



American Chronic Pain Association Kits for Wellness

Understanding Chronic Pain At the time of diagnosis



Kit One

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Introduction

Welcome to the American Chronic Pain Association kits for wellness. The purpose of these kits is to provide skills and techniques which will help and guide each of us to a greater understanding of how we might live full lives in spite of chronic pain. Join us as we travel the highways and byways of coping with chronic pain. We'll discover that life doesn't have to stop because of pain. Throughout the many kits we'll learn coping skills, understand our role in recovery and hear from others like us who live with daily pain.

Each kit has been designed to be added to a binder one kit at a time. As each kit is completed, the next kit can be ordered and put into the binder. This allows each person to work at his or her own pace and choose the kits they feel most important to their recovery.



Take time working each kit as each of us gains insight to how we might begin to make a slow, but progressive journey from the role of a patient to that of a functioning person. If at any time throughout this manual you have questions please contact the National Office of the American Chronic Pain Association at 916-632-0922 or E-mail at: ACPA@pacbell.net.

Now let us begin our journey from patient to person.



Understanding Chronic Pain At the Time of Diagnosis



When we become ill the first thing that we do is visit our doctor or nurse practitioner. Expectations are usually positive that a cause and cure will be made available to us. With all the advances in medicine today we expect our pain and suffering to be quickly and effectively treated. A headache that never goes away, a back that hurts no matter what we do, or any other pain that simply will not stop is unacceptable by today's standards. Yet for more than 86 million Americans, daily pain is a reality. It is called chronic pain and it can destroy lives if not treated.

If you're reading this you know what is involved in the search for pain relief. We realize that there may be a certain level of pain that we must live with. But we find it very difficult to believe that there is nothing that can relieve our suffering. Much of our efforts are spent looking for the right doctor, the next surgery, the right combination of medications or other forms of therapy to relieve pain. Our search may last for years.

The realization that we may have pain for the rest of our lives is a difficult one to face. That's when we need to become involved in our recoveries. To help with the first step in moving from a patient to a person, let's look at how to start our journey toward accepting pain.

What is chronic pain?

Chronic pain is defined as any pain that lasts longer than six months. Receiving the best medical care may still not alleviate chronic pain. It is difficult to accept that medicine has limits given the incredible advances that have been made in recent years. Yet there are still many health problems that conventional medicine cannot completely "heal." It is not a lack of caring on the part of health care providers; rather limits on what's known that may prevent complete elimination of pain. However, ACPA's step-by-step program will help in attaining a better quality of life, in spite of your chronic pain.

Who is responsible for recovery?



Our past experiences with illness have taught us that when we're sick, a visit to the doctor who prescribes the right combination of medicines and therapy gets us back on our feet. Recovery from chronic pain isn't so easy. Some who live with chronic pain would argue that recovery is an inappropriate term when discussing chronic pain. Perhaps we should look at recovery more as stages of healing.

Healing is what the individual who is ill brings to the curing process. *Jim Downs, The Book of Positive Qualities*

Healing is whole-making; we search for something lacking that will bring us back to balance and wholeness. *Marti Lynn Matthews, Pain The Challenge and The Gift*

Healing

The descriptions of healing above suggest that there can indeed be healing even though there may be ongoing pain. Healing can be within our ability to allow. In spite of the many emotions created by chronic pain—anger, guilt, fear, worry, despair, abandonment—however even though we have to deal with the wide range of emotions, healing can take place. Chronic pain is not entirely hopeless. It is within our power to have some hope for an improved quality of life on the journey which lies ahead. Know that the path of healing is filled with others who have made the same journey. They are there to help the novice to see the light at the end of the tunnel. All that is required of us is that we hold fast to the belief that there are others who can help us. They have walked in our shoes.



Acceptance

It is with the ACPA's first step, acceptance, that healing begins.

The American Heritage Dictionary of the English Language defines **acceptance** is defined as (1) the act or process of accepting (2) the state or condition of being accepted or acceptable (3) favorable reception; approval (4) belief in something; agreement; assent.

There are a million reasons we can think of to prevent acceptance of the pain. After all, why should we have to live with pain when medicine can give a person a new heart? Unfortunately, medicine is not logical nor does it follow clear-cut guidelines. Each person is different, individual bodies react differently, and what may have helped one person is ineffective for another.



