain hour at night, you have to tell them. Remember, it is each person’s responsibility to make his or her needs known.

You may, however, run into a member who continues to call after you have asked them nicely not to call at a certain time. If this occurs let them know they are calling at a bad time and tell

them that you will get back to them the first thing in the morning or whenever it is convenient. If they continue to call, simply tell them that you will call in the morning and hang up before they can pull you into a long dialog on why they called. They will stop if you do not take the time to talk with them.

Problem: *“There is a member who seems to complain about everything. No matter what we talk about, they complain about it. They are very negative and it is difficult for the group to get anything done. How can we turn this member around?”*

Solution: The group may not be able to turn this member around. Some people seem to look at everything through black glasses, nothing is good, nothing is right, nothing is fair. Ask the negative member to write the substance of the discussion down, i.e., benefit of relaxation on pain levels. Have them make two columns. One will be for the negative things and the other for the positive things. It is their job to fill in that list throughout the course of the meeting. The last fifteen minutes of the meeting should be reserved so they can read their list. If they have little or no positive items on their list, ask each member to give them one thing to write down. Then ask the member to read his or her list each day.

At the next meeting, begin by asking the member to read his or her list once more. Then ask how they feel about both the good and bad points of view. This should help them to realize that there are two sides to every situation.

If after numerous attempts to help them examine both the good and bad side of a situation fail, you may suggest that they seek counseling.

Problem: *“What do you do with a member who continually talks in a negative way about their doctor? When they start in on their doctor, we seem to lose control of the meeting and everyone talks about how the medical community does not want to help people with chronic pain.”*

Solution: Look in the blue workbook, *Staying Well*, which goes into detail on how a person can make the most of their visit to the doctor. Explain that each person has a choice of doctors.

And, if they have tried everything to communicate with the doctor without success, they have the right to fire that doctor and hire one that understands chronic pain. And remember, the ACPA does not make doctor referrals. All we can do is help our members be good consumers when it comes to their medical care.

Problem: *“How do we help the group when one of our members tries or actually does commit suicide? It is possible that some of the members may feel they could have done more to help the person and perhaps prevented it. What do we do as a group to understand this situation and know how to handle it?”*

You nor any of your members have control over another’s actions.

Solution: Every suicide threat should be taken seriously. However, it is very important to realize that you nor any member of the group has control over another’s actions. The most anyone can do is to show the person who talks about suicide that you really care for them and are concerned. You may suggest they actively seek out professional help.

You may also want to invite a counselor to a meeting as a speaker. Many counselors are trained to deal with this issue and may have some helpful information for all members. In addition, if a member has followed through with his or her threat, having a speaker can help members deal with their feelings. The meeting should allow time for members to openly discuss their feelings about the topic.

Problem: *“There are two members in the group who seem to enjoy their own conversation during group discussions. It is not only rude, but interferes with what is going on in group. Is there a way to prevent this?”*

Solution: You can simply ask them to stop, explaining that it is disruptive to the group. If they continue, ask them to sit apart.

If they still continue, ask them to please share their discussion with the group or step outside until they are finished.

If the group reaches more than \$100 in their kitty at one time, then the group must file a financial report to the National ACPA Office.

Problem: *“Our group has been really good about giving a small donation each week to cover the cost of the refreshments and postage. But, now several members want to know where the money is and who is in charge of it. I feel like they do not trust us. What can we do?”*

Solution: Don't place anyone in that situation to begin with. If the group is good about giving regular donations, then the group needs to have a committee to keep track of the money. There should be two members who count the money after each meeting. A record should be kept of revenues and expenses with receipts to back up expenses. A brief financial report should be given at the beginning of each meeting. And if the group wants to purchase something like a book or membership for a needy member, they need to vote on it.

Group funds should be kept in a place that is known to both people who count it and it should be clearly marked as ACPA funds. If the group reaches more than \$100 in their kitty at one time, then the group must file a financial report to the National ACPA Office along with your annual report each year.

There are bound to be other problems that come up in the group. Please feel free to call the National Office with any questions you have. That is one of the benefits of being part of a national organization.

Section III

Outside the ACPA Meeting

ACPA groups are much more than meeting two or three times a month. They are about providing support for people with pain each day. In order to accomplish this, the group needs to establish a strong network of members helping members outside of the group meetings. This next section will help to establish, maintain and share the responsibility for the work that needs to be done outside of the meetings.

Chapter 13 ACPA Sponsor Program

The sponsor program is designed as a support system for anyone who is involved in an ACPA group. It will benefit both the sponsor and the new member. Through creating connections between established ACPA members and those attending their first meeting, the progress of the new member can be significantly improved. For the first time the new member will have someone who knows what it is like to be confronted with all the issues related to chronic pain. It will be much easier to learn to trust one person rather than a large group of people. Trust of the entire group will come in time, but the new member has one person he or she can be comfortable talking with.

Those involved in the program, whether the sponsor or the friend, will quickly see that the program fulfills a number of their needs. Let us use the word "friend" for the one who will be sponsored.

How does a sponsor benefit from the program?

It gives the sponsor an opportunity to share what he or she has learned with others.

In giving back to the group, the sponsor is learning to regain control of his or her own life.

The sponsor grows in self-confidence as well as gaining a more personal understanding of pain management.

The sponsor builds his or her own wellness and self-esteem by being responsible for someone else.

How does a " friend" benefit from the program?

Provides the friend with a personal support system.

The sponsor and the friend should spend some time together outside of the group setting.

Provides a type of understanding that only personal contact can offer.

Lends personal insight into what might be happening with the friend and helps him or her feel less like a "freak" and more "normal" in some of the feelings that he or she experiences.

Conveys that the friend is not alone. Someone else has had a similar type of experience.

To set up a sponsor program you should ask members who are interested in becoming a sponsor. Although all persons attending ACPA meetings should be asked to think about becoming a sponsor, the best sponsors are generally those who have experienced improvements through the ACPA group process.

Responsibilities of a sponsor should include the following:

To avoid an inappropriate match the sponsor should attend a group meeting with the friend before the sponsor is actually assigned.

The sponsor and the friend should spend some time together outside of the group setting.

Established members who agree to become a sponsor should prepare a brief statement of introduction about his or her background for the friend. It should include:

1. His or her experience with the ACPA
2. Why he or she wants to sponsor a friend.
3. The best time to be contacted.

4. Background information about his or her personal life, i.e., family, job, hobbies.

The sponsor should always encourage their friend to attend ACPA meetings.

The group's sponsors must meet to discuss the program about every three months and share new ideas on how to improve the program.

Sponsors must attend ACPA meetings regularly.

How to use the "*Ten Concepts in Moving from Patient to Person*" as guidelines in working with the friend through the sponsor program.

1. A friend can learn what to expect from the pain, thus reducing the fear associated with the pain problem.
2. He or she learns why it is important to become involved in their own recovery.
3. The sponsor can help the friend set personal priorities.
4. The sponsor can also help the friend set realistic goals.
5. Through conversation with a sponsor, the friend hears more about his or her basic rights.

A sponsor will try to help the friend maintain a positive attitude.

6. Through the sponsor, the friend learns to explore his or her own feelings.
7. The sponsor may help the friend with relaxation techniques and emphasize the importance of relaxation in general, knowing that reducing stress can decrease

pain levels.

8. A sponsor might discuss where the friend is in his or her exercise program, and may offer to exercise with the friend.
9. In general, a sponsor will try to help the friend maintain a positive attitude.
10. After a year, the sponsor may encourage his or her friend to become a sponsor for another new member so that he or she, too, can become more independent. The involvement will help to maintain his or her own wellness.

To maintain the program you must make the program attractive for people to be involved. Here are some things you might want to think about.

Give a certificate or some form of recognition to those who have been active in the program for a year.

Conduct special meetings with all the sponsors at least twice a year.

Hold a social gathering at least once a year for all the sponsors and their friends. This is a task that can be delegated to group members.

Let the sponsors know that the program will work both ways. There will be times when their friends can help them through rough periods.

Establishing a system in which each new person joining the group meets with a sponsor helps the new person feel less alone. It will immediately bond the friend to his or her sponsor. And, it lets the new person know that someone cares.

This program can be implemented at any time in the life of the group. However, it is best to wait until the group has formed a solid core in order that you might feel confident that the

program will work.

Chapter 14

Outreach

To maintain a healthy ACPA chapter it is important to make an effort to let the community know about the group. There are several groups where outreach can be very beneficial.

If the local health care facilities offer a pain management program, make sure you inform them about the group.

