Fibromyalgia Network

Community, Education & Support

SINCE 1988

Support Group Leader Starter Kit

Thank you for your request for information. This information packet is designed to help patients diagnosed with fibromyalgia syndrome (FMS), chronic fatigue syndrome (CFS), and related disorders to form new support groups and sustain existing ones.

In this packet you will find:

Starting a Support Group

- What is a Support Group
- Getting Started
- Self-Help Group Ingredients
- Working Together
- Keeping the Group Going
- Challenges

Self-Help Coping Tips

- Searching for You in the Midst of Your Illness
- Life in the Fibro Lane
- Taking Back Your Life
- Comebacks for Hurtful Comments
- Handling Unwanted Advice

Advocacy and Research

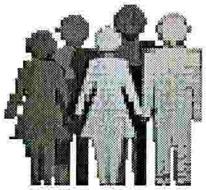
- The American Fibromyalgia Syndrome Association (**AFSA**)
- May 12 Awareness Day
- Your Rights as a Patient
- The Basics of Letter Writing

Finding More Information

- Fibromyalgia Network Information
- Help for Your Support Group
- Helpful Websites
- Other Helpful Information

The information in this packet was prepared by the Fibromyalgia Network. It is based upon the experience of others and is intended to help support groups achieve their goals. Every support group is unique, therefore some of the ideas presented may be useful, while others may not suit your group's needs. The goal of the Fibromyalgia Network is to provide people with the most reliable information possible. For additional information, call toll-free (800) 853-2929. Our office hours are 9:00 a.m. to 5:00 p.m., Monday through Friday, MST. Or visit our website at www.fmnetnews.com.

Starting a Support Group



What Is A Support Group?

People who provide one another with mutual support.

- A support group offers emotional support, encouragement and understanding. The group is a place where people can share their experiences without fear of being judged or criticized.
- A support group is a place where people can discuss common concerns, reduce the feeling of isolation, and share different perspectives on issues in a confidential setting.
- A support group is a safe place to unburden frustrations, disappointments, and fears. It is also a place where people can share their successes and insights, and where members can benefit from the experiences of others.

What Should We Do?

Every support group is unique.

- The driving force behind any group comes from the leaders, co-leaders, and participating members of the group. There is no cookie cutter pattern to follow. Each group must develop its form according to the needs of the people who are actually participating in it.
- The information contained in this packet is based upon the experience of others. You will find lots of ideas and helpful information in the following pages. In the end, however, what you do with your group is up to you. While some groups focus on outreach and advocacy, others choose to focus on helping each other cope. Some groups may choose to invite speakers to their meetings, and others may prefer to keep them as small discussion groups.
- Remember, the character of your support group will reflect the character of the group members. Planning is important, but so is flexibility!

GETTING STARTED

- **<u>Group Name</u>:** This can be as simple as the "FMS/CFS Support Group." The name of the group can always be changed later, after your group really gets going.

- **<u>Phone Contact:</u>** Who can prospective group members call if they want more information about your group? You will need someone to act as spokesperson for the group.

- **<u>Meeting Place:</u>** Many meetings start out in a patient's home and then they move to a library, hospital, church or a business establishment.

- **<u>Newspaper Announcement:</u>** Once you have the above information, you are ready to submit an Activity Announcement to your local newspaper. A two week notice is typically required. You should contact the office of your local paper to inquire about any other specifications (i.e. must be typed and include the name, address, and phone number of the person submitting the notice). A sample announcement follows:

  FMS/CFS GROUP

  Get acquainted mingler on Wednesday, June 8
  4-6 p.m., 1234 E Main Street
  Meet other people with these conditions.
  For details, call Susan at 290-5508

- **<u>Get Listed!</u>**
  If you would like to be listed on the Fibromyalgia Network referral list for your area, please fill out the form at the back of this packet.

Self-Help Group Ingredients

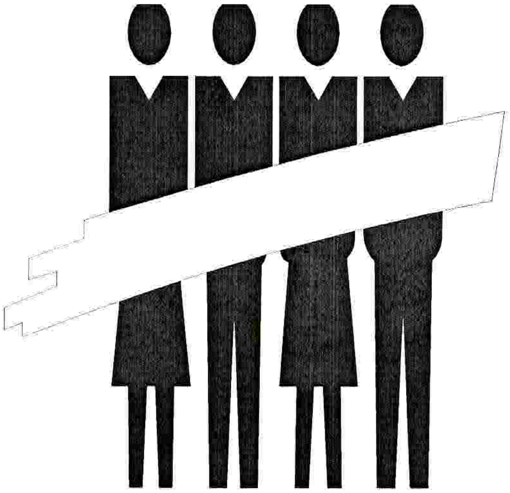
RECIPE FOR SUCCESS

✯ Several active participants
✯ People with a caring attitude
✯ Support from a local physician
✯ Assistance from a community organization
(Dues and officers are like salt ... they're optional!)

Keeping a support group alive takes effort, but if it is well-organized, it shouldn't be too much of a burden on any of the people involved.

Alice, leader of the Philadelphia, PA group has two co-leaders and four people to assist her in returning patient phone calls. She summarizes everyone's involvement by saying, "You do what you can, when you can." Then she adds that the informal structure takes the stress out of participating and it tends to produce a warm and caring environment for patients who are seeking help.

Alice took on the leadership of the group two years ago with the assistance of her physician, **Charles Pritchard, M.D.** "His office lets all new patients know that we have a support group—they even hand out a sheet with my name and phone number on it. The patients initially talk to me, and I give them encouragement and information about the monthly meetings."



While Dr. Pritchard is not intricately involved in the day to day activities of the group, his participation is a key ingredient to its success. He volunteers to be the group's guest speaker once a year and his name lends credibility to the group. Pritchard also had the clout within the medical community to make arrangements with a local hospital to provide the group with a meeting place, as well as much needed publicity.

This may not seem like a very time consuming role for a physician—and it isn't—but if a group can get a doctor to assist them, they are more apt to survive.

In addition to enlisting the help of a physician, the support of a hospital or other community organization (such as a public library or church) can come in handy. "The Abington Hospital generously permits us to use a meeting room free of charge," says Alice. "They also place announcements in the local papers for the group meetings, which is good exposure for both the group and the hospital! If that weren't enough, the hospital allows us (without charge) to mail our monthly meeting announcements through their mail room."

"Our group is unstructured in that we have no dues, no board of directors or officers. I have two assistant co-leaders and we take turns coordinating the meetings. I also have a member, Doug, who types the monthly announcements on his computer and delivers them to the hospital for the mailing."

"We are all compassionate people who understand how difficult it is to live with this terrible syndrome. We try to offer friendship, understanding and hope for a better future. But most importantly, we offer people a place (a refuge) where they can be candid about their fears and disappointments, where they can cry or laugh—and we will understand."

"Working with the group is a privilege for me. Sometimes in the throes of pain, I'll receive a phone call from a new patient who is scared and desperate to talk to someone. I'll rise to the occasion and forget for a while—as I try to comfort the other person—that I'm not feeling too well myself. Isn't the human spirit wonderful?

Alice provided the following message written by Doug: **"When you reach the end of your rope...tie a knot in it and hang on...yell for us and we will help you as much as we can."**

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WORKING TOGETHER

Support groups mean different things to different people. For some, it is a place to feel accepted and understood; it is where you share with other people your failures and your successes in how you have managed to cope with your symptoms. For others, support groups are a pipeline of great information: handouts and speaker events. Fulfilling these divergent needs isn't always easy, but it is essential for the group's survival.

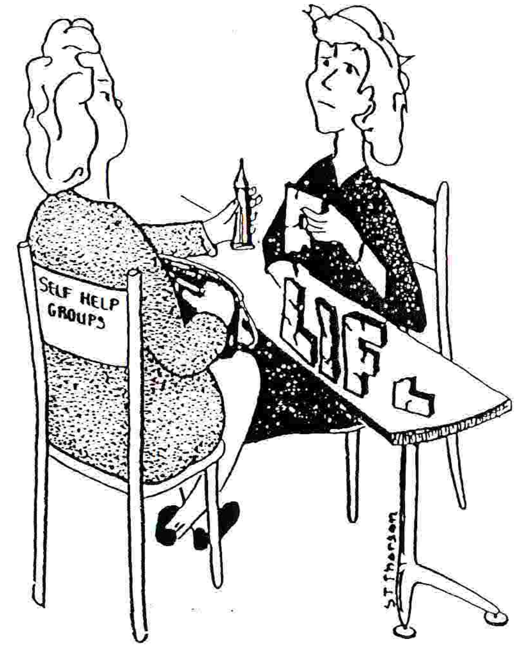
Successful groups are not comprised of a facilitator who leads everyone in attendance around by the nose. Instead, all members must truly adhere to the motto of "self-help." Anyone who has attended at least two meetings should strongly consider volunteering to do some task or perform a function that is routinely needed by the group. Don't let the fact that you live inside a chronically ill and often unreliable body stop you. Most everyone in your group has this same problem! Yet if everyone tries to pitch in, the group will still function well when you aren't feeling up to attending.