Many people fear that accepting the pain means giving up the search for a way to reduce their pain. They fear that it means giving into a life filled with nothing but pain. This is not so. Accepting the pain means realizing that we've had all the tests, treatments, and therapies available and that there's still a certain level of pain. Some of us may know why we have pain. Unfortunately, for others the

cause of pain is still unknown.

To begin the healing process, the person with pain must be involved. We need to learn as much as we can. We need to continue doing everything we can to reduce our sense of suffering. Accepting the pain means that we are willing to try our best to get to a place where we can "live" with the pain.

One of the ACPA's support group members gives this advice:

What would I say to someone who just found out they have chronic pain?

That living with chronic pain is not easy, but it does get easier over time. That particularly now it will seem as if your whole world is turned upside down and that is very hard. It's important to have hope, because things will get better. You learn to do things differently. You approach life differently in order to find happiness and peace in life again.



I would also recommend that to educate yourself as much as possible, you connect with two types of organizations. One, the ACPA (of course), and the second one disease-specific so that you can keep up with the research regarding your own situation and make your visits with health care people more helpful for everyone. It is important to be open to a lot of facets of treatment, and to try different methods without it totally becoming the only part of your world. Nothing in itself will likely rid you of chronic pain, but many things in conjunction with one another can help lessen symptoms, and improve life quality. I would explain some of the things that worked for me, but emphasize that what works for one may not be best for someone else. It is important to be open to different ways of approaching the chronic pain in ones' life.

Chronic pain may be with you for the rest of your life, but it doesn't have to be chronic hardship and misery. Time is a big healer.

ACPA member

It is important to maintain open communication with our doctor to ensure that we understand what treatments are available, what to expect from such treatments, and our role in the treatment process. Accepting our pain doesn't mean stopping all medical treatments or giving up hope of being pain-free some day. Anything is possible. In the meantime, it is important to accept the pain for today and become an active member of the treatment team.

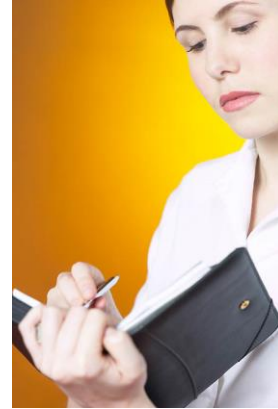


Another ACPA member shares these thoughts:

The most important thing for me was to find out that there isn't a magical cure. And that it was not me that was the problem. For so long, I felt as though I must be doing something wrong to have had this happen to me. I felt as though if I could just find that one thing to change, I would be magically cured and be well again. I still find myself thinking this way sometimes, unfortunately. There is a fine line between healthy self-evaluation and acceptance of the pain.

I wish I had also had more confidence in myself in terms of what is best for me. Over the years, I listened to so much advice and spent so much time and money trying everything everyone suggested.

*Jan Widdowson
Petaluma, CA*



Things we might do to ensure we're involved as part of the treatment team at the time of diagnosis:

- talk with the doctor about what he or she believes is the cause of the pain
- obtain as much information as possible about the cause and known treatments for our pain problem
- inquire about resources that would provide additional peer support and consumer-oriented information
- ask for a clear guide to what limits should be followed given the circumstances and then follow them
- discuss possible exercise programs with the doctor
- ask questions when we're not sure of what our doctor or other health care provider told us
- have regular check-ups



The American Heritage Dictionary of the English Language defines **validation** as (1) to declare or make legally valid (2) to mark with an indication of official sanction (3) to substantiate; verify.

Validation:

I had to stop and ask myself what would have helped me in the beginning of my journey from patient to person. What could my doctor have said to help me? After giving it a great deal of thought I realized that the most helpful thing would have been for him to simply say, “I believe you.”

It is important from the beginning to feel validated. If you’ve been looking for months, perhaps years for a way to eliminate the pain, you will understand. It is essential to know that we’re believed. Families and friends can be as skeptical about our pain as some health care providers and employers.. After all, our level of functioning varies greatly from day to day. One day we are a “normal” person, then for the next three days we can’t seem to get out of bed. Such behavior would be confusing to anyone. But wouldn’t it be nice to not have to justify ourselves daily, to simply be believed?



Well, guess what? I believe you. Why else would you be reading this if you did not have pain?



An ACPA member writes:

When the doctor first told me I was going to have chronic pain foreeeeeeever, I was devastated. I went through a grieving period where I was alternately angry, sad, stunned, lost, or in denial. But, since that time, I have found many helpful tools which lessen the pain and allow me to live a full life. It may not be the life I expected, but I am satisfied with it (most of the time!).

