

## **American Chronic Pain Association**

### **ProActive Communication Kit**

Welcome to the ProActive Communication Kit, a program designed to help health care providers who are working with people who have chronic pain. It is presented by the American Chronic Pain Association and is supported by an educational grant from TEVA Pharmaceuticals.

Since 1980 the American Chronic Pain Association's mission has been to facilitate peer support and education for individuals who are living with chronic pain, as well as their families, so that they can live fuller lives in spite of their pain, but it's also very important to us to raise awareness among health care providers, policy makers and the public at large to better understand all of the issues surrounding chronic pain.

The key to what the American Chronic Pain Association provides to a person with pain is that you are not alone. You are not the only person in the world who is living with a chronic pain problem and more importantly you can live a full life in spite of your pain and hope for a better tomorrow.

Just for a minute, let's just take a look at what chronic pain is. As you all know—it's a pain that lasts longer than 3 months, it can go on for months or years due to a chronic condition, and it really has an impact on one's ability to function and the quality of life. But what's really interesting about it and makes it so confusing, not only for the person with pain – but for all those around them, is that pain waxes and wanes – you'll have good days and bad days. And it makes it really confusing never knowing when the pain is going to hit – how well they're going to be able to function.

Pain is the number one cause of disability in the country. According to the Institute of Medicine's Report on the Relieving Pain in America, it's estimated that there are 100 million people are living with some form of pain – that's 1 out of every 3 people.

The cost of pain is enormous. It's over \$600 billion dollars in lost working days, medical expenses and other benefits. That's more than heart disease, diabetes and cancer put together.

Chronic Pain is what takes an active functioning person and changes them into a patient who is looking to their healthcare providers to fix them, so that they can come back to their everyday life.

The American Chronic Pain Association tries to take that passive patient looking to their health care providers to fix them and make them an active part of the treatment team so that they can become a person again.

We've all come to look to the medical community to fix us and they can perform amazing miracles today – they can give us new hearts, new lungs, new livers. So our expectation is that all we need is that one thing to fix our pain to make it go away and become an active person again. Unfortunately we get stuck in a complex maze, going from one health care provider to the next, looking for that one simple answer to take away the pain.

What you have to keep in mind about chronic pain is that it's invisible – you can't see it, you can't measure it, you can't taste it, you can't smell it. There's no way to validate the person's report of pain. And quite often what we're told is to simply learn to live with it and this is what it looks like ... it's an impossible task. And what makes it even more difficult is that as we sit there and listening to our health care providers we're not always understanding what they're telling us and we're really afraid to ask them – so we sit there and we shake our head. And when we leave the appointment not really having a good comprehension of what we were told and what we should do. One of the things that the ACPA has been working very hard on lately is to change that very complex formula into something so simple as  $1 + 1 = 2$  – everyone understands that it doesn't matter how intense your pain is –  $1 + 1$  is very easy to understand.

The goal of pain management is to improve the quality of your life, increase function and reduce your sense of suffering. But the key to all of this is communication with your health care provider. When you don't have that communication, when your patient isn't understanding what you're saying, quite often they become non-compliant.

In order to help that person move from the passive patient back to an active participant, you have to see them as part of the treatment team. We have to work together as a team and our goal is managing our pain.

ACPA provides a number of communication tools that are easy to understand, they're informative, and they're efficient to be used. All of these tools that I'm going to be talking about are on our webpage, they're free, all you have to do is print them out or you can download them directly into your medical records. Let's take a look at some of these medical tools.

Our first tool is preparing for your healthcare visit. It asks you what's changed since the last time, what they've tried, has it helped, has it not, and most importantly, any questions they may have. On the other side of this sheet we're asking them to list things like their prescription drugs, their over-the-counters, their herbal supplements, and their vitamins. And they can actually rate them whether they're better, the same, not sure, or worse. And that goes for things that they've tried and also any changes in their mood, their appetite, and their sleep.

There's also a sheet on having them rate their daily activities, things like driving, walking, cooking, sleeping, and they can let you know how difficult they are for them to do. What you might want to give to your patients is something called a "Med Card." And this allows them to keep track of all their medications that you've prescribed for them, and it can fold up, it's a little card, and it simply fits in their wallet. That way, when they go to the pharmacist, maybe to buy over-the-counter medications, and they're not sure how it's going to interact with their prescription drug, they can pull it out and ask the pharmacist.

One of the hardest things is when you ask a person what's their pain level on a scale of 0-10, what does that number really mean when 0 is no pain and 10 is the worst pain possible? If I say it's a 5, what does that mean to you? Your 5 and my 5 can be completely different.

What's really important is--what is their level of functioning? How is their pain impacting their life? So we've developed what we call our Quality of Life Scale. The scale is reversed, 0 meaning they can't even get out of bed, all the way up to 10 where they function where they never even had any pain. And in-between that are all of the numbers, but it describes exactly what they can do. That way, when they tell you they're a 4, you know exactly how pain is impacting their life.

One of the most important things for a person with pain is to have that pain believed, to have it validated. Often they will go on and on, keep in mind you will have 5-10 minutes for this visit so we have to use it efficiently. Instead of them trying to describe everything that's going on in their life, and explain their pain, we've created several tools.

