

Kit Three

Getting Involved



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American Chronic Pain Association

Step Two

Getting Involved

A journey of a thousand miles must begin with a single step. Chinese proverb.

What does being involved in your recovery really mean? It means quite simply that you are willing to work at improving the quality of your life. And the journey from patient to person begins with a single step. A step that you must take. It is a step that only you can take. However, you may rest assured that you will not travel alone.

We want you to become a prominent member of the treatment team and assume more responsibility for recovery. You will have the opportunity to regain more control of your life. This may sound like an impossible task considering your degree of pain, but it is possible. Anything is possible. Investing your time and energy in yourself and your well-being may be the most important step in your journey back to becoming a person.



Ninety percent of the world's woe comes from people not knowing themselves, their abilities, their frailties, and even their real virtues. Most of us go almost all the way through life as complete strangers to ourselves. Sydney J. Harris

Getting Started

Of course, with any building or renovation project there must be planning and preparation for a good foundation. If these steps are rushed through, or entirely skipped, failure is almost certain. The same holds true when rebuilding a life ravaged by chronic pain.



The first preparatory step of the project is a careful review of your resources. You will be taking a thorough personal inventory, which includes attitudes, beliefs, assets and talents. Hopefully you will be brave enough to look at both your strong and weak elements. Once this is done planning and actual renovation can begin.

Your Personal Attributes



First, take a look at the attributes you possess, which are the attitudes and beliefs. Things that have allowed you to get to this point in your journey where you're willing to become involved. They are the core of you—what is commonly referred to as character, or personality. They are what make each of us unique, and, for those with chronic pain, give us the strength to continue the rebuilding

process. We'll start by taking a personal inventory of your attributes. On the next page you will find a list of attributes. Place a check beside the items that describe you. What attributes make you who you are? This exercise will help you recognize those attributes useful for your journey from patient to person.

HINT: Take a blank calendar (next page) to your office supply or drug store, and make several copies for future months. Or use a conventional calendar if you have one with squares large enough for this exercise. It must be dedicated to this purpose alone.

At the top of each page³ note the month and fill in the appropriate numbers to indicate the days of the current month. Hand the calendar somewhere you will see it at the end of each day. Remember, this is part of recovery, your responsibility in the search for improving the quality of your life. Just in the same way as you would expect your doctor to give you his or her undivided attention during an office visit, so too must you give yourself the same undivided attention at the end of each day.

Place a check by each item that applies to you. Be honest with yourself as you go through this list. When a person is faced with chronic pain, it can be difficult to see one's attributes, but you have them. During this exercise step back from yourself and try be objective.

☐ pleasant	☐ assertive	☐ congenial	☐ dignified
☐ humorous	☐ friendly	☐ reputable	☐ compassionate
☐ courageous	☐ precious	☐ youthful	☐ ambitious
☐ confident	☐ wise	☐ dreamy	☐ principled
☐ self-respecting	☐ idealistic	☐ mature	☐ ethical
☐ humble	☐ independent	☐ strong	☐ anger
☐ imaginative	☐ hopeful	☐ individualistic	☐ forgiving
☐ enthusiastic	☐ stylish	☐ maturing	☐ flexible
☐ expressive	☐ tolerant	☐ motivated	☐ knowledgeable
☐ determined	☐ loving	☐ honest	☐ sober
☐ persistent	☐ candid	☐ talented	☐ patient
☐ serene	☐ interesting	☐ studious	☐ educated
☐ proud	☐ thorough	☐ opportunistic	☐ passionate
☐ understanding	☐ tough	☐ upbeat	☐ grateful
☐ daring	☐ instinctive	☐ practical	☐ committed
☐ loved	☐ focused	☐ loyal	☐ blessed
☐ charitable	☐ objective	☐ gentle	☐ original
☐ perceptive	☐ approachable	☐ clean	☐ likable
☐ professional	☐ unique	☐ optimistic	☐ reliable
☐ easygoing	☐ conservative	☐ sensible	☐ pragmatic

If you have at least five items checked, then you have the necessary attributes to become involved in your own recovery. There is really only one other element necessary for success. That is the desire to gain more control of your life.

Your Assets

Next, we need to identify your other resources. In other words, what can you do? Perhaps the best way to answer this question is to take a closer look at your assets. In the exercise below you're asked to take a closer look at your assets. The way you're feeling right now may make you respond by saying, "I have nothing." But that isn't true. We all have assets. Unfortunately, like so many other people, we don't see what is right in front of us. So, for the next half-hour give serious thought to your assets. And remember, taking a close look at every part of your life may reveal things you would not have considered assets before your pain.