Get healthy spouses, family and friends involved in the group meetings. There may be tasks that patients with FMS/CFS are not able to perform, such as setting up tables and chairs. People who have access to photocopy machines might want to volunteer to reproduce speaker hand-outs, event calendars and other items that group members wish to share. In fact, there might be a specific article in this or past newsletters that you would like to discuss with your group. Let us know! Perhaps **FM Network** can help you out with this chore as well.

Group members who don't get out much might enjoy the job of calling patients to remind them of the next meeting. This is usually accomplished by a phone tree, whereby any given person has the responsibility of contacting a maximum of ten people per meeting. **Joal Fischer, M.D.**, director of Support Works, a self-help clearing house in Charlotte, NC, suggests that phone conversations be kept short. Avoid situations he refers to as "dial-a-fix" in which everyone's problems are resolved on the phone and then patients decide that it is no longer necessary to attend the meetings.

Once most people in the group display a vested interest in it, how do you resolve the conflicting needs of people who want to share and people who attend the meetings for informational purposes only? Set up an information display table at each meeting. People who are there for the handouts can feel free to pick them up and leave if they are not interested in that month's sharing topic. If you have a speaker event, everyone should be on the lookout for newcomers. Make new members feel welcome and let them know that you would be happy to talk to them during the scheduled break.

Finally, every support group should have rules and they should be unbiasedly enforced. For example, you might have a limit on how much floor time a person has to talk (typically two to five minutes). If someone needs more time, a seasoned member of the group should volunteer to talk further with them during the break. Never let outspoken, angry or overly aggressive people disrupt the serenity of your meetings!



Need some glue?

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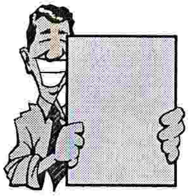
Keeping Your Group Going



Speakers/Topics

Lining up good speakers can often be a problem. You may want to contact FM Network for a Health Care referral listing for your area (just send an self-addressed stamped envelope with 41 cents postage). Even if you don't have medical doctors pounding down your doors to speak at your meetings, you can still have other people from the Health Care community give presentations that will be valuable to your members (but don't give up on the doctors; some of them will come around once you have had a few successful meetings). In addition to the medical doctors in your town, here are suggestions for other good speakers:

Pharmacist - A pharmacist can tell your members everything they want to know about the types of medicines that patients with your condition commonly take. They can also offer invaluable advice on how to take various medications (e.g. with a meal, in the morning or evening) and what you should know about drug interactions and side effects.

Physical Therapist - Physical therapists (PT) are trained in a variety of areas and you may want to have more than one PT speak to your group each year. Some of the topics that a PT might discuss are: acupressure and self massage, spray and stretch, pain relieving tips to use in your home, muscle relaxation tips, how to stay active/mobile while avoiding activities that could cause more pain or fatigue, how to strengthen postural muscles and discussion of what types of supportive aids might be helpful. Physical therapists can give great hands-on demonstrations as well, so members might want to bring their spouse or a friend.

Massage Therapist - These specialists can offer great hands-on demonstrations.

Occupational Therapist - These specialists can offer methods to help you to re-adjust your work and home to make life easier.

Counselor - Counselors come with varying specialties: rehabilitation, family issues, stress reduction, coping in general, etc.

Attorney - Topics can range from insurance issues to disability.

Elected Official - Don't be shy. Ask your district representative to speak on health care, insurance, and research funding issues that are being discussed on Capitol Hill. This meeting will also give members an opportunity to offer your elected official feedback on patient needs.

Other Health Care Specialists - These professionals may be able to focus on specific symptoms or problems that members of your group are interested in.

- Dentist (TMD/TMJ)
- Neurologist/Pain Specialist (headaches)
- Gastroenterologist (IBS/stomach problems)
- Psychiatrist (depression/anxiety/sleep)
- Chiropractor
- Acupuncturist
- Nutritionist

Sharing Sessions

Speaker meetings are often alternated with sharing meetings in which patients get together to meet new friends and discuss coping ideas. These sessions are often more productive and positive if the meeting is focused on a particular topic that many members are having problems with. People can walk away from these meetings feeling that they have learned a new or useful way of coping with a given problem.

Here are a few ideas just to get you started:

- How to relate to family and friends (you could also have a counselor "sit in" on this session)
- How to save on energy
- Self-help tips on riding the tide of a pain crisis
- Finding new hobbies or recreational activities that are fun but not too taxing
- Employment/unemployment issues
- How to keep a positive attitude
- Useful adaptive aids (bring in your favorite one!)

Phone Trees

The purpose of a phone tree is two-fold:

☎ It alerts patients of the upcoming meeting while saving money on postage.

☎ Patients often prefer to hear from another patient once a month so that they don't feel so isolated, especially if they can't attend the meeting. However, conversations should be held to a minimum to conserve everyone's energy.

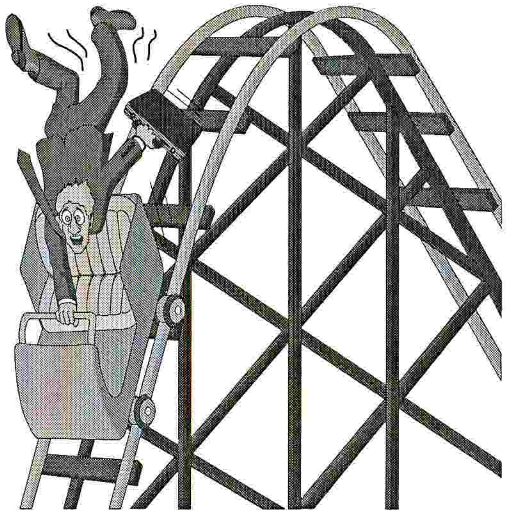
Flyers

You can circulate flyers about your group or group meetings at the local hospitals (you may need to get permission first) and ask people in your Health Care community to post them in their offices.
Community centers, libraries and other public locations often allow groups to post notices as well.

Finances

- ★ Donation box at each meeting
- ★ Postage stamps or self-addressed, stamped envelopes (SASE's) for support group flyers.
- ★ Enlist free services from members and their family, such as photocopying of flyers (and other non-copyrighted material) and computer word processing.
- ★ Participate in the *Fibromyalgia Network's* Support Group rebate program. (You will automatically be sent forms for this program when you are added to the referral list for your state.)

CHALLENGES



Too Much to Do ?!

Delegate as much as possible and always try to have a co-leader. Make others feel in charge of a specific function, such as:

- Librarian
- Phone contact(s)
- Greeter for newcomers
- Program Coordinator
- Public relations
- Secretary

Difficult Phone Calls & Questions

➤ **People asking for medical advice**. Unless you are a licensed physician, you should avoid giving medical advice. The best way to handle these situations is to refer the patient back to their physician or to offer them another doctor to contact. Although you can't tell people what medications to take, you can still provide them with information about FMS/CFS and help on coping with the symptoms.

➤ **Many patients are understandably frustrated**. If the person on the other end of the phone breaks into tears or expresses anger, remember that they are probably not upset with you ... they are likely unleashing their frustrations.

➤ **Some people don't respect your limited energy**. You may have to remind some people that you, too, have the condition ... but try to do this in a kind fashion.

Getting the Medical Community Involved

➤ Always be polite and persistent

➤ Invite them and their patients to your functions. If you believe that they could offer helpful advice, ask them to be a guest speaker. If they say no, ask them if the timing is bad and if they could recommend someone else. Always keep your options open. Stay in touch and inquire again at a later date.

Public Awareness

Getting the word out is not always easy. Some groups have handed out literature at their local health fair (you can always contact the Fibromyalgia Network to get free information handouts). Others have been able to get their local newspaper to run a feature story about their health condition and their support group efforts. When approaching a newspaper reporter, you will usually need to provide them with one Health Care Professional reference, i.e. a doctor whom they can interview as well. Along these same lines, you may be able to convince your local TV station to run a short 2-minute spot on FMS/CFS and reference your group as a local contact. If you don't want to be flooded with calls, you can also give out the FM Network's address and phone number. For more information on public awareness, see the section Research and Advocacy.

Patient Advocacy

It is hard to ask people who aren't feeling up to par to pound out a few letters each year to their elected officials. However, if patients do not speak up, no one else is going to do this task for them. Find someone in your group who has a computer with a word processor and turn this challenge into a "Group Project." See the section on 'The Basics of Letter Writing.'

Coordination with Other Self-Help Groups in Your Area

Link up with other chronic illness support groups in your region. You may wish to exchange ideas and speakers. You might also want to consider coordinating a large speaker event together.

Coordination with Other Self-Help Groups Across the Country

With today's access to the Internet, e-mail and mobile phones, the possibilities are endless.