I realize that I need the support of other people. Although close friends and family members have the best of intentions, no one can understand what I am going through like another person with chronic pain. It was such a relief to find kindred spirits who really understood how I felt emotionally and who had experienced some of the same fears, losses, and frustrations as I. These are the people who helped me to laugh again and to grow spiritually.



If you have been recently diagnosed with chronic pain, or if you have reached a seemingly endless plateau, I pray that you will not judge all of your tomorrows by the way you feel today. We all have more courage than we think, and I hope you will use that courage to keep knocking on doors until you find the one that is there just for you.

*Tanya Hanton
Santa Cruz, CA*

Pain is invisible. No one can see or feel our pain. If only we could hold our pain in our hand for everyone to see, it would not be necessary to describe the pain to others. We can't. Attempts to convey to our family, co-workers, friends or our health care provider the magnitude of pain are often inadequate. We may find that we spend a lot of time thinking of ways to explain the degree of suffering we endure daily. No matter how creative or imaginative we might be, nothing works. We're the only one who can feel our pain.

If our pain has been given a name (diagnosis) it might make us feel that people in our lives will understand. Perhaps they will finally comprehend the way pain interferes with our life. Maybe not. For those who don't even know the reason for their pain, it can be very difficult to make the people in their life understand. It's difficult to make them understand even with a diagnosis.



I remember that I used to say that if only I knew what was causing my pain I would be able to handle it. I realize that wasn't true. My sense was that if the doctor knew what



was causing my pain, then he should be able to fix it. Chronic pain is not logical and follows no predetermined path. Chronic pain simply consumes our life and steals our hopes for tomorrow if we allow it. There may never be a way to have everyone in our life understand or even support our efforts. Believing in ourselves and regaining control is all that we really need to begin our journey from patient to person.

Thoughts of an ACPA member:

I think one of the biggest hurdles I had to get myself over was this thing called “acceptance.” For me that doesn’t mean that this is necessarily going to go on forever and resigning myself to my “fate.” It does mean, however, that I have to accept where I am in this moment, for today only. By breaking time down in this way, I am much better able to cope with whatever is going on. I am better able to manage the daily things or ask for the help I need to get through this minute, this hour, this day. And, believe me, I don’t always do it gracefully! “Gracefully” often goes out the window when my pain level exceeds my threshold of patience and tolerance. Asking for help and support has never been one of my strong suits.



I don’t view the pain as “the enemy” any more. If I were to hate and reject it, then I would be hating and rejecting a part of myself. If pain becomes the enemy, then so do I, and I can ill afford to be at war with myself. I am not my body, but my body—for better or worse—is part of me. I can’t change that fact any more than I can change the color of my skin or my age. And, so, I accept even the parts of me that ache and burn and betray me at the most inopportune times.

Lois Randall
ACPA Member



Pain is not something anyone welcomes into his or her life. None of us is immune. Pain does not single out bad people. Pain does not choose people according to age or gender; it simply happens to anyone at any time in his or her life. For those harboring guilt about their pain, there is an excellent book that might help to better understand that you are not “deserving” of your pain, rather it simply happened. *When Bad Things Happen To Good People*¹ can provide some insight into why things happen, and answer many of our questions about “why me.”

Conclusion

Chronic pain can take away our identity, hopes, family and friends, and even our ability to work. Pain changes everything in our lives. Pain forces us to rethink many areas of our life; career, family, retirement, social life, and much more. Accepting the pain and all the problems that the pain creates will be the most difficult step in pain management. Know that the American Chronic Pain Association is here to help. Contact the National Office for a local ACPA chapter. If there is not one, think about getting one started. The ACPA can help. Interacting with peers can help. As we begin our journey from patient to person why not take along others who understand, who have walked in our shoes?



The ACPA will provide each person with tools to begin the long and difficult journey. It is up to each one of us to begin the journey knowing that we are not alone. We, all the people involved in the ACPA, are walking beside each other.

¹ Kushner, Harold S., *When Bad Things Happen To Good People*, Avon Books, New York, NY, 1981.



There are additional sections available which address a variety of issues common to chronic pain. The Ten Steps From Patient to Person are also available in individual sections. All inquirers can be directed to the ACPA.

For more information you can contact the:

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