Some examples of assets that you have would be your family, friends, supportive spouse, children, home or job. Your assets are things that can empower you.

My Assets

I am willing to become involved in my own recovery. In order to do that I must clearly identify the assets that I have. Those assets that will help me remain strong, focused, feel loved and supported, and get me through the difficult times ahead.



_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

You Abilities

Now it's time to take a close look at your talents and other characteristics. Each move you make and thought you think takes ability. What are you able to do? Better yet, recall those talents you haven't used in years, such as picture painting, riding a bicycle, or making cupcakes? With determination and practice even those rusty abilities can be enhanced and expanded.

In the space below list everything you are able to do. Take into account tasks as simple as getting out of bed in the morning. Often overlooked abilities, such as reading a newspaper or your involvement in a literary guild should be listed. Don't leave out anything.

My Abilities

This image shows a blank sheet of white paper with horizontal ruling lines. The page is divided into two equal-width columns by a vertical center fold. Each column contains ten evenly spaced horizontal black lines, providing a template for handwriting practice or note-taking.

Your Actions

With a clear idea of your attributes, assets, and abilities you have the tools necessary to start working on your plan-of-action.

Think of these things as the tools

of your trade. Each tool has its own unique function to contribute to your overall plan. Now you need to develop a plan of action.



The following are some examples of how your attributes, assets and abilities can be helpful in your overall involvement in your recovery. They may help identify how you can best use these tools for advancing your healing.

- **A sense of humor:** We have heard many people say that if it were not for their sense of humor they wouldn't have survived chronic pain. There are some times things seem so glum that all one can do is laugh. Laughter actually helps. Your body releases more of its natural painkiller (the endorphins) when you have a good belly laugh.
- **Time on your hands:** Having an abundance of time can work to your benefit. Each day you'll have time to devote to your job of recovery. If you are at home all day, you will be able to schedule time for exercise, relaxation training, socializing and even work through these kits.
- **Enjoyment of reading:** There is a wealth of printed information available to you in books and article that can help you with your recovery. Additionally, the Internet has many sites with up-to-the-minute medical information. The more information you have, the more involved you can become in your recovery. **A WORD TO THE WISE:** Do remember that much of what you read is only one person's opinion. With medical information you need to scrutinize and cross-check its validity with at least one other source.
- **A support system:** Support from your spouse, significant other, or friends and family is very helpful. They can become part of the treatment team by distracting your attention from the pain, refusing to treat you as a patient, and helping you to stay focused on what is really important.

- **A doctor truly willing to work with you:** This may be one of your greatest assets. Maintaining good communication with all of your health care providers should eliminate many fears you might otherwise have to cope with. When they understand your commitment to regaining control of your life, they should be more willing to help you with your journey.

I know what it is to live with chronic pain and it is very difficult. However, you don't have to give up. There are ways to get help living with chronic pain. Have you gone to a support group? One of the best things I did was go to a support group. I got involved with the ACPA and that changed my life. The first meeting I went to, was overwhelming for me. I cried from relief, because I had never felt so much support. It was overwhelming to be in a roomful of people who understood what it was I was living with. I didn't have to explain myself to anyone because everyone there had chronic pain. That did more for me than I can ever express. Find support in any way you possibly can.

Take the time to look at yourself with a critical eye. Not necessarily to put yourself down but to see what it is that you can do to improve your situation. You may not be able to get rid of the pain but you can do things to alter your behavior to better deal with it. This is an important step.

Find a doctor who is not afraid to prescribe proper pain medication. You have the right to pain relief and often that is through proper pain medication. If your doctor is not willing to provide you with it, find a doctor who will.

Jan Widdowson
Petaluma, CA

Personal Involvement

Your involvement in recovery requires a large degree of personal accountability for your well being. Tracing what you do, and when, eventually shows a pattern of which activities are, or are not, effective for recovery. Because there are so many remedies, techniques, and combinations thereof, you need a reliable method for documenting your actions and responses. Below is a calendar to help with tracking your level of involvement. Each day you will note what you did to stay involved in your recovery. A few simple words on the calendar can document your progress for the day. At the end of the month it will be easy to see just how much you did. You may be able to make a connection between your involvement and the way that you feel. Some simple instructions before you begin. Make sure to enter something each day.