SELF-HELP
COPING TIPS

Searching for You

in The Midst of your Illness

Illnesses like fibromyalgia syndrome (FMS) and chronic fatigue syndrome (CFS) can not only be life-disrupting, but also life-consuming. While it's important to keep your health care appointments, remember to take your medicines, vitamins and other supplements, watch what you eat, stick to a rigid sleep and activity schedule, and do what it takes to manage your symptoms—you don't want to lose sight of your identity.

Linda Noble Topf, M.A., author of You Are Not Your Illness writes: "No matter what the diagnosis, the name of the disease or the mode of treatment, always remember that who you are is not somebody with an illness. Who you are is somebody, somebody who matters!" Yet to find you in the midst of your illness, to seek out that person that really does count, will require you to look beyond your medical condition.

Topf, a person surviving with multiple sclerosis, points out that people are not just flesh and bones, nor can a person's existence be sized up by a string of accomplishments—just unemotional acts of doing. Viewing yourself within the realm of your medical condition and the limits it may impose can magnify your inabilities and minimize your perception of yourself as a person ... somebody who really does matter.

But how do you find that emotional, spiritual and caring side of you? Topf comments that you may temptingly tell yourself that you "haven't got time to deal with your emotions," to untangle yourself from the day-to-day hassles, and search for your true identity and missions in life.

"I have been there myself," writes Topf, "and discovered that in spite of all the other challenges, our own feelings about our illness are at the center of all other issues we are facing. How we address those most difficult emotions will determine whether we reclaim ourselves, and live our lives successfully, or sacrifice our very souls to the illness."

In our stress-ridden and materialistically-driven world that trains us from a young age to size people up by their physical accomplishments, it is more important than ever to not just see yourself in terms of your medical condition. This can place too much emphasis on your losses, your pain and your physical limitations. You Are Not Your Illness is a compassionately crafted self-help guide to assist people in regaining freedom from their chronic illness. It also helps people focus on their missions in life. Whether or not you read this book, you may simply try to take a few minutes out of each day to disengage yourself and your thoughts from your FMS/ CFS and think about things that bring joy to your life.

"When we look carefully at people with clear missions in their lives," claims Topf, "we find that while they feel that what they are doing gives their life meaning and purpose, they are also deeply nurtured in return ... Usually, what truly nurtures us are the simple pleasures in life, experiences we might take for granted if we didn't actually take time to stop and think about them."

You Are Not Your Illness is published by Simon & Schuster (ISBN 0-684-80124-8). The cost is $14.95.

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Life in the Fibro Lane

... pastimes patients endorse

One of the challenges of adjusting to FMS/CFS is finding hobbies and pastimes that don't aggravate your symptoms. Better yet, you want to seek out activities that provide you with gratification whenever possible. Fibromyalgia Network received roughly 100 letters from patients who described what they did to get their minds off their pain. Here are the top pastimes mentioned:

Photography

One person who took photography lessons at the local community college says she carries a camera in her purse all the time. "I never know where the right picture will happen ... I also shop for unusual frames to keep my pictures in or to give them away to family members or close friends."

A second women says: "When I took my first photography class several years ago from a naturalist at our local nature center, little did I know how it would affect my life." As she strolls with her husband around the parks, she shoots pictures of birds or beautiful stone monuments. "I can soon forget how bad I hurt ... nature is very relaxing."

"During the first three years following the injury that led to my FMS, I gave up softball, work, fishing, hiking, writing, and training my children for sports," says another patient. She went back to school and now has a new job, but due to her need to take regular breaks, she makes up for this by reviewing work-related files on the weekends. "A few months ago, I remembered that I have a nice camera with a telephoto lens. I also learned that I love watching the helicopters land and take off at the local hospital. Now, on the weekends, I take my work, my dog, and my camera to the hospital parking lot. I work until a chopper is coming in or out. The pictures that have resulted from this are wonderful. The feeling of accomplishment is tremendous. I still miss softball. I still have bad days. I still have occasional anger about the pain and limitations of this illness. The difference is that today, I have choices."

Computer Art & Stationary

Computers are becoming less of a novelty and color printers are improving in quality while dropping in price. Some patients are beginning to use their computers not only for their Internet access, but also for their artistic outlet.

"I design personalized cards on my computer to send to others in pain or in need of encouragement. This not only brightens their day, but it is a great outlet for me as I concentrate on the needs of others. Also, for my friends who like to write letters, I've designed personalized stationary for them to use. For my niece and nephews, I put together birthday packages, which include banners, invitations, posters, games, and name cards."

Dancing

Dancing of all types provides aerobic exercise, if you are up to it. You may also just try "going through the motions" for the social benefits various types of group dancing can offer. Contact your local community centers, YMCAs and hospitals for activity listings.

"My main distraction is Country Western line dancing. It is a wonderful form of aerobics, with all the pleasure and none of the sweat. Although my husband and I both dance, it is not necessary to have a partner. I seem to derive the same benefit from dancing as I do from massage."

"What do I do for distraction? Square dancing! It's not just for old folks anymore. It's good clean fun and you'd never know that you walked three miles in an evening. One of the first calls you learn is a "yellow rock" which means hug the person you're looking at. No alcohol is allowed because you have to be able to follow directions (hopefully your attention isn't too bothered by fibro-fog). It's teamwork in action, plus food, fun, friends and exercise."

Learning Something New

One patient recommended taking a new class each session at a local community college or arts school. "It must not become routine, or something that you always do by yourself." You might start out with a class in history, to learn more about your ancestors. Or, you might take a class in calligraphy. Regarding this last suggestion, one person stated: "I was interested in calligraphy, but I didn't know if I could do something that exacting with my hands, which tire and cramp quite easily. But, what the heck. I took the class to see if I could do it. I was elated when I found out I could and, with practice, I do it pretty well! Now I incorporate calligraphy into handmade cards for the holidays ... a papermaking workshop last fall added the possibility of another dimension to my artwork and cards."

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Preparing for the Holidays Year-Around

Specially made gifts (even if it is just the card that is attached to the gift) often provoke kind or loving feelings. It signals that a person went out of their way to make something just for you. Even if the gift didn't cost much, it's always the thought that counts.

Before you know it, November will be here and are you prepared? Many patients suggested a great way to get ready for the holidays: make a list of the people who you wish to give presents to and then as a year-around hobby, start making them gifts.

"Bargains from flea markets and garage sales are what I dress up to make presents. Sales items help my pocketbook; already worn thin from the cost of medications. A touch of lace, a bit of ribbon, some fancy buttons and ideas from women's magazines can create unique 'made myself' gifts."

Use the arts, crafts and hobbies that you have learned to make gift-giving special. Then when the season rolls around, you will be able to enjoy it instead of wearing yourself out at the shopping malls.

Deck the House for All Holidays

Enjoy the cheer of holidays without some of the hassles.

"I like bright colors in my house. I decorate for each holiday by stringing lights on a table, desk, shelf or fireplace." In addition to using lights, you can also use scented candles that remind you of the season and place you in a happy mood—it's called aroma therapy! Your family can all join in the holiday celebration by making colorful decorations to be displayed.

Herb & Flower Gardens

Squatting down to plant and continually weed a flowerbed may flare up your sore muscles. Instead, one patient suggested that you might be more able to tend to a few small pots that line the sill of your kitchen window or a ledge on your patio. Get a few plastic pots (even ice cream containers will do). Fill the bottom two inches high with small stones for water drainage. For the rest, use potting soil mixed with sand. Common herbs to grow are: parsley, oregano, thyme, sage, and spearmint. Small seasonal flowers can also be planted to add color to your garden. Another way to add color is to decorate your pots. "There is nothing that can quite compare with the flavor of food or a cup of hot or iced tea prepared with fresh picked herbs."

Music

Many patients claimed that music helped keep their mind off their pain. However, one patient wrote to us explaining the ups and downs of creating music: "I have played the violin since I was eight years old and have taught myself piano, guitar and other instruments when I can. Each instrument taxes a different set of muscles. My problem is my compulsiveness. I would play for hours if I could ... bad idea! On days that I can not play any instrument, I take some time to surf the Internet for new music to play."

Writing

Writing can be a creative outlet for many people. One patient who used to be a physical education teacher and dancer, decided she needed to focus on something else. "Since I couldn't dance professionally anymore, and my husband was a journalism major in college, I decided to teach myself creative writing with some help from him ... I have taken several classes at Senior Citizen Centers, which are laid back and non-competitive. When I am really hurting, I sit at my computer for 15 minutes at a time and write anything that comes into my head ... I've written several short stories, a novel, and many articles ... Thirty minutes a day of writing takes my mind off the pain."

How Do Other Patients Rate Their Therapies

A survey of the use and effectiveness of conventional and alternative therapies for FMS was presented at the November American College of Rheumatology meeting by **Sumedha Dalvi, M.D. Ph.D.,** and **Charles Pritchard, M.D.**, of Abington, PA. Here are the responses they received from the 117 patient surveys obtained:

- Opiods provided more pain relief that acetaminophen (Tylenol) and led to higher well-being scores than did NSAIDSs (e.g., ibuprophen), Tylenol or tramadol (Ultram).