Health Care Community

Reaching out to the health care community can ensure that awareness of the group remains current. If the local health care facilities offer a pain management program, make sure you inform them about the group. Offer to give a brief presentation to the staff about the ACPA and what it offers. There is a 22-minute ACPA video, *Ten Steps From Patient to Person*, available for use in your presentation. It will provide an overview of the ACPA. Simply call the National Office if you are interested in obtaining a copy.

If there is a pain management program in your community, make an effort to visit the unit at least once a month. Perhaps members of the group who have graduated from the program might also be willing to make an occasional visit. It is helpful for the people in the program to see that there is a support system waiting when he or she leaves the program. It will also be a way to attract new members.

Local Clubs

The very first time that the ACPA was presented to a group of people was at a local women's club. From that twenty minute talk, a newspaper article was written about the ACPA in the local paper, five new members attended the next meeting, and the word quickly spread into neighboring communities.

It can be useful to contact the local Chamber of Commerce to inquire about other organizations which meet in your

Make sure past members know they are welcome any time.

community. Find out who the contact person is and call to inform the chairperson of your willingness to speak to his or her group. You may also want to check with the Social Service Department of your local hospital to see what types of groups use the facilities for meetings and obtain contact information about these groups as well.

Health Fairs

Communities today pride themselves on their efforts to provide a wide range of services to the public. It is not uncommon to find a local mall or convention center hosting a health fair. Occasionally call these places to see if any health fairs are being planned and how the local ACPA group might become involved. The members of the group can set up a booth as a means to spread the word about meetings.

Other Resources

Make sure that a group member does periodical checks on the posters placed in the community. Also make sure that PSAs are sent out on a regular basis.

Members that have stopped attending meetings for a while might appreciate a friendly call from a group member to see how he or she is doing. Sometimes members who have left the group are hesitant to attend an occasional meeting. By contacting him or her you are providing a connection which would make it much easier for the member to “visit” the group. Sometimes we believe if we leave a group it is not possible to return. Each one of us needs a “booster shot” occasionally. Make sure past members know they are welcome any time. You may just be helping them more than you can image.

Chapter 15

Funding Local Chapters

Background

It has long been the position of the ACPA that local chapters are affiliates of the organization and not an inherent part of it. Put another way, the ACPA sees itself as providing materials and support to local groups that provide the direct services to members. A variety of mechanisms have been developed for communication between the ACPA and its affiliated groups. These include:

1. Manuals and other written materials distributed to coordinating members by the ACPA.
2. Periodic newsletters for members.
3. ACPA conferences.
4. The Members' Advisory Committee.
5. Regional resource person(s) of the ACPA provide support and guidance to local groups. Contact the National Office to find out if there is a regional resource person available in your area.

None of these mechanisms of communication is meant to constitute control over the local chapters. Chapters are independent organizations. Affiliation only provides the chapter with access to materials and supports the right to use the ACPA name for identification of its program.

Fund Raising

Any funds raised in the name of the ACPA must be thoroughly accounted for both for tax purposes and for administrative ones. It is impossible for the ACPA National Office, with its very limited staff, to oversee the finances of all the ACPA groups worldwide. Therefore we cannot permit groups to raise funds in the name of the ACPA unless all funds raised are for the organization as a whole and sent immediately and completely to the National Office.

Local groups may, however, raise funds for local use in other ways. First, they may collect voluntary donations from among their members to cover the incidental costs of the meetings, e.g., coffee and snacks. Second, they may incorporate as separate charitable organizations (e.g., The Eastern Oregon Chronic Pain Association) with separate Boards of Directors, bylaws and officers. In order to retain an affiliation with the ACPA, all such organizations must be constituted as not-for-profit and all funds must go directly to providing support and help for those with chronic pain. No funds may be converted to personal use in any fashion. The ACPA will provide limited nonfinancial assistance to groups wanting to incorporate independently.

Directive from the ACPA Board of Directors approved on August 10, 1994

Chapter 16 Getting Help From the National Office

You are not alone in your efforts to establish and run a support group. The ACPA National Office can help in a number of ways. All you have to do is ask. If you need help or have questions, then it is up to you to contact the National Office at 916-632-0922. There is someone in the office from 9:00 a.m. until 5:00 p.m. Monday through Friday and the answering machine is always on. Your calls are important to the ACPA National Office. If you call and no one answers, please leave a message. We will return your phone call.

Supplies

When you become a facilitator, you are provided with enough materials to get you started. While you cannot make copies of any of the ACPA manuals, you can make copies of the following items:

- ACPA posters
- ACPA New Member Introduction
- ACPA order forms
- ACPA group stationary
- ACPA Responsibility of Facilitating Members and Group Members

All other ACPA materials and handouts must be obtained from the National Office. We have provided an order form for your convenience.

ACPA Supplies Order Form

Item

ACPA Help and Hope Pamphlet

(yellow pamphlets) \$5 for 20

ACPA Coping With Pain

(gray pamphlets) \$5 for 20

ACPA Pain Unit Guidelines

\$1 for 20

ACPA Catalog

\$1 for 2

ACPA Facilitator Guide (**must be ACPA Member**)

\$10

ACPA Booklet (8 pages)

\$1.50 each

ACPA Video Rental

No cost for 30 days (\$25 deposit required.

Refunded upon return)

Please add \$3 **for every \$10 ordered** to cover cost of shipping and handling

TOTAL

Name:

Chapter

Address

Phone #

Send to: **ACPA**

P.O. Box 850

Rocklin, CA 95677

Quantity

Cost

Total

If the caller leaves a message on your answering machine, please call them back.

Referrals to the Group

Anyone who calls or writes to the National Office for information will also receive the name and phone number of the local ACPA group when available. It will be up to you to provide the caller with information about when and where the meetings are held. If the caller leaves a message on your answering machine, please call them back. They, too, are in need of help and the majority of them will not make a second call. Show that their call is important to you and return the call in a timely fashion. Your prompt response will be greatly appreciated.

ACPA Facilitator Section of the ACPA Chronicle

As mentioned earlier, it is difficult to stay in touch with each of the ACPA facilitating members. There is a way, however, to make sure each person is informed about the ACPA . . . the *ACPA Facilitator Section*, a quarterly publication which is included in the *ACPA Chronicle*. The section is filled with useful information that will help the group better understand the concepts of pain management. In addition, the section will provide the latest information about the ACPA, new materials available, news from other ACPA groups, information about upcoming events and much more.

It is important to file this in January of each year.

Group Annual Reports

At the beginning of each calendar year groups are asked to fill out an annual report, a brief overview of the group. **All groups who return their annual report will receive a Group Certificate.** It is the document that recognizes your group as an affiliate of the ACPA National Office in good standing. It is important to file this in January of each year. Unless the annual report is received at the National Office by **March 15** of each year, the National Office will not refer people to the group. The Group Annual Report can be found on pages 108-109 of this manual.

ACPA Memberships

Simply attending ACPA meetings does not entitle a person to receive the newsletter.

No one has to be a “card-carrying member” of the ACPA to attend meetings. As you know, anyone with chronic pain who is willing to help him or herself is welcome to attend meetings. However, attending meetings does not entitle one to a membership. The ACPA Memberships were established by your peers—other members of the ACPA—to help support the work of the ACPA. If you or any person in the group would like to be a member of the national ACPA they must fill out the membership form and mail it with the requested donation to the National Office.

ACPA Chronicle

The ACPA Chronicle is the quarterly newsletter published for and by ACPA members. It is available as part of the ACPA Membership. For additional information please see the ACPA order form. Simply attending ACPA meetings does not entitle a person to receive the newsletter. Each member must send in his

or her own order.

Regional Resource Person

In many areas there are Regional Resource Persons available to ACPA groups. A Regional Resource Person is someone with pain who is or has been an ACPA facilitating member. They are familiar with many of the issues that arise in ACPA groups.

Many Regional Resource Persons conduct two or more meetings a year where all the facilitating members in the region are invited. It is an opportunity for them to get to know each other as well as share the local resources. The resource person is available to help answer any question. They can provide you with community resources as well. In addition, they can help you locate an ACPA meeting in another area of the region.

To find out if there is a Regional Resource Person available to you, please call the National Office.

Member Advisory Committee

In 1993 a committee of ACPA members, facilitating members and Regional Resource Persons was formed to give a voice to all ACPA members. This committee represents the entire membership of the ACPA. It is the responsibility of this committee to bring concerns, comments and suggestions directly to the Board of Directors. The Chairperson of the committee attends two ACPA Board meetings each year. A list of the Member Advisory Committee (MAC) members appears in *The ACPA Chronicle* once a year. They are there to help you. Don't hesitate to contact a member of the committee.