Before beginning: You may want to develop a scale from one to ten (one being no involvement at all and ten being very involved) to indicate your level of involvement for that day. You could also design a list of words to indicate what you did that day. An example would be: E (exercise), W (took a walk), R (read book or researched your pain problem), D (doctor appointment), T (talked with a family member or friend) and so on. Finally, you might consider a simple system that uses rubber stamps. There is a wide variety of shapes and sizes from which to choose. Select three or four different stamps to indicate your level of daily involvement. A sunshine stamp could mean very involved, a cloud could mean somewhat involved and a snowflake could mean no involvement at all. Use your imagination tracking daily involvement. Remember, you are taking valuable time and effort for an important person . . . YOU. Aren't you worth the effort?

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Month:

Month:

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

So, how did you do? Looking at your calendar for the past month could provide insight into how involved you are in your recovery. If you feel you could have been more involved you might go back and review your attributes, assets and abilities. Ask yourself if your resources were wisely used during the month in a way to promote your health and wellness. Continue to keep track of your involvement for the next few months. It can be very difficult to remain involved in your recovery at the beginning because early improvement usually comes in small steps. It also takes some time to identify patterns of activities that work for you.

Your Rights

We've mentioned before that being an active member of your healthcare team is vital for recovery, yet there are often problems in the doctor-patient relationship. Many of us feel intimidated by our health care providers. We're regularly dismissed, scolded, told "it's all in your head," or "learn to live with it," so we fear having in-dept discussions about our problems. Questions that might help us remain involved in our recovery go unasked. Too often we do as we're told because we believe that others know what's best for us.

Adopting this type of attitude will prevent full involvement in your own recovery. You will continue to look to others to "make you well." You may believe that any involvement on your part will be minimal and ineffective. However, as a person with pain you have certain rights regarding your treatment. Knowing those rights as a "pain patient" will provide you with the sense that you have not only the right and the obligation to be involved in your recovery.

Pain Patient's Bill of Rights

The rights listed below will help you to receive adequate, prompt and helpful care as a person. Knowing and exercising your rights will greatly increase your chances of receiving prompt, thoughtful, appropriate and dignified care.

Pain Patient's Bill of Rights

You have the right to:

- ⦿ Has your pain prevented or controlled adequately.
- ⦿ Have your pain and pain medication history taken.
- ⦿ Ask how much pain to expect and how long it might last.
- ⦿ Develop a pain plan with your doctor.
- ⦿ Know what medication, treatment, or anesthesia will be given.
- ⦿ Knew the risks, benefits, and side effects of treatment.
- ⦿ Know what alternative pain treatments may be available.
- ⦿ Sign a statement of informed consent before any treatment.
- ⦿ Be believed when you say you have pain.
- ⦿ Have your pain assessed on an individual basis.
- ⦿ Have your pain assessed using the 0 = no pain, 10 = worse pain scale.
- ⦿ Ask for changes in treatments if your pain persists.
- ⦿ Compassionate and sympathetic care.
- ⦿ Receive pain medication on a timely basis.
- ⦿ Seek a second opinion or request a pain care specialist.
- ⦿ Your records upon request.
- ⦿ Include family in decision making.
- ⦿ Remind those who care for you that pain management is part of your diagnostic, medical, or surgical care.

Jane Cowles, Ph.D., reprinted with permission from *Pain Relief, How to Say No to Acute, Chronic, & Cancer Pain!*, Copyright 1992. They can be found on page 57 of her book.

What's in a name?

An important part of becoming involved in every aspect of your recovery is how you define yourself. Are you a “pain patient,” a “chronic fatigue person,” a “bad back,” or are you simply someone with a pain problem? Do you see yourself in terms of your pain? Or have you been able to keep your identity in spite of the pain?

If you are to be actively involved and make progress, the way you look at yourself can make a difference in your progress. The term “pain patient” is such a negative term. It sounds hopeless, and it can prevent you from adopting a positive attitude. Think about it, how would you feel about a person who introduced him or herself as a “pain patient” or “headache sufferer?” Your first inclination might be to turn and run the other way.

You will see that throughout the literature of the American Chronic Pain Association that our goal is to help you make the transition from a patient to person. There is something very positive about that statement. Be mindful of how you refer to yourself. You are a person!