- Tricyclic antidepressants (e.g. Elavil, Sinequan, etc.) and cyclobenzaprine (Flexeril) were better at aiding sleep than were drugs in the SSRI cetegory such as Prozac or Paxil.

- Exercise and massage offered higher pain relief, sleep, well-being, and function scores than acupuncture and better function scores than chiropractic treatments.

- Meditation and malic acid supplementation achieved higher scores with regard to well-being than acupuncture.

- Here is a breakdown of some of the alternative therapies used: vitamins (68%), ointments (41%), herbs (38%), magnesium (35%), malic acid (25%), CoQ10 (21%), exercise (70%), massage (54%), chiropractic (41%), meditation (34%), and acupuncture (20%).

Taking Back Your Life!

"What do you do for fun?" is a common question **Carol Burckhardt, R.N., Ph.D.,** asks her patients with fibromyalgia syndrome (FMS) and chronic fatigue syndrome (CFS). Burckhardt says most patients look at her as though she must be from another planet and out of touch with reality! This couldn't be further from the truth. Dr. Burckhardt is a mental health professor at Oregon Health Sciences University and has been working with the pioneering "Oregon Team" for over ten years to help patients get on with living. The problem is that pleasurable, leisure activities have become a foreign concept to many people who battle the chronic hassles of FMS/CFS.

It's not your fault. Not only has your body gone through many unwanted changes, but your life has been a long and intense roller coaster ride. You have gripped onto the many things you thought important, but somehow the fun in life slipped through your fingers. Loss of careers, social interaction and self-confidence are other problems that patients face says Burckhardt, who spoke at the Oregon '96 patient conference.

How do you get your life back on track? How do you recapture what is rightfully yours? How do you slay the FMS/CFS beast within? How do you find the time to have fun again? The syndrome is chronic and the drug treatments aren't ideal, but putting these aside, Burckhardt says, "Everyone has the capacity to get better." Yet, getting better requires that you take steps on your own in order to boot your terrible symptoms out of the driver's seat and force them to take a back seat in your life.

"Self-management of your FMS/CFS," says Burckhardt, "is a skill that needs to be learned. You're the one who is going to manage this business of fibromyalgia. You are the captain of the team here." For years, you might have viewed your physician as your team captain. That was okay for clearing up problems like a strep throat or an ear infection. But you have a chronic illness that has the capacity to consume every moment of your day if you don't learn ways to control it; ways to whittle down its life-sucking existence.

Burckhardt says to view your control over your illness as a continuum (see next page). "You have virtually no control over how people react to you. Their reactions are entirely theirs. On the other end of this control continuum are your own emotional reactions, such as the things you say to yourself and the way you treat yourself."

In between, you have pain, fatigue and daily hassles—what Burckhardt refers to as the big three. You have some control over these by enlisting the help of your doctor and by cutting down on the effects of daily hassles (see July '96 issue for advice), but Burckhardt's self-management focus is on the left side of the continuum: how you treat yourself.

Before you can really get started on self-management techniques, make a daily or weekly schedule. Although this may sound hard, Burckhardt encourages patients to do this for at least two weeks. Why? "One reason is because you have a right to have some planning in your life," says Burckhardt. "You need to be able to fit in an activity, maybe something that you enjoy, and make it a priority. Secondly, if you keep a schedule for a while, you will begin to see what you were able to do ... it's a good way to chart your progress."

Listen to Your Thoughts

Pay attention to what you say to yourself day after day. There are many negative things you can say to yourself when burdened with a chronic illness and the limitations it imposes. A few examples might be:

- Why bother getting out of bed tomorrow, I never seem to get anything done?
- I didn't cook my kids fresh vegetables tonight; I'm a terrible parent.

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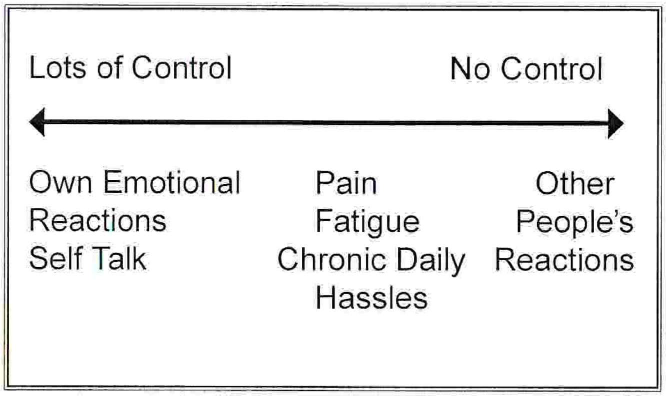

- The laundry is piling up and I'm lazy for not doing it.
- I should know why I feel so bad today.
- I can't get a job; I'm good-for-nothing.

Question Your Thoughts

Every time a thought pops into your head, try to ask yourself the following three questions:

? Does this belief help me feel better? (Do I feel better every time I think about this?)

? Does this belief help me accomplish my goals? (Does it really motivate me to get help or do something about my condition?)

? Does this belief help me get along with others? (Does this really help my home life or my social interactions?)

If the answer is NO to the above questions for any given thought you might have, then Burckhardt recommends that you try using countering techniques. A countering technique is a form of self-talk that puts a positive spin on what might otherwise be a negative thought. If you don't combat negative thoughts with countering techniques, your sense of control will slip away and your feelings of self-worth will diminish as well.

Countering Statements

Burckhardt gave five common examples of countering techniques to re-shift your focus away from the negative "out-of-control" feeling to a more positive "I've got a handle on this" feeling.

- Utilitarian statements (i.e., is this thought useful to me right now?)
  Example: "I am really worried that my FMS/CFS will get worse." Naturally, your goal is to get better, so a utilitarian statement might be: "I am working hard on my daily stretching and exercise program so I can improve my endurance."

- Alternative interpretation (i.e., try another way of thinking about a problem.)
  Example: "I took my medication last night, but I didn't sleep well. Those pills are no help at all." Two possible alternatives might be: "I slept fairly well three out of the last four nights. Or, maybe I need to ask my doctor about changing my dose or switching to a different medication."

- Anti-catastrophic reappraisal (i.e., what's the likelihood that what you are thinking will actually happen?)
  Example: "My pain is awful and it's never going to get better." A reappraisal might be: "Yes, the pain is unbearable today, but the last time it was this bad it did get better."

- Coping statements (i.e., focus on ways you have coped in the past that have worked for you.)
  Example: "I woke up feeling horrible today." A coping statement might be: "I can handle it; I just have to take one day at a time."

- Label shifting (i.e., watch your language for negative labels about yourself and use other words.)
  Example: "I'm depressed." Use label-shifting to say to yourself: "I am a normal human being. Sometimes I get depressed just like everyone else."

Burckhardt summarized her speech at the Oregon '96 conference by saying: "If you take back your life and actively work at managing it, you can have the strength to do the important tasks in your life. You can have inward tranquility when your day is done and you can even have the energy to enjoy the beauty of a rainbow."

Medically reviewed and edited by Carol Burckhardt, R.N., Ph.D.

Comebacks for Hurtful Comments

With invisible conditions like fibromyalgia syndrome (FMS) and chronic fatigue syndrome (CFS), people are bound to make insensitive and hurtful remarks. They can't see your illness and they don't understand your limitations. Psychotherapist and rehabilitation specialist, **Don Uslan, MA, MBA, CRC,** of Seattle, says: "In my practice, everybody, both young and old as well as people with other chronic diseases that can't be seen, struggles with this issue."

The problem of other people's reaction to your illness, according to Uslan, is a double-sided issue. One side of this complex issue is your level of confidence in your medical diagnosis and the limitations it imposes on you. If you are shouldering any doubts about your capabilities, this can impede your ability to swiftly diffuse unfriendly remarks—which are on the other side of this issue.

Assuming that you are confident about your limitations, what's the next step? Uslan has patients ask themselves: Who is important to me and where do I have the greatest return on investment (as far as the relationship goes)? Your spouse/partner, children, parents, employer, and a few others may comprise your inner circle of people who are most important to you. Everyone else is on the outer circle.

"For several people in your outer circle, it may be worth it to make a modest effort toward educating them about your illness," says Uslan. Yet, you have limited energy and you may wish to concentrate on the people you love first.

Following are specific life situations and Uslan's recommendations on how you might respond to them—to minimize hurt feelings and to improve the other person's level of understanding.

Spouse/Partner

Hurtful comments can be made by your partner because they feel like their needs are not being met or that they are being taken advantage of when it comes to the housework. Some things need to be renegotiated, while other problems require better communication.

Example: I wish things could be the way they used to be.