Section IV

Resources

It is not unusual to have a member need additional information about a certain topic. Sometimes this may be related to their pain, other times it may not. You see, pain is not always the main issue for ACPA members. Life is filled with many situations that, when a person has chronic pain, can aggravate and/or increase pain levels.

Knowing where to look for information enables you to help your members and perhaps even yourself. The following section is a collection of resources that can be helpful to all ACPA members. Realize that this list was prepared at the end of 1998 and some information may have become out-dated. If you have a problem contacting any organization listed, please contact the ACPA National Office for the latest update.

Chapter

17Resources

Where to Find Further Help

While the ACPA can provide you with information and support to aid you in your recovery, we cannot provide you with specific information about your health care problem. In this chapter you will find a list of resources that you may contact for additional information. Knowing where to look for help allows you to be a well-informed consumer regarding your health care.

Alcoholism

Alcoholics Anonymous
P.O. Box 459
Grand Central Station
New York, NY 10163
(212) 870-3400

Ankylosing Spondylitis

Ankylosing Spondylitis
511 North La Cienega
Boulevard Suite 216
Los Angeles, CA 90048
(800) 777-8189

Alzheimer's

Alzheimer's Association
National Headquarters
919 North Michigan Avenue
Suite 1000
Chicago, IL 60611-1676
(312) 335-8700
800-272-3900

Anorexia and Bulimia

National Association of
Anorexia and Associated
Disorders
Box 7
Highland Park, IL 60035
(312) 908-7434

Amyotrophic Lateral Sclerosis

The Amyotrophic Sclerosis
Association
21021 Ventura Boulevard
Suite 321
Woodland Hills, CA 91364
(800) 782-4747

Rational Recovery Systems

Lotus Press
Box 800
Lotus, CA 95651
(530) 303-2873

Charcot-Marie-Tooth

Charcot-Marie-Tooth
Association

601 Upland Avenue
Upland, PA 19015
610-499-7486
(800) 606-2682

Colitis and Ileitis

National Foundation for
Ileitis and Colitis

444 Park Avenue, South
New York, NY 10016-7374
(212) 685-3440

Depressive Illness

National Foundation for
Depressive Illness, Inc.

P.O. Box 2257
New York, NY 10116
(800) 248-4344

Diabetes

American Diabetes
Association

1660 Duke Street
Alexandria, VA 22314
(800) ADA-DISC

Disability Resources

Four Glatter Lane
Centerreach, NY 11720
(516) 585-0290

Endometriosis

Endometriosis Association

8585 North 76th Place
Milwaukee, WI 53223
(800) 992-Endo (US)

Fibromyalgia

Fibromyalgia Network

P.O. Box 31750
Tucson, AZ 85751-1750
(520) 290-5508

Fibromyalgia Alliance of
America

P.O. Box 21990
Columbus, OH 43221-0990
(614) 457-4222

Headaches

The National Headache
Foundation

428 West St. James Place
Chicago, IL 60614
(800) 843-2256 or
773-388-6399

Brain Injury Association

National Head Injury
Foundation, Inc.

1140 Connecticut Ave., NW
Suite 812
Washington, DC 20036
(800) 444-NHIF

Huntington's Disease

Huntington's Disease of
America

140 West 22nd Street
Sixth Floor
New York, NY 10011-2420
(800) 345-4372

Lupus

1300 Piccard Drive, Suite
200
Rockville, MD 20850
(301) 670-9292

(800) 558-0121

Lyme Disease

Lyme Disease Foundation

One Financial Plaza

18th Floor

Hartford, CT 06103-2601

(888) 385-8787

Multiple Sclerosis

Multiple Sclerosis

Association of America

706 Haddonfield Road

Cherry Hill, NJ 08002

(609) 488-4500

(800) 833-4672

Chronic Pain Letter

Box 1303

Old Chelsea Station

New York, NY 10011

Peripheral Neuropathy

Neuropathy Association

P.O. Box 2055

Lennox Hill Stations

New York, NY 10021

(800) 247-6968

Polio

International Polio Network

4207 Lindell Boulevard

#110

St. Louis, MO 63108-2915

(314) 534-0475

Reflex Sympathetic

Dystrophy Syndrome

RSDS Association

116 Haddon Avenue, #D

Haddonfield, NJ 08033

(609) 795-8845

**Repetitive Motion
Syndrome**

Association for Repetitive
Motion Syndromes

P.O. Box 471973

Aurora, CO 80047-1973

(303) 369-0803

Rheumatoid Arthritis

See Arthritis Foundation

Scleroderma

Scleroderma Federation

1725 York Avenue

New York, NY 10128

(212) 427-7040

**Shingles and Post-
Herpetic Neuralgia**

VZV Foundation

40 East 72nd Street

New York, NY 10021

(212) 472-7148

(800) 472-8478

Sjogren's Syndrome

Sjogren's Syndrome
Foundation

333 North Broadway

Jericho, NY 11753

(516) 933-6365

Sleep Apnea

American Sleep Apnea
Association

2025 Pennsylvania

Ave.,NW

Suite 905

Washington, DC 20006

(202) 293-3650

Syringomyelia

American Syringomyelia
Alliance Project, Inc.
P.O. Box 1586
Longview, TX 75606-1586

**Trigeminal Neuralgia/Tic
Douloureux**

Trigeminal Neuralgia/Tic
Douloureux Association
P.O. Box 340
Barnegat Light, NJ 08006
(609) 361-1014

Other Resources:

National

**Spinal Cord Injury
Hotline**

2200 Kernan Drive
Baltimore, MD 21207
(800) 526-3456

The Dole Foundation

1819 H Street, NW
Suite 850
Washington, DC 20006
(202) 457-0318
Helps people get back to
work. National grants to
provide employment
opportunity

AirLifeLine

6133 Freeport Boulevard
Sacramento, CA 95822
(916) 641-7800

(800)-446-1231
Provides air transportation
to ambulatory patients in
need of financial assistance.

**Family Caregivers
Alliance**
425 Bush Street
Suite 500
San Francisco, CA 94108
(415) 434-3388

**National Coalition for
Brain Research**
3050 K Street, N.W.
Suite 310
Washington, DC 20007
(202) 293-5453

**National Institute of
Health HIH/Nids**
Bethesda, MD 20892
(800) 352-9424

**National Voluntary
Health Agency**
(800) 654-0845

**National Council on
Patient Information and
Education**
666 11th Street, NW
Suite 810
Washington, DC 2000
(202) 347-6711
Promotes patient
information about
prescription medication use.
Offers a publication list and
a wide variety of public

awareness materials.

**National Organization of
Rare Disorders**
P.O. Box 8923
New Fairfield, CT 06812
203-746-6518
(800) 999-6673
Serves as a clearinghouse
for information on rare
disorders.

**Free Medical Care Low-
Income People**
Hill-Burton Program
U.S. Department of Health
5600 Fisher Ln, Room 1125
Rockville, MD 20857
(800) 638-0742

Hospice and Home Care
National Hospice
Organization
1901 North Moore Street
Suite 901
Arlington, VA 22209
(800) 658-8898

**Medicare/Medicaid
Information**
Health Care Financing
Administration
Office of Public Affairs
U.S. Department of Health
and Human Services
200 Independence Ave, SW
Washington, DC 20001
(800) 638-6833

NOSSCR
6 Prospect Street

Midland Park, NJ 07432
800-431-2804
Helps with Social Security
issues you can get advice
from an attorney who
specialize in Social Security
problems by contact
NOSSCR

**Consumer Credit
Counseling Service**

8611 Second Avenue
Suite 100
Silver Springs, MD 10910
(800) 388-2227
A nonprofit organization
with seven hundred offices
nationwide to help you
establish a budget, plan
future expenses, and repay
creditors. Also available is a
Credit Recovery Program
that helps you return to the
credit market after repaying
your debts.

Chapter 18 Some Good Reading

Compiled by Blair Hurst in 1996

No matter how far we travel in our journey from patient to person, there is always a need for additional information. It seems the more we learn, the more we realize we need to understand. This chapter identifies some books which may provide you with insight into a variety of topics about pain management, personal growth, and more.

Pain Management

The Arthritis Helpbook by Kate Loring, R.N., Ph.D., and James F. Fries, M.D., Addison-Wesley Publications, 1986. The premise of this book is that no one treatment is right for everyone. The book outlines a number of techniques that may help relieve pain, maintain or increase mobility, and prevent deformity. The book has an excellent chapter on relaxation.

Back Ache Relief by Arthur C. Klein and Dava Sobel, Times Books, 1985. A survey of 492 people with back pain is the basis of this book. Some of the information is dated (the MRI was still a newcomer on the diagnostic scene). The value of the book is in the comments from people with back pain. They tell what worked and what didn't work. Most of the information is relevant to any type of muscular skeletal pain.