One of them is called the "Fibro Log." On this tool it's all graphical; first of all we're going to measure their pain. Then, let's look at these other things, we can measure where their pain is, the intensity, the quality of their life, their function, their sleep, their movement in the morning, their fatigue, all they need to do is circle each of these items and then hand it to you. What that allows you to do is quickly at a glance look at their pain level, perhaps how it's changed since their last visit, but then you can begin to connect the dots on things that may have changed, things that contributed to their pain levels. They're not sleeping right, they're not eating right, maybe they're not exercising, or their fear of pain has greatly increased.

The nice thing about this tool is it's now available online. This tool, you need to create a log-in, it's a secure site. Once they create a log-in they can go in every day and track each of their different measures. The nice thing about this is when they come to your office, if you have a computer available to them, they can log-in and print it out right there or simply download it into your medical records.

On the first screen they see they can actually get help, they can click on "Help" and a drop-down box will explain how to use the tool. But simply, all they need to do is click on where they're at in their pain level, click "OK," and it'll go to the next screen.

The nice thing about this tool is every time they come back from day-to-day, it'll show them where they were before, and then it'll highlight where they are today. Click "OK," go onto the next one, you see they can go through each of these where their pain is, the intensity of it, quality of life, and at the end of all of those 18 measures what they do is click "Save." Then, they can simply print it out they can choose 1 month, 3 months, 6 months, a year, or all time, and hit the "Print" button. And again, they can do this in your office when they log in.

This is what you'll see; you'll see a graph of each of those measures. You will again be able to have a conversation with them pointing out where they may need to focus their attention.

Another really nice tool, and this one is for Fibromyalgia, we have another one for Diabetic Peripheral Myopath—on this one they can choose "man" or "woman," and then they go to a screen and it's going to give a picture of a person, front-view and back-view.

All they have to do is click where their pain is. There'll be a drop-down box, and they can click a number of different sensations. They click how it feels, whether it's a deep, intense aching, and then the level of pain, the intensity of it. Click the little close bar, the icons stay on top, they can click it to the back, do the same thing; where the pain is, how it feels, the intensity of the pain. Then they hit the print button, and again, here is a picture of all of exactly how their pain is, where it is, how it feels, the intensity of the pain.

Imagine how long this would take them to explain this to you, and here it is, captured. A picture's worth a thousand words.

We also have one called our "Pain Log" for general pain. We measure our pain levels, but again, we have all our different levels, the measure of stress, their exercise, activity, sleep.

A couple ones I'd like to point out to you are "taking medications as prescribed," "their side effects," "constipation," and their sexual activity. Especially the constipation and sexual activity, people rarely are going to volunteer that kind of information, and this allows you to begin to focus on some of these issues that may have an impact on their pain score.

Again, this is also available online, they can go in on a daily basis and print it out just like the Fibromyalgia Log, or you can have them do it in your office and download it directly to your medical records.

When the patient is sitting in front of their healthcare provider, quite often it's hard to comprehend everything that they're telling us and remember everything that they've told us. So, what we've designed is called a "Follow-up Sheet." This tool is to remind them of all of the things that you told them: the tests that you recommended, the treatments, when is their next appointment, restrictions, their dietary restrictions, and then their recommendations.

When our healthcare provider provides us with a prescription, we look at it, they ask us if we have any questions, we say no, we go to the pharmacist, they fill it, we pick it up, ask if we have any questions, we say no we don't, and then we take it home.

Then we look at it. Now I know that the FDA said that all of the inserts have to be at the fifth-grade reading level, that doesn't always happen. It's very confusing but it's so important for someone to take their medications as prescribed. So, we've developed a tool to help them with that.

On this tool, all you have to do is circle whether it's morning or night (or if it's specific times of the day you can fill in the times on the clock), with food or without, things that they should avoid, just simply circle them, things that it may cause (the side effects), and most importantly, where do you store your medication and how do you dispose of it. And just circle all of those and that way when they pull out the prescription and they look at it and they look at the card, they'll know exactly how they're supposed to take this medication...and that's a huge part of their treatment.

We've just shared some of the many tools that we have available on our website. They're free, you can use them in your practice, you can print them out, you can download them directly into your medical

records. They're there because we want to help you help that person with pain so they can make the transition from patient back to person.

What's really important for a person with pain is to understand how complex pain management is. It's never just about that one thing. To help that person understand how complex pain management is and what is involved in it, we like to use the analogy of a person with pain as like a car...except they have 4 flat tires.

Their expectation is to give me that one quick fix, that's all I need. The problem is, that only puts air in one of their tires. They still have 3 flat tires. So we have to ask ourselves, what else do we need? And for each person, it's going to be different.

It may be acupuncture, physical therapy, some counseling; it can be a number of different things. And once they have all 4 tires filled, it's their job to maintain that car on a day-to-day basis. You don't take your new car back to the dealer and say, "Fill her up, wash my windshield," that's your job. When something goes wrong, you take it back in for a check-up.

That really helps them to see that it's much more than just one simple fix. So often people have tried so many different things and nothing's worked, and that's because they put air in one tire, and then let it out, and kept putting it back in.

Chronic pain is a complex formula of a number of different modalities, and the person with pain has got to be a part of the treatment team in order for them to begin their journey from patient back to person and live a full life.

For more information, you can visit our website [www.theacpa.org](http://www.theacpa.org). We have a toll-free number, 800.533.3231.