If you and your partner used to engage in all kinds of sports and activities together, and you are no longer able to do this, then you may want to sit down with your partner and say: "Honey, I have six good hours a day. Three of it's spent with the kids, two of it's cooking and doing the chores, and I need an hour by myself. Let's figure out a way that we can spend more time together, but after that, I also want you to enjoy yourself. Play tennis with your friends. I'll tag along and watch you play whenever I can, but please have some fun ... it would really make me happy."

Example: I do all the housework around here and you do nothing.

If this comment was made off-the-cuff (or something else that implies that you are not carrying your load), then Uslan recommends that you say: "I wish you would be more direct with me rather than to zing me like that. I'm trying as hard as I can. It's not my intention to take advantage of you. I've been in a flare-up for days now and I appreciate everything you're doing. I can understand why you are upset; I'm upset too. Maybe we should just accept that we will have a more cluttered home. You're exhausted and I'm exhausted, and one of us with FMS/CFS is enough."

If the comment made by your spouse about doing all the housework is said in the heat of an argument, Uslan recommends that you say: "You know that's not true and it was a hurtful thing to say. I would like to have this conversation when we are calmer." Then try using the previous statements once things have settled down.

People at Work

"There is a line between 'my co-workers don't get it' and the law, which is the American's with Disabilities Act (ADA)," says Uslan. "The ADA says that you can receive no harassment or hostile comments in the workplace because you have an illness or disability." So if your co-workers are expressing resentment that you have time off for your illness or that you have special accommodations, that's not allowed under the

ADA law. Uslan urges you to bring these types of issues up with your employer because it is their legal responsibility to handle them. Now, here is how you may deal with the people who seem to be well-intentioned but they just don't understand your illness:

Example: Gee, you look wonderful today. You sure don't look tired or in pain.

"People behave like kids with their parents sometimes," says Uslan. "We test each other, but it is not a win or lose situation; it's a test of your confidence." If this person is important to you, you have to pass the test and here is what you might say: "I'm glad you think I look good, and frankly, I am feeling better this week. As you know, though, this condition of mine has its ups and downs." You may wish to spend a few minutes further explaining FMS/CFS—it all depends upon how much time you want to invest in this person.

People in the Outer Circle

Similar to the above example on co-workers, it is in people's nature to test you. Whenever comments are sarcastic or insensitive, be prepared to respond. Don't let others simply get away with hurting you.

Example: Well! How are we doing today? (Perhaps someone is really wondering if you are "being all that you can be.")

Uslan says that sarcastic comments like this may be approached by saying: "Are you asking me how am I doing or do you want to tell me something directly? If you are asking about my health, thank you for being concerned. The truth is that after working all week long, I just haven't been able to clean the house."

Example: I saw you playing around with your kids (or grandkids) in the front yard yesterday. Guess you must be doing much better. (Perhaps a well-meaning neighbor who does not understand that you can have good and bad days.)

Uslan says that if this is a good neighbor, they often just need a dose of reality: "Yes, I really enjoyed playing with my kids. Unfortunately I woke up stiff and achy this morning. This darn condition of mine always flares up the instant I overdo it."

Example: You look great! You're just using your illness to get out of going to the party (or some other event).

"This is a hostile statement," says Uslan. He recommends replying: "I resent that. I am not using my illness as an excuse. I'm glad you think I am looking great, but I don't need to prove myself to you." Uslan claims, "Many people will calm down after that and say that they are sorry." They might even add: "I guess I just don't get it. You say you are so sick and yet you look so well." This gives you the opportunity to respond: "That's the problem I struggle with all the time. Still, I'm not feeling well, and I need to stay home and take care of myself."

Example: You're so lucky, you don't have to work.

This can apply to patients not working or those who have had to switch to a part-time job or to a less demanding position. The point is, this person is being unsympathetic and they need to be corrected. Here's what Uslan recommends: "I would rather be working any time. I miss my old job. I miss the socialization, the gratification, the income, the health insurance. I had challenging projects and great promotions—I'm not getting any of that now."

Consider modifying the above verbal "comebacks" to suit various situations that occur often in your life. "Patients don't need to walk away from people's remarks feeling angry and hurt," concludes Uslan. If the person really matters to you, find a way to say something that will improve your level of communication and understanding with that person. Have one of our "Patient Guide" brochures to hand then as well. They are available in bulk quantities for a self-addressed stamped envelope (see flyer insert).

Medically reviewed and edited by Don Uslan, M.A., M.B.A., C.R.C.

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Handling *Unwanted* Advice

by Don Uslan, MA, MBA, CRC, NCC

As a psychotherapist and rehabilitation counselor experienced in treating people with fibromyalgia syndrome (FMS) and chronic fatigue syndrome (CFS), I often counsel patients on how best to handle feedback and information from friends and loved-ones.

First, you must always keep in mind your own energy level and how much time you have to respond to comments made by others. There is so much information available on FMS/CFS—not all of it's good—and you have to be wary about the advice that you get, even from health care providers. Next, you have to place in order of priority the people in your life whom you value the most. It seems that almost everyone has an opinion, but realize that it's not possible to listen and respond to everyone who has advice about your condition.

Hearing the same unsolicited advice, again and again, such as: "You should try acupuncture, or massage, or a particular nutritional supplement," or "I think you're taking too many medications," can be very distressing. These situations may even leave you with anxieties and doubts about your care.

So, how do you respond to the person who tells you to try this-or-that?

- If the person pushing the advice is not close to you, just simply say, "Thanks for sharing your opinion."

- A response to a close friend might be, "My doctor made the same suggestion, but we're waiting to see how my other therapies are working first."

- If it is someone who is very close to you whom you trust, perhaps you will want to take the time to talk with them further. Ask them why they think you should try a given therapy, what they have heard about it, and who is a good provider for this type of therapy? Then be honest about what you think—which may include your desire to try the suggested therapy, but for now you may not have the time or money to check it out.

Most reasonable people will accept the limits and boundaries on their input. Some people, however, can be forceful. Dealing with them can be emotionally trying. There may be no other way around being assertive with people who are maneuvering to become more involved in your care than you want them to be.

For example, if a person tells you: "You should really try this doctor. You will feel better if you see her." This is not constructive input. You're response needs to be clear, firm, and final: "I'm happy with my doctor, and I don't want to change." A sensible person will get the message. But, if this person persists with, "If you really want to get better, then you should give this doctor a call," you are dealing with someone who is disrespectful of your boundaries. They are probably less concerned with your health care than they are with being heard or being "right." Your comeback might be: "I don't think it's a good idea to discuss this anymore."

When it comes to handling advice about your condition, directness or "tough love" may be the best approach for a relationship, even a marriage. Ultimately, you are responsible for your own well-being. Your support system needs to respect your judgment and take your feelings into consideration.

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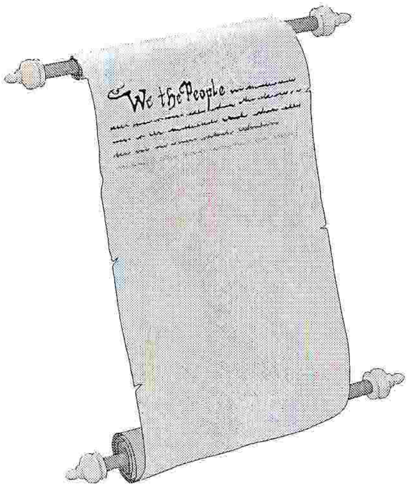
Advocacy And Research



Your Rights As A Patient

It is important that you know your rights as a patient and where to turn for help!

- **Prompt and definitive diagnosis of health condition(s).**

- **Full-spectrum treatments.**
  The *Fibromyalgia Network* gives referrals to Health Care Providers. In addition, information about the treatments and therapies that are available can be found in the *Fibromyalgia Network Journal.* Call 1-800-853-2929 or visit www.fmnetnews.com.

- **Education.**
  In addition to the *Fibromyalgia Network Journal*, there are many books that have been written on the subject. For a partial list of what is available, see the section titled "Finding More Information," or check with your local library. Some medical centers also have libraries that are available to the public.

- **Support.**
  Fibromyalgia support group meetings. A list of support groups in each state is also available through the *Fibromyalgia Network.*

- **Employment Assistance.**
  Americans' with Disability Act (ADA) Law. For a free information booklet or to speak with an ADA specialist, call 1-800-514-0301 Monday-Friday from 9:30 a.m to 5:30 p.m. (EST). Thursday hours are 12:30 p.m. to 5:30 p.m.
  Job Accommodations Network provides information concerning on-the-job rights, etc. More information is online at www.ada.gov.