Chronic Back Pain: Moving On by Julie Zimmerman, P.T., Biddle Publishing Company, P.O. Box 1305 #103, Brunswick, Maine, 1989. The author gave up her career as a physical therapist because of debilitating chronic pain. She considers herself to be a "happy productive person," and this book explains why. One helpful aspect of this book is its suggestions for adapting home and work place to accommodate mobility problems (sitting, reaching, carrying, etc.)

The Culture of Pain by David B. Morris, University of California Press, 1991. This book is both a scholarly study of the most up-to-date medical knowledge about pain and an exploration of the history of pain in Western culture, literature, and fine arts. Topics include: the meaning of pain in ancient times and today, pain that is essential in some types of comedy, pain in the arts, and pain in religion. This is not an easy book to read--it's impossible to skim--but if this kind of book interests you, the reward is worth the effort.

Defeating Pain: The War Against the Silent Epidemic by Patrick Wall and Marvyn Jones, Plenum Press, 1991. This is an important book. Dr. Wall has dedicated his medical career to the study and treatment of pain. This book explains, in detail, the current findings and theories of how pain--acute and chronic--occurs in humans. The book dispels myths about chronic pain, and explains how those theories are outdated and speculative. He gives hope that the future will hold even greater understanding and more effective treatment of pain.

The Fine Art of Recuperation: The Guide to Surviving and Thriving After Illness, Accident, or Surgery by Regina Sara Ryan, Jeremy P. Tarcher, Inc., 1989. Although the title suggests this book is for acute conditions only, it's not. The concepts and specific suggestions for self care are relevant for all who want to improve their quality of life. Sample topics are: enriching your home environment, music for relaxation, and adult amusements and involvements.

Free Yourself From Pain by David Bressler, M.D., Simon and Schuster, 1979. In this book, David Bressler explains his theories of chronic pain and what traditional medicine and physical therapy can do. He also introduces some alternative methods including journal keeping and visualization.

The Headache Book: Effective Treatments to Prevent Headache and Relieve Pain by Seymour Soloman, Consumer Report Books, 1991. Research in headaches has resulted in new findings, new diagnostic techniques and new terminology. People with headaches can turn to this book to find up-to-date

information about headaches and new treatments. The text is written for the consumer and is very readable. The book treats people with headaches with respect and understanding.

Healing the Body Betrayed: A Self Paced Self-Help Guide to Regaining Psychological Control Over Your Illness by Robert A. Klein and Marcia Goodman Landau, Ph.D., DCI/Chronimed Publishing, 1992. This book is a welcome newcomer to the pain management literature. It explores aspects of chronic illness not found in most books about pain. The authors clearly listened when people with chronic illness explained what living with chronic illness is like. One example is the chapter devoted to how pain affects judgment and the ability to think clearly.

IBS: A Doctor's Plan for Chronic Digestive Trouble: The Definitive Guide to Prevention and Relief by Gerard Gillroy, M.D., Hartley & Marks, Inc., 1991. IBS stands for irritable bowel syndrome, which is a collection of various digestive problems. Reading the book is like sitting in a compassionate doctor's office and asking questions and getting answers and suggestions you can use right away, at home.

Living Creatively With Chronic Illness by Eugenic E. Wheeler and Joyce Doce-Lombard, Pathfinder Publishing, 1989. This book reinforces many of the concepts in the *ACPA Workbook Manual*. Numerous personal quotations make reading this book seem like going to a support group.

Living With Chronic Pain: Days of Patience and Passion by Cheri Register, Macmillian, Inc., 1987. The author is a woman with chronic illness who interviewed other people with chronic illness to write this book. Despite the diversity of physical problems, there are many common challenges, difficulties, satisfactions and insights. For this reason, the book can be validating and inspiring for anyone with chronic pain.

Mastering Pain: A Twelve-Step Program for Coping With Chronic Pain by Richard A. Sternbach, M.D., Ballantine Books, 1987. Despite the title, the book is not a 12-step "recovery" program, but a book about twelve specific behaviors and attitudes needed to manage chronic pain. The book covers

traditional pain management techniques, with a big emphasis on self reliance.

Migraine: Expanded and Updated by Oliver Sacks, M.D., University of California Press, 1985. This book may have been written for physicians, but the author's insight, compassion and interpretations of the migraine experience make the book interesting to lay people as well. It is not a "how to" book. The format is based on brief case studies followed by an analysis by Dr. Sacks. (Oliver Sacks also wrote *Awakenings* and *The Man Who Mistook His Wife for a Hat*. Both books are fascinating.)

No More Aching Back: Dr. Root's 15 Minutes a Day Program for a Healthy Back by Leon Root, M.D., N.Y., Villard Books, 1990. "Welcome to my office," are the opening words of this conversational and informative book. If you've wondered why orthopedists do what they do during an office visit, you find out here. The author covers the essentials of back problems and back care in a reassuring personal manner.

Pain: Free Yourself for Life by Dr. David Corey, New American Library, 1989. The author is a behavioral psychologist. The "free" in the title doesn't mean cure. It means cutting the chains that bind a person with pain to self defeating behavior. The main emphasis of the book is on the behavioral and psychological changes we can learn to make. The book's cartoons allow us to laugh and let up on ourselves.

Pain In Children: Nature, Assessment and Treatment by Patricia A. McGrath, The Guilford Press, 1990. This is the definitive book about children's pain, acute and chronic. It's used as a textbook for health care professionals, especially those in psychology, behavioral medicine, nursing and pediatrics. If you had pain as a child, or know a child who has pain, this book will be enlightening and helpful. The book dispels the myth that infants do not perceive pain because their nervous system is not fully developed.

Relief From Back Pain: The Tollison Program by C. David Tollison, Ph.D., Gardner Press, N.Y., 1987. The book provides information about the anatomy of pain, theories of back pain, and psychological factors related to pain. He presents a clear

explanation of conservative treatments and provides a guide for reconditioning the body.

The Scottsdale Pain Relief Program: The Revolutionary Seven Day Drug-Free Program to Reduce Pain by Neal H. Olshan, Ballantine Books, 1987. This book is prefaced with The Bill of Rights for People with Pain. For example; "I have the right to control decisions regarding pain." "I have the right not to prove that I am in pain." The book describes in detail a self-managed pain program. Another book by this author is *Power over Your Pain*.

We Are Not Alone: Living With Chronic Illness by Sefra Kobrin Pitzels, Workman Publications, 1985. The book begins with a description of the author's life when chronic illness, Lupus Erythematosus, overwhelmed her. It ends when her illness is manageable. The book discusses the impact of chronic illness on the family, talking to children about illness, keeping friendships, and dealing with health care providers.

Inspiration and Humor

An Interrupted Life: The Diaries of Etty Hillsum 1941-1943, Washington Square Press, a division of Simon Schuster, 1985. This book is a diary of a young Jewish woman living in Nazi occupied Holland. It shows, by example, how we can see our lives in new ways. Written in the last two years of the author's life, the diary reveals her intellectual and spiritual transformation in spite of terrible adversity. "Each day," she writes, "I learn new things about people and realize more and more that strength comes not from others, but from within."

Carnal Acts: Essays by Nancy Mairs, Harper/Collins, 1990. Nancy Mairs is a writer with multiple sclerosis. She uses her skill as a writer to explore and transform the experience of living with a chronic illness. One of the more provocative essays is "Challenge: An Exploration," in which she explains why she prefers the term "cripple" to phrases such as "physically challenged."

Flying Without Wings: Personal Reflections on Loss, Disability,

and Healing by Dr. Arnold Beisser, Bantam Books, 1990. The author is a severely disabled psychiatrist. His book is an account of the struggle to form a new way of living. The chapter on acceptance is excellent. He believes that people with permanent physical problems not only go through the well known "stages of grief," but they go through "stages of acceptance" at the same time. For example, the first stage of grief is denial. The first stage of acceptance is to try unfamiliar options (like asking for help or changing personal roles.)

Man's Search for Meaning by Viktor E. Frankl, Pocket Books, 1963. This is a classic book on suffering and the power of hope and meaning. Viktor Frankl is a physician and scholar who survived three years in Auschwitz. Through the unspeakable horror of his experience, he developed a philosophy which enables us to take a hopeful view of people's ability to transcend any predicament and find meaning. To have meaning attached to one's suffering makes it not just bearable, but transforming.

Patient or Person: Living With Chronic Pain by Penney Cowan, Gardner Press, 1992. Penney Cowan is the founder of the American Chronic Pain Association. In her book, she opens up her heart and tells the story of how she turned her life around while on a pain management unit. She shares her struggle to change herself from a confused and angry patient to a self-aware and functioning person.