To Review:

Involvement with your own recovery is absolutely necessary if you are to have any hope for a better tomorrow. You, the person with pain, must become and remain an active member of the treatment team. You need to become a well-informed consumer about your health problem.

At the end of this kit a resource list is provided on a wide variety of organizations. Their purpose is to answer specific questions you may have about your specific pain problem. Many of them have booklets and/or active Websites to help you with understanding and managing what to expect as well as how to approach your particular pain condition.

What you can do to get involved in your own recovery

- ❖ Learn as much as you can about your particular problem.
- ❖ Keep a line of communications open with your healthcare providers.
- ❖ Let your healthcare team know that you will be working with them to improve the quality of your life.
- ❖ Seek out all the information you can about your condition. The Internet is a good place to begin. If you do not have access to the Internet, your public library can provide access as well as a wealth of printed information.
- ❖ Get involved in a peer support group like the American Chronic Pain Association. There are also many self-help groups geared toward specific health care problems.
- ❖ Try to maintain an active role in your family life even if you cannot fulfill the role you had before. Your family can provide you with needed support.
- ❖ Find a doctor that you are comfortable with and follow his or her advice.
- ❖ Ask questions about things you do not understand.
- ❖ Don't be afraid to obtain a second or even a third opinion when it comes to surgery or other invasive procedures.

Health Resources

Academy for Guided Imagery

P.O. Box 2070
Mill Valley, CA 94942
800-726-2070

ACHE Headache Support Group

875 Kings Highway
Suite 200
Woodbury, NJ 08096-3172
(609) 423-0043

American Academy of Neurology

1080 Montreal Avenue
St. Paul, MN 55116-2325
(651) 695-1940

American Council for Headache Education

875 Kings Highway, Suite 200
Woodbury, NJ 08096
(800)255-2243
*about 45 support groups, will
provide list of AASH physicians in
area*

American Diabetes Association

1660 Duke Street
Alexandria, VA 22314
800-ADA-DISC
800-232-3472

American Foundation for Urologic Disease Prostate Cancer Overactive Bladder Hotline

1128 N. Charles Street
Baltimore, MD 21201-5559
410-468-1800
written information, support groups

The Amyotrophic Sclerosis Association

21021 Ventura Blvd. Suite 321
Woodland Hills, CA 91364
800-782-4747

Ankylosing Spondylitis Association

511 North La Cienega Blvd., #216
Los Angeles, CA 90048
(800) 777-8189

Arachnoiditis Support Group

Valerie Kruser
W 265 N 2094 Sawgrass Lane
Pewaukee, WI 53072
(262) 695-3334 or (262) 695-3341
EMAIL: CAMTech@pitnet.net

Arthritis Foundation

P.O. Box 19000
Atlanta, GA 30326
(800) 283-7800

National Alliance for Breast Cancer Org.

9 East 37th Street, 10th Floor
New York, NY 10016
1-212-889-0606
*written material and over 300
support groups*

Y-ME org. For breast Cancer

212 W. Van Vuren, 4th Floor
Chicago, IL 60607
312-986-8338 OR 1-800-221-2141

Susan G. Komen Breast Cancer Found.

5005 LBJ Freeway Suite 370
Dallas, TX 75244
1-800-462-9273 OR 1-972-855-1600

written material, support groups

Cancer Care

1180 Avenue of the Americas
New York, NY 100365
212-221-3300 OR 1-800-813-4673

written material, telephone support groups, will locate other community services in area

Candlelighters Childhood Cancer Foundation

7910 Woodmont Ave, Suite 460
Bethesda, MD 20814
301-657-8401 OR 1-800-366-2223

written material over 400 support groups and contacts for family members

CARE

The Rehabilitation Accred. Comm
4891 East Grant Road
Tucson, AZ 85712
520-325-1044

Carpal Tunnel Syndrome, ARMS

P.O. Box 471973
Aurora, CO 80047-1973
303-369-0803
www.certifiedpst.com/arm

Chronic Fatigue Syndrome (CFIDS)