- **Legal Assistance.**
  For a disability attorney referral, call the National Organization of Social Security Claimants Representatives (NOSSCR) at 1-800-431-2804 or online at www.nosscr.org. A free packet of information is also available through the *Fibromyalgia Network.* Send a 9 x12 self-addressed, stamped envelope with 4.60 postage to P.O. Box 31750, Tucson, AZ 85751. *Please indicate that you would like the disability packet.*

- **Research.**
  Contact the American Fibromyalgia Syndrome Association, Inc. (**AFSA**). **AFSA's** primary goal is to raise funds for researching FMS/CFS and related disorders. For more information on their organization, or to make a donation, please send correspondence to AFSA, Inc., PO Box 32698, Tucson AZ 85751 or visit their website at www.afsafund.org.

May 12 Awareness Day

The Meaning of May 12

Chronic immunological and neurological diseases are some of the fastest growing health concerns in the world today. Four of the largest are the overlapping conditions known as fibromalgia syndrome (FMS), chronic fatigue syndrome (CFS), multiple chemical sensitivity syndrome (MCSS) and Gulf War syndrome (GWS). These illnesses are often characterized by overwhelming fatigue, severe muscle pain, concentration problems, sleep disorders, headaches, allergic symptoms and numerous other problems that usually last a lifetime.

In order to shed some light this these growing health concerns, May 12 of each year has been designated as International Awareness Day. Individuals battling to survive these illnesses and the people who care about them are strongly urged to voice their concerns on May 12 as well as the two weeks preceding it.

May 12 was chosen to memorialize the birth date of Florence Nightingale, an English army nurse and hero to thousands of soldiers in the Crimean War. It was her selfless dedication to those less fortunate that inspired William Dunant, a Swiss banker to found the International Red Cross in her honor. Florence Nightingale is eulogized in our history books as a fighter and rightfully so. She lived out the latter part of her life battling symptoms reminiscent of CFS, FMS, MCSS and GWS. Nightingale never gave up and neither should you. Despite her illness, Nightingale managed to found the first school of nursing.

In memory of Florence Nightingale, May 12 has been selected by RESCIND Inc. (Repeal Existing Stereotypes about Chronic Immunological and Neurological Diseases) as the International Awareness Day for chronic fatigue syndrome (CFS), fibromyalgia syndrome (FMS), multiple chemical sensitivity syndrome (MCSS) and Gulf War Syndrome (GWS). There are many support groups and individuals from around the world who have worked long and hard to bring the tragic toll of these interrelated illnesses to the attention of the medical community, the government, the media and the public at large. We are forever in their debt and hope that May 12 Awareness Day will provide a catalyst to bring more patients together in their efforts to strive for a better life ahead.

Every Bit Counts!

You do not have to go to Washington, D.C. to advocate for your cause. Local grassroots efforts are equally important. There are may ways to pitch in on the May 12 activities. Here are just a few ideas:

- Donate books or other educational materials to your library, asking them to post a flyer about May 12.
- Ask you local hospital, if you bring them Awareness Day flyers to post them at their front reception along with pamphlets on the syndrome. If you can think of other health organizations or business establishments that would be willing to assist in a similar fashion, give them a call. Enlist the help of as many healthy people as you can.
- Host an information table at a health fair in your shopping mall or other public place.
- If you live in the United States, write letters to your elected officials who work on your behalf in Washington, D.C. These people in Congress can influence the amount of research dollars that are spent to study your illness. If you do not like to write, then consider making a few phone calls. All people in Congress have local offices as well as their offices in Washington, D.C.
- Other government health agencies can also be contacted, such as the Center for Disease Control (CDC), the National Institutes of Health, the Department of Defense (for Gulf War Syndrome) and the department of Health and Human Services. Check your phone book or go on the Internet for contact information.

The Media

Approach your local newspapers, TV and radio stations at least one month in advance of May 12 to request that they do a story on FMS, CFS, MCSS, and or GWS.For newspapers, you will want to look up the name of the Lifestyle or Health/Fitness section editor—this information often appears in each daily issue. You may also consider contacting a reporter directly if you have seen their name in print for several health-related articles in the past. To request that an article be written about your medical condition, you will probably have to do this in writing, but you might save time by calling the media outlet to find out what their policies are. When officially contacting the media for an article, a news announcement, or a talk-show radio spot, be prepared to provide them with the following:

1. Concise information about your medical condition (perhaps one of FM Network's Patient Guide brochures and our Political Case Statement). You may also write a paragraph or two on how this condition has impacted you. Everything should be typewritten.

2. Your name and a phone number that you can be reached at, as well as the names with phone numbers of other members of your local support group (if you have one).

The media usually likes to focus on human interest articles when it comes to medical conditions and awareness efforts. They will want to interview at least one person with the condition, so if you give them a few phone numbers, this will ensure that they will be able to get in touch with someone. Reporters are usually nice people who are trying to do a good job within a set period of time. They have deadlines, so the more to-the-point you are with your answers to their questions, the greater your chances are of getting a story in print. Be prepared to answer such questions as:

- How does it feel to have FMS, CFS, MCSS, or GWS?
- How has it impacted your life?
- How does your family and/or employer deal with your chronic illness?
- Did you have problems getting diagnosed? Or, are there problems with treatments? (Please do not bash doctors in your medical community; this will not go over well. You can still bring up the problems in general because this is the reason why we have May 12 Awareness Day, but just don't mention names and try not to sound bitter. Although your past history may be horrible, remember that you are attempting to improve the future situation for all patients.)
- If a person reading the proposed article believes that they might have the medical condition (or they have already been diagnosed with it), what should they do? Good answers might be: Contact your support group leader (giving local name and phone number) and/or, call the Fibromyalgia Network toll-free at (800) 853-2929.
- If a person reading the proposed article has been diagnosed with the medical condition, can you offer them some simple self-help advice? For example, you might tell the reporter about two or three coping tips that you use to deal with your chronic illness. Self-help is a very popular topic these days.
- Is there a good doctor or other health care provider in your town whom the reporter can call? Be prepared with names and phone numbers. As an alternative, you can have the reporter call FM Network. We can provide them with factual information from the medical journals, articles that have been medically peer reviewed, and potentially a researcher's phone number, but we cannot disseminate medical advice.

Please, don't let the long list above turn you off. It really isn't as difficult to get media awareness as it may appear. It is just much more helpful if you approach the media, prepared to answer their questions. This will ease their job, which greatly improves your likelihood of getting them to work with you!

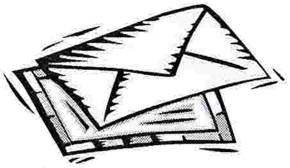
You can help make May 12 Awareness Day a powerful catalyst that unites millions of patients with FMS, CFS, MCSS and GWS to strive for a better life ahead!

May 12 Awareness Day
Is Your Chance to Get Your Voice Heard!!

Contact the Fibromyalgia Network for:

Educational Brochures on FMS/CFS
May 12 Awareness Day Posters
"Fibromyalgia - It's REAL" Purple Wristbands, Car Magnets, Removable Decals, Pins, and Bookmarks
View the items at www.fmnetnews.com/awareness
or call (800) 853-2929

The Basics of Letter Writing



Who To Write

Write to your local or state officials. If you don't know the names of your Senators, Representatives or state Governor, call your local voter registration office or go online to www.usa.gov.contact.shtml. Letters should be addressed, "The Honorable name, title (U.S. Senator, House Representative, Governor, etc.)."

What To Say (keep it to one page!)

Introduce yourself as a person with FMS. If you wish, you can indicate your age, sex, marital status, number of children you have (if any) and whatever else you feel may be pertinent to depicting you in your situation. You don't need to go on at length about "what" FMS is--simply attach one of FM Network's brochures and political fact statements, then reference them.

Describe how FMS has negatively impacted your life. Here are some points you may want to address. Remember, this section should be brief--one to two paragraphs long.

* How many years you have had the syndrome, including the time you hobbled along without the benefit of a diagnosis.
* How much money and how many doctors it took you to get a diagnosis.
* The difficulties you have had with finding a knowledgeable and compassionate physician to treat you (dollars wasted, number of wrong diagnoses or inappropriate surgeries/treatments, and mention one of the most insulting comments or humiliating situations you had to endure during this troublesome time).
* The number of various treatments you have tried and how ineffective they have been.
* Any problems you have had with your insurance company not paying for your FMS treatments.
* **Has FMS affected your employment status?** Do you consider yourself to be disabled by FMS (fully or partially)? And if so, are you receiving social security disability benefits or other forms of government compensation? Have you applied for financial assistance but been turned down?
* **The impact that FMS has had on your family life**: Has it cost you a marriage? Does it impair your ability to function as a parent?
* **Have you dropped out of sight "socially" due to lack of energy and uncontrollable pain?** Social isolation is a nasty enemy to people who suffer daily from chronic illnesses such as FMS!
* Mention if there are other members in your family, especially children, who are struggling with the symptoms of FMS.

Finishing Touches

Express your thanks. Always be polite and thank your official for taking the time to read your letter. Let him or her know that any help that they can offer would be greatly appreciated. You can also state that you would be eager to hear about any suggestions that they could provide you.