Thumbs Up by James Brady, William Morrow and Co., 1987. During the attempted assassination of President Regan, James Brady suffered a gun shot to the head. His book tells of his life and struggle with devastating disabilities. The book provides good guidance for "learning to live with it" and fighting--and winning--to have a meaningful life.

When Bad Things Happen to Good People by Harold S. Kushner, Schocken Books, 1981. The author has a great ability to turn terrible situations into positive experiences. By telling about a tragedy in his life, he teaches his philosophy of life: take time to love each other and enjoy every moment. This is a modern classic.

Psychology and Self-Help

Anger: The Misunderstood Emotion by Carol Tavris, Touchstone, 1989. There are many misunderstandings about anger, for example: "It is always good for you to express your anger," and "Suppressing anger is always unhealthy." Not so, say Ms. Tavris. She explains anger from the point of view of anatomy, gender, stress, marriage, the law and personal behavior. She suggests strategies for living with anger and getting beyond anger.

The Angry Book by Theodore I. Rubin, 1978. This book states that there are various types of anger and therefore various appropriate responses. Anger which is not handled constructively can lead to further problems. Dr. Rubin lets us know we all get angry because we are all human.

The Dance of Anger: A Woman's Guide to Changing Patterns of Intimate Relationships by Harriet Goldhor Lerner, Ph.D., Harper and Row, 1985. This book is also available on audio cassette. The author uses many examples to illustrate how, when and why an event causes anger. Her approach to how to deal with anger is very reasonable, and she shows how self awareness is a very important part of dealing with anger.

Darkness Visible: A Memoir of Madness by William Styron, Random House, 1990. In 1985 William Styron, a Pulitzer Prize winning author, suffered a bout of depression. This book describes his experience eloquently. Anyone who has not had depression can read this book and come to understand the anguish of the illness. His account is moving and uplifting.

Feeling Good: The New Mood Therapy by David Burns, Signet, 1980. This book about depression is a classic. The author, a psychiatrist, shows how to defeat depression through a change in how we think. The book has self-help forms and charts to help the reader learn to overcome negative, depressive thinking.

Healing the Child Within by Charles L. Whitefield, M.D., Health Communications, Inc., 1987. The premise of this book is that people are best understood within the context of their families and their experiences as children. If the family has several

problems, the child adapts his or her behavior for protection. If the old patterns and strategies used in childhood continue into maturity, the behavior and beliefs may interfere with living a happy life. This book is about how to find and help the part of the adult which remains a wounded child

Overcoming Depression by Demitri Papolos, M.D. and Janice Papolos, Harper Collins, 1992 (revised edition). This is a comprehensive book on depression. It explains, in depth, the nature of the illness, the varied treatments for depression, including antidepressants and other drugs; how the illness affects the family; and how to deal with the world after recovery.

When I Say "No" I Feel Guilty by Dr. Manual J. Smith, Dial Press, 1988. Have you ever felt you lacked the skills to achieve what you wanted without losing your temper or self-respect? If so, this book is certainly worth reading. It discusses how to cope effectively with other people in a variety of situations.

Journal Keeping

The New Diary by Tristine Rainer, J.P. Tarcher, Inc., 1978. The author tells us that keeping a journal or diary is much more than keeping a rigid calendar with entries about the day's events. If you want guidance for using your journal to tap inner resources, solve problems, bring joy into your life, and clarify your goals, give this book a try.

Recovering: A Journal by May Sarton, W.W. Norton, 1980. This is not a "how to" journal, but one of May Sarton's published journals. May Sarton is a poet, writer and a journal keeper. *Recovering* was written at a time when she was experiencing loss and illness. This is a literary piece, with beautiful language and wonderful insights which may cause the reader to see life events in new ways.

Writing Down the Bones: Freeing the Writer Within by Natalie Goldberg, Shambala Publications, Inc., 1986. This is not exactly a book on journal keeping, but it can be used as one. The intent of the book is to help us start writing, easily, and without the self-consciousness we learned in school. The book gives us

permission to have imperfect grammar and spelling and punctuation. It helps open the door which may have been shut by a teacher's red marking pencil.

Mind and Body

Anatomy of an Illness as Perceived by the Patient by Norman Cousins, Bantam Books, 1981. Most people with chronic pain have heard or read about this book which tells how laughing helped cure Cousins of an "incurable" disease. This book is worth reading. Laughter is just a part of what he did to regain his health.

Being Home: A Book of Meditations by Guinilla Norris, Bell Tower, 1991. This is a short but beautiful book which honors the home and what transpires within it. The meditations are about small things like making the bed, climbing the stairs, paying bills. The wonder of the book is that it focuses on the "now" of life. It honors the ordinary and opens our eyes to simple things. The black and white photos harmonize with the text.

Creative Visualization by Shakti Gawain, Bantam, 1982. This book has a bit of theory, but the author says the book is meant to be an introduction and workbook for learning and using creative visualization. The book has many techniques from which readers may choose those that work best for them.

Healers on Healing edited by Richard Carlson, Ph.D. and Benjamin Shield. If you are curious about the variety of ideas about healing and whose ideas may be helpful to you, this book could help. It contains essays and articles by many of today's leaders in healing and alternative medicine. Each writer, including Bernie Siegel, Gerald Jampolsky, Hugh Prather, and Lynn Andrews, try to find "the golden thread" that ties divergent ideas together.

Health and Healing by Andrew Weil, M.D., Houghton Mifflin, 1988. If you've ever wondered about "alternative medicine" this book is an excellent reference. Dr. Weil carefully explains techniques like osteopathy, holistic medicine, Chinese medicine,

homeopathy, and a myriad of other types of medical treatments and philosophies. The chapter "The Nature of Healing" is especially thought provoking.

Healthy Pleasures by Robert Ornstein, Ph.D., and David Sobel, M.D., Addison Wesley, 1989. This book may surprise you. The authors, a renowned brain researcher and an expert in preventative medicine, use the latest research to show us a healthier way to live using a concept they call the Pleasure Principle. They believe simple pleasures--a hug, a movie, a bubble bath, an occasional hot fudge sundae--have a positive effect on our ability to ward off disease. They say that helping another person may actually lengthen your life.

How Shall I Live: Transforming Surgery or Any Other Crisis into Greater Aliveness by Richard Moss, M.D., Celestial Arts, 1985. The book is written by a physician who became a patient. His experience before, during, and after surgery changed his view of traditional medicine. He came to see health problems as a way of transforming into a person who experiences life more fully and feels the connection between all living things.

Minding the Body, Mending the Mind by Joan Borsenko, Ph.D., Bantam Books, 1987. This book teaches the reader why it is important to learn to relax. With easy to understand explanations and plenty of assurances that it's hard for everyone to learn relaxation techniques, she describes how to evoke the relaxation response. The relaxation response is a state of mind and body which helps the body to overcome the physical and emotional effects of stress.

The Therapeutic Touch: How to Use Your Hands to Help or Heal by Dolores Kreiger, Ph.D., R.N., Prentiss Hall, 1979. Dolores Kreiger is a professor of nursing at New York University who developed, or rather, has been able to describe and teach the ancient art of using one's hands, heart, and intuition to relieve distress in another human being. This technique is used in some hospitals, often in the nursery with premature infants. It also is used to help people with chronic pain.

Exercise (*Be sure to check with your doctor or therapist before attempting any new exercise.*)

Angela Lansbury's Positive Moves: My Personal Plan for Fitness and Well Being by Angela Lansbury, Delacorte Press, 1990. The book begins and continues on a positive note: it's never too late to start to take steps to regain and maintain mobility and to engage in life more fully. The book is a detailed account of Ms. Lansbury's daily routine of activities for the body and spirit, including diet, relaxation, exercise, and interesting activities and friendships. It's fun to watch her television show, "Murder She Wrote," because you can see that she practices what she preaches.

Chronic Fatigue: Your Complete Exercise Guide by Neil F. Gordon, M.D., Ph.D., MPH Human Kinetics Publishers, 1993. The book offers comprehensive advice on how the chronically fatigued can determine just how much exertion is enough to improve overall health without increasing the chance of injuries. There are many diagrams and illustrations which help to explain why and how each exercise should be done. The author describes the book as a blueprint from which a person--along with the doctor--can create an appropriate exercise program.

Freedom From Back Pain: An Orthopedist's Self-Help Guide by Edward A. Abraham, M.D., Emmaus, PA, Rodel Press, 1986. The book is helpful to anyone with muscular-skeletal pain. When the author says "self-help," the emphasis is on "self." When he says "freedom" he does not mean "cure." He means getting personal control of your pain. The chapters on exercise include exercises to do in a pool as well as at home in a chair and on the floor.