P.O. Box 220396
Charlotte, NC 28222-0398
(800)442-3437

Crohn's and Colitis Foundation

444 Park Avenue South
New York, NY 10018
(800) 932-2423

**Crohn's Research Organization
Hoping for needed Support**

C/O Penny Graham
7708 Braun Avenue
La Vista, NE 68128
402-339-3254
402-427-7274

**National Foundation for
Depressive Illness, Inc.**

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

Fibromyalgia Network

P.O. Box 31750
Tucson, AZ 85751-1750
(520)290-5508
800-853-2929

**Huntington's Disease Society of
America**

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

Int'l Endometriosis Association

8585 N. 76th Place
Milwaukee, WI 53223
(800) 992-3636
(414) 355-2200

Interstitial Cystitis Association

P.O. Box 1553
Madison Square Station
New York, NY 10159
(800) 435-7422

**Lupus Foundation of America,
Inc**

4 Research Place, # 180
Rockville, MD 2080-50-3226
(800) 558-0121

Information Line on Lupus

1717 Massachusetts Avenue, NW,
Suite 203
Washington, DC 20036
800-558-0121

**National Brain Injury
Association**

1140 Connecticut Avenue
Suite 812
Washington, DC 20039
800-444-NHIF
800-444-6443

National Chronic Pain Outreach

P.O. Box 274
Millboro, VA 24460
(540) 862-9437

**National Coalition for Cancer
Survivorship**

1010 Wayne Ave. NW, 5th Floor
Silver Spring, MD 20910
*written materials and will refer to
support group nationwide*

National Headache Foundation

428 West St. James Place
2nd Floor
Chicago, IL 60614-2750
(888) 643-5552
www.headaches.org

National Institute of Health

www.nih.gov
Bethesda, MD 20892
(301)496-4000

**National Multiple Sclerosis
Society**

733 3rd Avenue
New York, NY 10017-3288
1-800-344-4867
*written material, support groups,
physician referral through local
chapters*

**National Osteoporosis
Foundation**

1150 17th Street NW, # 500
Washington, DC 20036-4603
(202) 223-2226

Peripheral Neuropathy

P.O. Box 2055 Lennox Hill Station
New York, NY 10021
800-247-6968

Phantom Pain

information and referrals
(410) 614-2010

**Restless Leg Syndrome
Foundation, Inc.**

4410 - 19th Street, NW
Suite 201
Rochester, MN 55901-6624

**Reflex Sympathy Dystrophy
Complex Regional Pain
Syndrome**

116 Haddon Avenue
#D
Haddonfield, NJ 08033
(609) 795-8845

**Sickle Cell Disease Assoc. Of
Amer, Inc.**

200 Corporate Pointe, Suite 495
Culver City, CA 90230-7633
1-800-421-8453
*Has written materials, will provide
physician in area*

Spondylitis Association
511 North La Cienega Blvd. Suite
216
Los Angeles, CA 90048
800-777-8189

TMJ Association, Ltd.
5418 W. Washington Blvd.
Milwaukee, WI 53213
414-259-3223
*Has written material, support
groups, no physician referrals*

Thoracic Outlet Syndrome
www.tos-syndrome.com
Book: Thoracic Outlet Syndrome:
A Common Sequela of Neck
Injuries, Richard J. Sanders, M.D.
& Craig Haug, M.D., Lippincott
CO., Philadelphia, PA 1991.

Trigeminal Neuralgia Assoc.
P.O. Box 340
603 Broadway
Barnegat Light, NJ 08006
(609) 361-1014

**National Office Patient
Information**
(904) 779-0333

**United Scleroderma Foundation,
Inc.**

P.O. Box 350
Watsonville, CA 95077-0350

Vulvar Pain Foundation

P.O. Drawer 177
Graham, NC 27253
336-226-0704
*prefer written requests and \$2 for
S&H*

VZV Research Foundation

VZV Information Hotline

Shingles & PHN

40 East 72 Street
New York, NY 10021
(212) 472-7148
Fax (212) 861-7033
800-472-8478



The above list of resources was compiled in late 1999. It is not unusual for these types of agencies to change locations, phone number or even discontinue offering services. If you are unable to contact a resource you can check with your local United Way Agency for current information.

Below is space to add your own personal resources for easy reference.

My list of resources:

Organization: _____

Address: _____

Phone Number: _____

Contact Person: _____

Hours of Operation: _____

Services Provided: _____

Organization: _____

Address: _____

Phone Number: _____

Contact Person: _____

Hours of Operation: _____

Services Provided: _____

Organization: _____

Address: _____

Phone Number: _____

Contact Person: _____

Hours of Operation: _____

Services Provided: _____

Organization: _____

Address: _____

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Services Provided: _____

Organization: _____

Address: _____

Phone Number: _____

Contact Person: _____

Hours of Operation: _____

Services Provided: _____