Sign off. Use Sincerely, Kindest regards, Yours truly, etc. Then sign your name. You may send out a neat photocopy of the body of your letter (if you don't have access to a word processor and printer), but please personally sign each copy that you send out!

Make copies of everything. Besides making a copy of your letter for your own files, PLEASE send us a copy as well. If you receive a response from your elected official, send us a copy too! Why? FM Network will continue to work with patients to keep the advocacy efforts rolling (we have over 25,000 members) ... but it would be of great help to us to know which elected officials have expressed an interest in FMS. Then we can send letters to other patients living in that particular official's voting district or state, encouraging these people to step up their letter-writing efforts. This is a nation-wide, team approach to advocacy, and your input will help ensure success. If possible, follow-up meetings with interested elected officials, or their staff members, will be attempted by FM Network to add more political clout to the letter that you have already written; sort of like a one-two punch!

Prepared by the Fibromyalgia Network
P.O. Box 31750, Tucson, AZ 85751
Call toll-free 1-800-853-2929
online at www.fmnetnews.com

The State of Wisconsin

OFFICE OF THE GOVERNOR

A PROCLAMATION

WHEREAS, Fibromyalgia Syndrome is one of the most common rheumatic conditions in the United States, affecting more than five million Americans; and

WHEREAS, Fibromyalgia Syndrome affects women 9:1 in comparison to men; and

WHEREAS, recent NIH funding of $1.4 million was designated to fibromyalgia research for the purpose of discovering the cause and improved treatments; and

WHEREAS, increasing public awareness is an effort to help those suffering with this disorder to be diagnosed earlier;

NOW, THEREFORE, I, TOMMY G. THOMPSON, Governor of the State of Wisconsin, do hereby proclaim May 12, 1999 as

FIBROMYALGIA AWARENESS DAY

in the State of Wisconsin, and I commend this observance to all citizens.

IN TESTIMONY WHEREOF, I have hereunto set my hand and caused the Great Seal of the State of Wisconsin to be affixed. Done at the Capitol in the City of Madison this sixteenth day of April in the year one thousand nine hundred ninety-nine.

Tommy G. Thompson

TOMMY G. THOMPSON

By the Governor:

DOUGLAS LA FOLLETTE
Secretary of State

JEB BUSH
GOVERNOR OF THE STATE OF FLORIDA

Chronic Fatigue Immune Dysfunction Syndrome and Fibromyalgia Syndrome Awareness Day

WHEREAS, Chronic Fatigue Immune Dysfunction Syndrome (CFIDS or CFS) and Fibromyalgia Syndrome (FMS) are complex illnesses which affect many different body systems and are characterized by neurological, rheumatological and immunological problems, incapacitating fatigue, extreme pain and numerous others symptoms that last for many months or years and can be severely debilitating; and

WHEREAS, persons with these syndromes often experience symptoms of sufficient severity to deprive them of the opportunity for gainful employment or normal family lives; and

WHEREAS, conservative estimates suggest that hundreds of thousands of adults and children in America have CFS or FMS or both; and

WHEREAS, it is imperative that education and training of health professionals regarding CFS and FMS be expanded and that there be greater public awareness of these serious health problems. While there has been increased activity at the state, local and national levels, more must be done to encourage further research so that our mission to conquer CFS and FMS and related disorders can be achieved.

NOW, THEREFORE, I, Jeb Bush, Governor of the state of Florida, do hereby extend greetings and best wishes to all observing *Chronic Fatigue Immune Dysfunction Syndrome and Fibromyalgia Syndrome Awareness Day*, May 12, 2001.

IN WITNESS WHEREOF, I
have hereunto set my hand
and caused the Great Seal of
the state of Florida to be affixed
at Tallahassee, the Capital, this
10th day of May in the year
of our Lord two thousand one.

Jeb Bush
GOVERNOR

SAMPLE
PROCLAMATION

AFSA
The
American
Fibromyalgia
Syndrome
Association, Inc.

THE AMERICAN FIBROMYALGIA SYNDROME ASSOCIATION, INC.

RESEARCH ... YOUR HOPE FOR THE FUTURE!

AFSA is the only charitable organization whose primary mission is to seed research in FMS/CFS. By stepping up research efforts on these syndromes, better diagnostic tools and treatments can found to minimize the impact of these painful and fatiguing illnesses. AFSA acknowledges that patient and physician education, public awareness and advocacy are all important ingredients in aiding in the lives of people with FMS and CFS. Over 90% of all funds raised go to AFSA's mission!

RESEARCH

Fibromyalgia Syndrome (FMS) is a chronic and often disabling medical condition characterized by widespread body pain and uncontrollable fatigue. It is often accompanied by many other problems such as irritable bowel, headaches, sleep disorder, and cognitive impairments. Conditions that may fall into the same category of syndromes as FMS are chronic fatigue syndrome (CFS) and myofascial pain syndrome (MPS).

In addition to looking for effective treatments and a definitive blood test for these syndromes, more basic science research is needed. This will help scientists better understand what is happening on a biochemical or patho-physiological basis. By further investigating possible abnormalities in neurotransmitters, hormones, metabolic processes and immune system factors researchers may be able to answer:

- Why do patients hurt all over?
- What is causing the extreme fatigue, headaches, concentration difficulties and GI upsets?
- Why do patients wake up from a night's sleep feeling stiff, achy and tired?

In addition, investigations into the role of genetics and the environment may further advance our understanding about these complicated and difficult-to-treat syndromes.

EDUCATION

Patients who understand their medical condition should be better equipped to cope with it. Based upon this philosophy, AFSA engages in the following educational activities:

- Publishing updates on research funding activities pertaining to FMS, CFS and related disorders.
- Distributing for sale educational booklets and note cards on FMS/CFS.
- Disseminating free brochures on AFSA, explaining what the organization is all about and how people can join in on the action!
- Sponsoring information booths at major medical conferences.

PATIENT ADVOCACY

More than 700 FMS/CFS support groups exist in North America. One of the Association's goal will be to lend advice and organizational assistance to these groups in order to provide a sense of cohesion among them. There is power in numbers and by uniting the groups (however loosely), FMS/CFS patient advocacy efforts can be strengthened. Other related activities that AFSA engages in are:

- Providing a phone service "warm line" for patients and their physicians.
- Encouraging new investigators to get involved in FMS/CFS research by seeding them with crucial grant money that may lead to expanded projects funded by the government.
- Provide patients with a resource list of helpful organizations.

CONTACT AFSA TODAY!

AFSA
PO Box 32698
Tucson, AZ 85751
visit **www.afsafund.org**
(520) 733-1570-phone / (520) 290-5550-fax

Finding More Information

WELCOME TO THE FIBROMYALGIA NETWORK!
Here is a brief description of who are we and what do we do:

Fibromyalgia Network is a small group of dedicated people whose mission is to educate and assist patients, pressure the National Institutes of Health (NIH) to spend more money on FMS research, increase awareness on fibromyalgia syndrome, and to provide free in-kind services to The American Fibromyalgia Syndrome Association (**AFSA**)—a research funding charity that grants research projects on FMS!

The Fibromyalgia Network has been active in its mission since 1988 and operates solely off of your Membership dollars. We accept no advertisements or government funding in our effort to provide patient-focused information that patients can put to use today. We offer the following essential services:

- The quarterly *Fibromyalgia Network Journal* packed with the latest research, treatment, and coping tips from the experts that you will not read anywhere else.
- Monthly *eNews Alerts* that provides 4-5 pages of original information to keep Members informed between issues.
- A toll-free line for patients to call 8 hours/day throughout North America.
- State-by-state support group and health care provider listings that are continuously updated to help people receive quality care
- Free educational brochures that concisely summarize the symptoms and treatments for FMS, to be used by patients and health care providers.
- A website, **www.fmnetnews.com**, with a wealth of credible information accessible to your family, friends, co-workers, and all.
- Free distribution of thousands of May 12 Awareness Day posters each year to people around the world to improve social awareness on this condition.

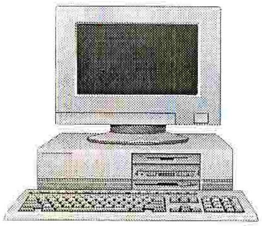
In 1997, The Fibromyalgia Network sponsored research experts to provide public testimony in Washington, DC, before Congress, concerning the need for increased spending at NIH on research. Since then, funding has gone from $300,000 a year to more than $7 million a year!

What can people expect from the *Fibromyalgia Network Journal*?

- The most up-to-date information available on FMS, written from a patient's perspective, but medically edited by the experts to insure accuracy.
- Self-help articles based on patient surveys and experienced patient input.
- *Q&A* columns answered by experts in the field.
- No advertisements ... so the information you receive is NOT tainted by monetary product endorsements.
- Summary updates on medical conferences and journal reports in which new findings and FMS treatments are discussed (including interviews with the researchers). None of this information is available on the Internet in a reliable, patient-friendly manner. Yet, Members are welcome to read the technically-oriented medical journal abstracts that each article is based on online.