Osteopathic Self-Treatment: Safe and Effective Self-Help Techniques for Relaxing Tense Muscles and Easing Pain by Leon Chaitrow, D.O., M.R.O., Thorsons Publishers Limited, England, 1990. Many of the practices osteopathic physicians use for soft tissue of the body can be adapted for use at home. The techniques in this book are gentle, and the goal of doing them is to reduce stiffness and restriction of movement.

Reach for Fitness: A Special Book of Exercise for the Physically Challenged by Richard Simmons, Warner Communications Company, 1986. A paraphrase of the "pledge" Richard Simmons asks readers to make is the best way to describe this book. Readers are asked to pledge to accept the idea that every cell in their bodies would be better, stronger and healthier with more physical activity; and that they will never again say they can't exercise. The book shows how to keep the pledge.

Stretching by Bob Anderson, Shelter Publications, 1989. Available with a companion *video: Stretching, the Video*, Donaldson Video Software. This is one of the best illustrated books on the market today. It shows you how to stretch and then strengthen your muscles. There are exercises for every part of your body and for every level of physical ability. The book is spiral bound, which lets you lay it flat next to you as you learn the stretches.

Walking for the Health of It: The Easy and Effective Exercise for People Over Fifty by American Association for Retired Persons (AARP), Scott, Foresman Co., 1986. Don't let the age in the title scare you off. The information could just as easily be in *Seventeen Magazine*. The book has everything you could want to know before starting a walking program. The information is readable, specific and practical. It makes no grand promises for miraculous results. It is a simple program with simple benefits: weight loss, stress reduction, better sleep and care of the heart.

Waterworks: 120 Water Exercises for Swimmers and Non-Swimmers by Bill Read, Harmony Books, 1985. True to its title, the book contains 120 water exercises. Each water exercise is explained in words. The benefit of exercising in water is explained. The author's premise is that readers, working with their doctors or therapists, can pick and choose the exercises that are right for them. The book breaks exercises into levels, beginning with easy and working up to difficult ones. The book maintains that no matter what the level, exercise gives a person a sense of control.

Relationships

The Book of Questions by Gregory Stock, Ph.D., Workman Publishing, 1985. This is a small book, only four by six inches, but don't let that fool you. The book can be a tool for self discovery and a way to start conversations with your family or friends. Each page has one question. There are questions about likes and dislikes, personal values and how to handle a dilemma. Some examples are: What would be a 'perfect' evening for you? Whom would you want as your dinner guest? There are no wrong answers, just opinions, and a means to communicate.

The Dance of Intimacy by Harriet Goldhor Lerner, Ph.D., Harper and Row, 1989. The book deals with all our key relationships. The author explains the "dance" or steps we can take toward and away from each other and still maintain intimacy. Although she doesn't deal with chronic pain per se, the content of the book is very relevant to people with chronic pain. She stresses the importance of a healthy sense of "I" in relationships because without an "I" there can be no "we."

Love Is Never Enough: How Couples Can Overcome Misunderstandings, Resolve Conflicts, and Solve Relationship Problems Through Cognitive Therapy by Aaron T. Beck, Harper Perennial Press, 1988. This book is a practical guide for couples who want to enrich and sustain their marriage. Although love is important, Beck says that mates need to cooperate, compromise, and be tolerant of each other's flaws and mistakes.

Mainstay: For the Well Spouse of the Chronically Ill by Maggie Strong, Penguin Books, 1988. The author of this book is the well spouse of a man with multiple sclerosis. She was asked to "write a book for us" (well spouses). Woven through the story of her life as a well spouse are issues such as sadness, sex, guilt, feeling trapped, loneliness, jealousy, anger and more. The book is for people with chronic pain and their well friends.

Self Care

Daring to Be Yourself by Alexandra Stoddard, Doubleday, 1990. Ms. Stoddard is an interior designer, but this book is not about interior design and it's not written for people with chronic pain. It doesn't have to be. Her message? Learn about yourself, develop your "personal style." Identify what is positive and life enhancing for you. Then put these things into your life, your home, your heart. She calls this a treasure hunt. As you develop your "personal style" and bring positive things in, you eliminate negative stress. The book concludes with a section entitled "What Special Gifts Do You Have to Offer Others?" It's a natural conclusion.

Guide to Independent Living for People With Arthritis edited and funded by The Arthritis Foundation, 1988. Whether or not you have arthritis, there is something in here for you. If you want to help yourself and discover new ways to do things you enjoy or that let you function more independently, this is a good place to begin the search. You'll find catalogues, organizations, equipment suppliers and pictures of people doing old tasks in new ways. This is the heart of self help. The book is available from your local chapter of The Arthritis Foundation.

Healing Environments by Carol Venolia, Celestial Arts, 1988. The book is written by an architect who believes you can change the quality of your life by making changes in your home. The book explains how light, color, sound (and noise), temperature and air quality can effect your health and self-esteem. The book has specific suggestions for improving the quality of life in your home.

How to Create Interiors for the Disabled: A Guidebook for Family and Friends by Jane Randolph Cay, Pantheon Books, 1978. This is a trail blazing book written when rehabilitative medicine was just coming into its own. Despite its age, many of the ideas and suggestions are useful now. Even through the focus is on people who use wheelchairs, many of the ideas apply to individuals with a variety of mobility problems. For example, door levers instead of door knobs can be helpful for people with arthritis, prostheses or carpal tunnel syndrome. The Dis of disabled means a person is not able to perform a specific task the way others can. Change the way a task is performed and change

dis able to able.

Jane Brody's Good Food Book by Jane Brody, Bantam Books, 1987. Jane Brody writes the Personal Health column for the New York Times. The book has five sections. The first explains nutrition basics and explains the new focus on more carbohydrates, and less fat, sugar, and salt in our diets. The second section is a guide to "good" carbohydrates: what they are and how they benefit the body. The third section is about healthy ways to maintain weight. The last two sections include cooking tips and recipes.

Speed Cleaning by Jeff Campbell and The Clean House Team, Dell Publishing, 1991. Whether we do it ourselves, delegate it, or pay someone to do it for us, cleaning our homes is inevitable. "Speed," in this case, means efficient. Efficient means less wear and tear. Less wear and tear means less you-know-what. The author is a man whose "Clean Team" cleans 15,000 homes a year. They know every trick in the cleaning book. Actually, they wrote the book! They've identified the best products and the easiest ways to clean EVERYTHING in a home. If you want to know how to "Sh-Mop" your kitchen floor and not wipe yourself out, this book is for you.

Streamlining Your Life: A Five Point Plan for Uncomplicated Living by Stephanie Culp, Writers Digest Books, 1991. This is a book written for a general readership, but it's a great guide for people with chronic pain. We need to "pace our activities." So does everybody else but for different reasons. The focus is on streamlining our lives by identifying our priorities and planning accordingly; eliminating excess "stuff," organizing what's important to us (like our closets, reading materials, medical records) and enjoying the freedom that comes from positive change.

Physicians

Advice to Doctors and Other Big People from Kids from the Center for Attitudinal Healing, Celestial Arts, 1991. The purpose of the book is to give children a way to offer their suggestions and to express their feelings about doctors, nurses

and other health care workers. This book speaks eloquently to adults . . . perhaps to the innocent, open child within. In response to a question about waiting to see the doctor one child said, "Once I had to wait for four hours. No one came to tell me that I would have to wait so long. I feel trapped when I wait for a long time."

On Doctoring: Stories, Poems, Essays edited by Richard Reynolds, M.D. and John Stone, M.D., Simon & Schuster, 1991. This is a collection of stories, poems, and essays about what it is like to be sick or cured, to win or lose in the world doctors inhabit every day. The collection is written by physicians and "just plain folks." The theme of the book is that the medical profession is a human profession. The collection draws from a wide range of sources including a poem by John Donne (1572-1631) and a short story by Ernest Hemingway

Understanding Medications and Chronic Pain

The Complete Drug Reference, Consumer Report Books (updated each year)

Prescription Drug Handbook published by The Association of American Retired Persons. AARP has recently revised its *Prescription Drug Handbook*, which is a guide to medications frequently prescribed for older people. The handbook describes nearly 1,000 brand-name and generic drugs, over-the-counter medications and vitamins. The book costs \$17.95 in stores or \$12.95 (plus \$1 postage and handling) through the AARP Pharmacy Service. To order you may call (800) 456-2277.

Chapter 19 Public Relations a Publicity Primer

The most important element in any publicity program is you.