When you Join the Fibromyalgia Network, you get much more than just a *Journal*. Your Membership dollars go toward forming a patient-directed, cohesive effort to push the envelope on better education and improved treatments for patients worldwide.

Join the Fibromyalgia Network Family today!

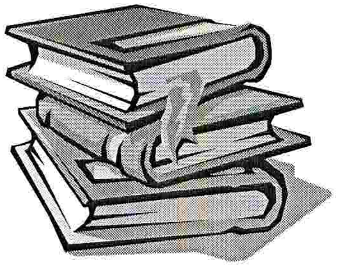


HELPFUL WEBSITES FOR FMS/CFS PATIENTS

Below is a list of various web sites that might be of help to people with FMS/CFS.

Organization	**Website Address**
The American Fibromyalgia Syndrome- Association, Inc. (**AFSA**)	www.afsafund.org
International Association for CFS/ME (IACFS/ME)	www.iacfs.net
Fibromyalgia Network	**www.fmnetnews.com**
Oregon Fibromyalgia Foundation (OFF) (Dr. Robert Bennett)	www.myalgia.com
Chronic Pain Treatment Guidelines:	
The American Pain Society	www.ampainsoc.org/
Partners Against Pain	www.partnersagainstpain.com/
The Pain & Policy study group University of Wisconsin)	http://medsch.wisc.edu webteam/au.html
Elected Officials and Government Offices	
U.S. House of Representatives	www.house.gov
U.S. Senate	www.senate.gov
The Americans with Disabilities Act	www.usdoj.gov/crt/ada/adahom1/html
The Center for Disease Control (CDC)	www.cdc.gov
Associated Disorders and Conditions	
Restless Legs Syndrome Foundation, Inc.	www.rls.org
Headache Help (Dr. Lawrence Robbins)	www.headachedrugs.com
Tempromandibular Joint Disorders (TMD) (Dr. Herbert Gordon)	www.TMJdisorders.com
International Endometriosis Association	www.endometriosisassn.org/

Finding more information



Over the years, there have been many books written on fibromyalgia syndrome, chronic fatigue syndrome, and related subjects. This short bibliography is a list of some of our favorites. This is, by no means, a complete list. You may want to check with your local library, bookstore or online bookseller for additional titles. We hope this list gives you a good start!

Hueme, Janet A. Fibromyalgia : A Handbook for Self Care and Treatment. Meerkat Graphics Centre. 1995. ISBN 1928812015

Berne, Katrina. Chronic Fatigue Syndrome, Fibromyalgia and Other Invisible Illnesses. Hunter House. 2001, ISBN 0897932803

Crook, William G. The Yeast Connection and the Woman. Professional Books/Future Health. 1999, ISBN 0933478224

Fransen, Jenny and Russell, I. Jon The Fibromyalgia Help Book. Smith House Press1996, ISBN 0961522143

Goldenberg, Don L. Fibromyalgia. Perigee Trade 2002, ISBN 039952780X

Lasater, Judith. Relax and Renew. Berkeley: Rodmell Press. 1995. Call 800-841-3123

Mason, John L. Guide to Stress Reduction. Celestial Arts. 2001, ISBN 1587610914

Pelligrino, Mark.
Inside Fibromyalgia. Columbus: Anadem Publishing. 2001.ISBN 1890018368
Fibromyalgia: Managing the Pain. Columbus: Anadem Publishing. 1993. ISBN-10: 1890018104
The Fibromyalgia Supporter. Columbus: Anadem Publishing. 1997. ISBN 1890018112
Understanding Post-Traumatic Fibromyalgia. Columbus: Anadem Publishing. 1996. ISBN 0964689189

Robbins, Lawrence.
Headache Help. Boston: Houghton Mifflin Company. 1995. ISBN 039570751X
Management of Headache and Headache Medications, 2nd. ed. Springer-Verlag. 2000. ISBN 0387989447

Wallace, Daniel J. All about Fibromyalgia. New York: Oxford University Press. 2002. ISBN 0195147537

To stay current on the latest research on fibromyalgia syndrome and chronic fatigue syndrome, look no further than the *Fibromyalgia Network Journal.* We research the medical journals and write articles in layman's terms that are medically reviewed by the experts before publication. Articles are for informational purposes only. You must consult your physician for treatment.

Help for Your Support Group

Free Brochures:

Fibromyalgia - A Patient's Guide is available to support group leaders for the cost of postage. Please send a self-addressed, stamped envelope with $4.80 postage for 50 brochures. The brochures provide an explanation of what it feels like to have fibromyalgia and how this condition overlaps substantially with chronic fatigue syndrome (CFS), a description of common symptoms, how the diagnosis is made, and a general description of frequently prescribed drug and non-drug therapies. If you need these brochures as handouts for an upcoming event, health fair, or activity, please contact us in advance for large quantities free of charge.

Submit an Event:

We welcome your group to submit your special activities to our Events page at **www.fmnetnews.com.** We encourage submission of one-half or full-day seminars, conferences, or activities **other than regular group meetings.** Whether it pertains to fibromyalgia, chronic fatigue syndrome, or any of the commonly associated conditions, we want to hear from you! There is no charge to have your event publicized on this site.

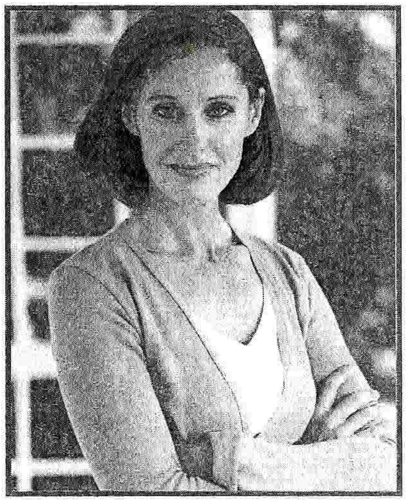
Support Group Questionnaire:

Please take the time to fill out the Support Group Questionnaire form that is included so you can be added to our referral network.

Rebate Information:

The Fibromyalgia Network offers support groups in the United States $5 rebates for new Members or two-year Membership renewals. We understand the financial limitations when running a support group and incidental costs that come into play. Attached is a sample copy of the Support Your Support Group form you will receive when you register your group with the Fibromyalgia Network. We will prestamp your group information on the forms for you.

SUPPORT ***YOUR*** SUPPORT GROUP



Take charge of your own health, stay on top of the latest in research and treatments, and contribute to your support group at the same time! Become a Member of FM Network, and learn why thousands of people around the globe depend on us for our advertisement-free information and support. Each issue of the *Fibromyalgia Network* journal contains the latest in research news, treatment options, and advice from experienced patients and physicians on how to best manage your symptoms.

FM Network understands the financial constraints of running a support group, and we offer a rebate program to help groups throughout the United States with the little incidentals. When you join FM Network for one year (or renew a current Membership for two years), your support group will receive a $5 rebate. Be sure to join by sending in the form below; no phone or Online orders will be accepted for participation in this program.

Fibromyalgia Network Order Form

Please complete this form and mail or fax to:

FM Network, PO Box 31750, Tucson, AZ 85751 • Fax: (520) 290-5550 • Phone: (800) 853-2929

Support Group Information:

Sample Copy

- ☐ **New Membership**: Join for one **year at $28.00** and your support group will receive $5.00.
- ☐ **Two-Year Membership**: Join for **two years at $51.00**—you save $5.00 and your support group will receive $5.00.
- ☐ **Renewing Members**: Renew your Membership for **two years at $51.00**—you save $5.00 and your support group will receive $5.00.
- ☐ **Diet and Exercise Supplement**—$10.00
- ☐ **Relationships Supplement**—$9.00

Order Total: $___________

Diet and Exercise Supplement: A 24-page publication on important dietary and exercise guidelines for FMS. Get "how-to" ideas on stretching, strengthening and increasing aerobic fitness without causing symptom flares, and learn how massage and managing hand and foot pain can reduce exercise discomfort. Plus, get suggestions on specific dietary approaches to symptom improvement. **$10.00**

Relationships Supplement: A 17-page collection of helpful advice on the social aspects of FMS. Experts weigh in on how to keep your personal relationships strong, enjoy intimacy in spite of pain and fatigue, and help children (or grandchildren) cope with your FMS. Improve your emotional well-being by learning to handle hurtful comments and unwanted advice. **$9.00**

Name: ______________________________

Address: ______________________________

City: ____________ **State:** ______ **Zip:** __________

Phone: (_____) ______________________

E-mail: ______________________________

☐ VISA ☐ MasterCard ☐ **Check/MO enclosed**

Make checks payable to: Fibromyalgia Network

Card Number: ______________________________

Expiration Date: ______________________________

Authorized Signature: ______________________________

Please allow 2-3 weeks for delivery. All prices ***include*** *shipping charges and a $3 processing fee.*
Prices subject to change without notice.