The following pages have been designed to help you begin the development of the group. Included are sample press releases, meeting announcements, and radio and television public service announcements. Other useful information is also included.

The primary goal of the American Chronic Pain Association is to teach people who suffer from chronic pain to live fuller, more productive lives. To accomplish this, however, we must first get people involved with our programs. As a group facilitating member, one of your most important roles will be to maintain visibility for the ACPA in your community. This "primer" is to help you do the things you must do in order to tell the world about our work. It's easy once you know how.

This primer contains models for you to use when placing announcements with the press. It contains copies of stories placed elsewhere to use as examples of what you can expect from the media. It also contains a checklist and suggestions for special promotional projects you may wish to undertake.

The most important element in any publicity program is you. Your personal involvement and responsiveness to the media will be the key to letting people know what the ACPA can do for them. Please feel free to contact the national office with any questions you may have. We have done all this before and can

help you avoid problems you might not be able to foresee.

Media Contacts: Who and How

Getting to know your local reporters and news directors will pay big benefits for the local ACPA group. A record of names, publications or stations, and deadlines, plus any other relevant information, can be kept in a card file or loose-leaf notebook and called up at a moment's notice.

Whenever you send out meeting announcements or press releases, do follow up in a few days with a personal call. This lets the reporter or news director know you care about seeing your information appear and gives him or her a chance to ask questions. Keep these calls BRIEF. Reporters are busy people and will be annoyed by lengthy or too frequent interruptions. A typical call might go like this:

You: Is this Carol Reporter? My name is John Smith of the American Chronic Pain Association. I sent you a release on Tuesday and I'm calling to see if you received it.

Reporter: Yes, I think it's here somewhere.
or
No, we've never heard of you.

You (if yes): Good. We're eager to let people know about our group. Do you have any questions? When are you planning to run it?

You (if no): I'm sorry. Let me check the address and send you another copy. Or: Your deadline is today. Can I give you the information now, or would you like me to drop a copy off at your office?

Reporter answers

You: Thank you for your help. Let me know if there's ever anything we can do for you as you

put together your stories. Good-bye.

Short, sweet, and to the point. Letting reporters know you are a resource for future stories is important. Remembering that newspapers must fill many column inches and radio and television stations must fulfill public service obligations will help you get over any initial shyness you may feel in calling these folks. They can help you and you can help them. It's a partnership.

We must protect the privacy of members.

The forms following this section can be used as models in setting up your group's media files. Adapt them to your local needs. They can help you track the publicity methods that work best in your area, be informed when you talk to members of the media and avoid too frequent contact, which can make you be perceived as being a "chronic pain."

Do Remember to Say Thanks

Media people are human, too. They like to know when their efforts have been successful. A brief note saying that you appreciate their work and telling them how many responses their stories generated will go a long way toward winning you friends in the working place.

Feature Story Placements

From time to time, local media will want to do a feature length story on the group. This will be very helpful and should be encouraged. But remember that, above all, we must protect the privacy of members. Before agreeing to a feature, select members of the group you feel will be good interview subjects and get their full cooperation. No one should feel pressured to comply. Photographs may not be taken in actual group meetings, but some members may be willing to simulate meeting activities for photographers. Most reporters will be willing to go along with this plan when you stress the need for privacy and express your desire to help them get the information they need in other ways.

Always follow these interviews with phone calls in a few days to see if the writer has all the information he or she needs and to thank him or her for time spent with the group. Express your interest and the reporter will respond with increased interest.

Once the story appears, a brief thank you is in order. And do please send a copy of the article to National Office. We want to know how you're doing, too.

AUDIO-VISUAL MEDIA CONTACT CARD

Name of station: _____

Address: _____

Assignments Editor: _____

Phone: (____) _____

Medical reporter _____

Phone: (____) _____

Talk show producer: _____

(there may be several for different shows)

Phone: (____) _____

Public Service Announcements or Public Affairs Contact: _____

Phone: (____) _____

Information sent:

Date	Nature of information	Contact
Response		

Placement with this station

Date	Nature of piece	Contact
Response		

PRINT MEDIA CONTACT CARD

Publication name: _____

Address: _____

Frequency of publication: _____

Deadline: _____

News editor: _____

Phone: (____) _____

Health and science editor _____

Phone: (____) _____

Calendar or events editor: _____

Phone: (____) _____

Feature editor: _____

Phone: (____) _____

Information sent

Date	Nature of information	Contact
_____	_____	_____
_____	_____	_____

Placement with this publication

Date	Nature of information	Contact
_____	_____	_____
_____	_____	_____

A CHECKLIST FOR GROUP PUBLICITY

A month before the event:

_____ Review media file for likely placement

_____ Prepare announcements for mailing

Two or three weeks before the event:

_____ Mail announcement to selected media

_____ Record information sent in media file

_____ Follow with personal calls in a few days

_____ Send announcements to members

The week after the event:

_____ Call or write reporters who covered the event to thank them for their work and let them know the results

_____ Send copies of any clippings to the national office

_____ Update media file with results of this event

Other Publicity Tools to Consider

Brochures may be left with physicians for distribution to their chronic pain patients. They may also be distributed to industry and business medical benefits offices. Contact the National Office for help with this.

Providing speakers to other community groups lets you talk directly with many potential members and their friends and families. Setting a speaker service up is time-consuming but puts ACPA where we want to be—out there in the community.

Community health days are often sponsored in malls or in neighborhoods. Get a list of dates ahead of time from the city or local government, or from mall or shopping district associations, and be present with a booth and brochures. Talking to people face-to-face is the best way to make the contacts you need, and word-of-mouth advertising is very effective.

American Chronic Pain Association Use of Opioids for Chronic Pain

Pain experts now agree that acute pain and cancer pain have been seriously under treated for many years. (For detailed information, call the Agency for Health Care Policy and Research of the Department of Health and Human Services at 1-800-358-9295 for a free copy of *Acute Pain Management: Operative or Medical Procedures and Trauma. Clinical Practice Guidelines* and *Management of Cancer Pain. Clinical Practice Guideline*.) All patients should receive adequate analgesics (medications that relieve pain), including strong opioids if they are necessary to provide adequate pain control. (Opioids are medications related to opium and include codeine, morphine, Demerol, Vicodin, Percocet, Dilaudid, and others.)

There is controversy as to whether opioid maintenance improves the quality of life in individuals with chronic nonmalignant pain. While some scientists, physicians, and patients believe strongly that opioids are helpful, there are others who find them to be of little use or even harmful. It is probable that some people are helped while others are not, but prediction of who will be helped and who will not is not yet reliable.

Some of the controversy about opioid use stems from misunderstanding the concepts of addiction, physical dependency, and tolerance. The table below may be helpful in better understanding these terms

Term	Distinctions
Tolerance	<p>Describes the fact that after repeated doses, narcotics (and some other medications) have reduced effects. This may result in the need to increase doses to maintain effectiveness.</p> <p>Tolerance is a property of certain drugs. It occurs in every person who uses these drugs for a period of time, and is not addiction.</p>
Physical dependency	<p>Describes the fact that after repeated administration of certain drugs, abruptly stopping them produces withdrawal symptoms.</p> <p>This physiological change is not addiction but can produce a desire for a drug to relieve symptoms.</p>
Addiction	<p>Characterized by 1) intense need for chemical with preoccupation with obtaining/maintaining a supply, compulsive use. 2) frequent loss of control of use (using more than planned), 3) continued use despite harmful effects. Addiction is more likely to develop when there is a personal or family history of dependence on alcohol or drugs, and when the drug is used for psychological coping rather than for pain.</p> <p>There is a strong tendency to return to use, even after withdrawal symptoms and pain subside. Patients who use narcotics only for pain easily taper off when the pain abates.</p>

Definition

Asset or liability? How can you determine whether opioids are helping you or harming you? Important clues can be found not just in your pain level, but also in your personality, mood, and function. Ask your family if you aren't sure. Since starting to take opioids, does your family think you are happier or more irritable? Are you more likely to participate in activities you enjoy or to recline and doze most of the day? How has the overall quality of your life changed? Is it better or worse?

If you elect to undergo a trial of opioid maintenance, it is important to have realistic expectations. While analgesics may be helpful, they are unlikely to be a complete solution, and it will be important to continue your other strategies for coping with pain to maximize your comfort and function.

It may be tempting to discuss pain medications at group meetings, but this should be avoided. A better approach is to communicate with your health care providers regarding the medications you are taking, the effect they have on your pain and quality of life, and any side effects you are experiencing. You and your health care providers are the only ones who have the total picture of your pain and the power to change your pain care plan when necessary.

*Prepared by: E.C. Covington, M.D., Colleen Dunwoody, R.N., MSN,
Christine Pasero, R.N., BSN for the ACPA 1996.*

ACPA DO'S AND DON'TS

DO look to the ACPA to help you improve the quality of your life in spite of your pain.

DO continue to seek proper health care while attending ACPA meetings.

DO feel free to talk about what your pain has done to your life and the changes that have occurred.

DO look to the ACPA group members to listen to what you are saying and give you feedback and support.

DO expect to learn coping skills that can help you to become involved in your recovery.

DO expect to have your needs met during group, if you let the group know what you need.

DO let the group contact person know if you are unable to attend a meeting.

DO make your own decisions and accept responsibility for your actions.

DO offer to help with the group. Ask the facilitating member how you can help make his or her job easier.

DON'T allow prolonged discussion about **physical symptoms** to take up group time.

DON'T talk about **medications** in group. We each experience medication differently and this should be discussed with your personal health care professional.

DON'T compare your progress with others. No one is looking for perfection, but rather we hope to help you achieve the personal goals you have set for yourself.

DON'T interrupt when someone is talking. Allow them to finish what they are saying before making comment.

DON'T give advice.

DON'T look for a miracle, the ACPA cannot take away your pain. We can help you to live more effectively despite your pain.

DON'T judge other group members.

DON'T discuss personal information about group members outside group. Respect confidentiality.

Need help or have a question? You have a National Office to help you. Please feel free to write or call.

National Office:

American Chronic Pain Association National Office
Post Office Box 850
Rocklin, CA 95677
916-632-0922
Fax: 916-632-3208
E-mail: ACPA@pacbell.net
Web Site: www.theacpa.org

Member Advisory Committee
Post Office Box 850
Rocklin, CA 95677

FACTS ABOUT CHRONIC PAIN

The following facts were published by the **American Pain Society** in 1996.

- Pain is a major public health problem in the United States with more than 50 million Americans partially or totally disabled by pain.
- 45% of all Americans seek care for persistent pain at some point in their lives.
- Headaches and low back pain are the most common forms of chronic pain.
- 22% of work-related injuries involve back pain.
- 150 million workdays are lost annually to headaches.
- Children lose one million school days annually due to pain.
- Chronic pain is frequently untreated or mistreated.
- Mismanagement of intractable pain has tragic and costly consequences such as: disability, depression, over utilization of diagnostic services and procedures, hospitalization and surgery, and overuse of inappropriate medication.
- Chronic pain *can* be treated effectively with early intervention by an appropriate trained specialist at an outpatient clinic at a reasonable cost.

Other facts about chronic pain:

- In 1992 the cost of chronic pain approached \$100 million dollars making chronic pain so wide-spread that it is considered to be an epidemic. (Jane Cowles, *Pain Relief, How to Say No to Acute, Chronic & Cancer Pain!*)

- A Consumer Report Book, *Mind, Body, Medicine*, quotes Dennis Turk, Ph.D., an expert in the field of chronic pain, that some 10 to 30 percent of American suffer to some degree from pain that serves no function and can become a tremendous burden. Chronic pain also has a high social cost. More than 11.7 million Americans are significantly impaired and 2.6 million are permanently disabled by back pain alone. One national survey found that more than 550 million days are lost from work each year because of pain. According to recent estimates, the cost of disability compensation and loss of productivity may be as high as \$100 billion annually. No consensus exists about gender difference in pain threshold and tolerance.

From a **Louis Harris and Associates** survey done for *Business & Health Magazine* in June 1996 come these figures on pain in the workplace.

- Back pain is the most frequently reported cause of pain in the United States, second only to headaches.
- The third most frequent reason for having surgery is because of back pain.
- Low back pain affects about 31 million adults at any given time.
- Pain will strike 80 percent of us at some point in our lives.
- Leading cause of absenteeism among workers of all ages is because of low back pain.
- The leading cause of work-related disability is back pain.
- Back pain afflicts 20 percent of workers for at least one week each year.
- Low back pain represents 25 percent of workers' comp claims by executives.
- Back pain consumes an estimated \$40 billion per year in lost wages, insurance claims and medical bills.
- 40 percent of all workers' comp cost are due to back pain.
- Averages \$7,400 per back-related injury claim.

Other facts about chronic pain:

- Chronic pain is any pain that goes on longer than six months and does not respond to conventional medical treatment.
- Seventy billion dollars a year are spent on medical costs, lost working days and workers' compensation due to pain problems. (J. Bonica, founder of the International Association for the Study of Pain and a member of the ACPA Board of Directors)
- Chronic pain disables more people than cancer or heart disease and costs the American people more money than both. (J. Bonica)
- The U.S. National Health Interview Survey in 1976 showed that 7.3 percent of the non-institutionalized American population was seriously limited in work, housekeeping, or attending school by chronic pain; the number grows to 14.3 percent if recreational, social, and civic activities are included.
- The problem is growing: in 1969, 9.3 percent of our population aged 16-64 were disabled from work for six months or more, while in 1980 that number was estimated to be around 12 percent.
- Chronic pain often leads to an endless cycle of anxiety, depression, loss of appetite, profound fatigue, and sleeplessness, all of which make the pain seem worse. (Kathleen Foley, M.D., 1984 president of American Pain Society.)
- Tolerance to pain does not vary according to gender or personality type.
- Eighty percent of all patients who consult physicians do so for pain problems.
- More than eight million Americans are permanently disabled by back pain with 65,000 new cases diagnosed each year. This is the number one complaint brought to pain clinic.
- There are 25 million migraine patients in the United States. This is the second leading problem brought to pain clinics.
- There are 30 to 50 million arthritics in the United States

with 600,000 new cases diagnosed each year.

- Americans consume 20,000 tons of aspirins a year at a cost of \$900 million.

Sources:

Dennis Turk, Ph.D., Pain Evaluation and Treatment Institute, Presbyterian-University Hospital, Pittsburgh, PA, 1989; National Institute of Neurological Communicative Disorders and Stroke, 1979; Vital Statistics, 1974; Paulley and Haskell, 1975; American Arthritis Foundation, 1976; Advertising Council, 1979.

Group Annual Report

**This report must be returned to the National Office
by March 15 of each year to receive your Group
Certificate**

Name: _____
Chapter: _____
Address: _____

(please note if this is a new address)

Contact Phone Number: _____

Our ACPA group has been meeting for: _____

Our ACPA group has not yet met, but we are in the process of making the necessary
arrangements: _____

Number attending meetings [____] male [__] female [__]

We meet [____] times a month

We meet at: _____

We find that the ACPA Workbook is:

very helpful in group sometimes helpful

not at all helpful difficult to follow

(The next series of question please feel free to check as many that apply to the group.)

The community in general has responded to our publicity by:

calling for information, but not following through by attending group

called for information and came to group only once

does not call

has allowed me to develop a strong core to our group

We have sent flyers and information packages about the ACPA and the local chapter to:

radio stations television stations newspapers

doctor's offices health clubs local hospital and rehabilitation centers

community help-lines (call for help) other

Our group shows the most interest in:

relaxation techniques exercise basic rights and assertiveness

understanding emotions self awareness family problems

where to find a good doctor that understands chronic pain ways to carry out daily activity

getting disability coverage social meetings having guest speakers

other _____

Our biggest problem with the group seems to be:

controlling the amount of time we spend talking about pain

talking about medications

doctor bashing

lack of willingness to focus on coping skills

members attending meeting regularly

members not calling when they can't come to group

accepting the fact that the ACPA cannot take away their pain

lack of understanding in the medical community

frustration at the expectations of family and friends

-
- not receiving disability payments
 - expense of an accredited pain management program
 - having no clear cause of pain
 - anger toward medical community

We feel the National Office:

- provides us with the support we need to conduct meetings
- does not support our efforts
- needs to provide more information about getting a group started
- helps us to create awareness in our community
- needs to provide us with more personal contact through phone calls
- helps our group in many ways to keep the group going

Our groups like the:

- ACPA Workbook Manual*
- ACPA Kits*
- ACPA relaxation tapes
- Family Manual*
- ACPA Chronicle*
- ACPA Topic Calendar

The ACPA Leadership Retreat:

- has been very helpful to us
- is not financially possible for our members
- is of no interest to us
- would be helpful if it were in our area

ACPA Regional Resource Person

- has been helpful to our group when we need it
- is something our group would be interested in learning more about
- are not available to our group

We find that most of the members are willing to financially support:

- our local group
- our region
- the National Office
- no part of the ACPA

Thank you for taking the time to fill this report out. **Once this report has been received at the National Office, we will send the group their ACPA Group Certificate.**

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