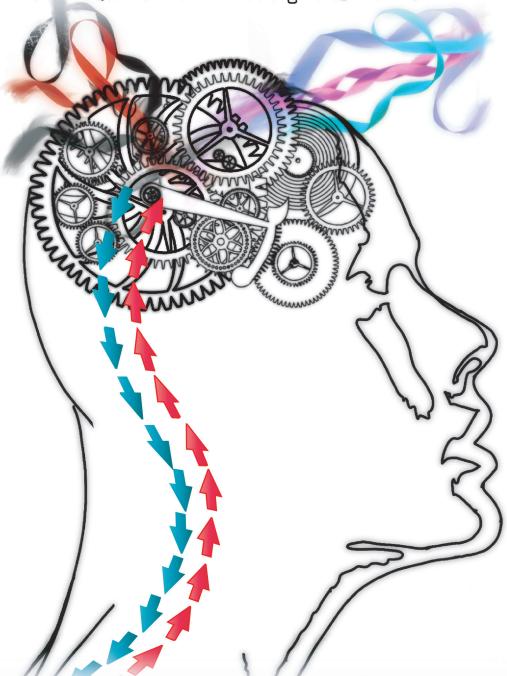
THE SMART BRAIN PAIN SYNDROME

The Primer for Teens & Young Adults in Pain



· GEORGIA WESTON, MSW· LONNIE K. ZELTZER, MD·

· Paul M. Zeltzer, MD·

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Are you in pain, feeling helpless, lonely, stressed, "out of control," sad, confused, afraid, anxious, angry, lost, tired, frustrated, different, restless, overwhelmed, hopeless ... maybe even a combination of these? YOU ARE NOT ALONE!

Your pain is real. We know that. And there are many young people out there (right now) facing similar challenges. The interesting thing is ... your pain may actually be a sign of your strengths that you can use to change your well-being.

Bright. Creative. Sensitive. Observant. Perfectionist.

Is this you? We see you. And this book can help.

There is a way out of this dark hole of pain, and it starts with YOU. This book is about understanding how your brain works and using the resources you already have (like your brain!) to help alleviate suffering.

This book alone won't make your pain go away. But, as you work with your health team it will guide you to use tools that have been proven to help smart brain people like yourself. We will show you how your own strengths and efforts will make traditional and complementary mind-body therapies work more effectively to get you where you want to be.

You are more powerful than you may think ... Start reading to learn how you can "unstick" your own pain neural loops and move on to the life you want to live!

The Smart Brain Pain Syndrome

The Primer for Teens & Young Adults in Pain

Georgia Weston, LCSW Lonnie K. Zeltzer, MD Paul M. Zeltzer, MD

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Creative Healing for Youth in Pain (CHYP)

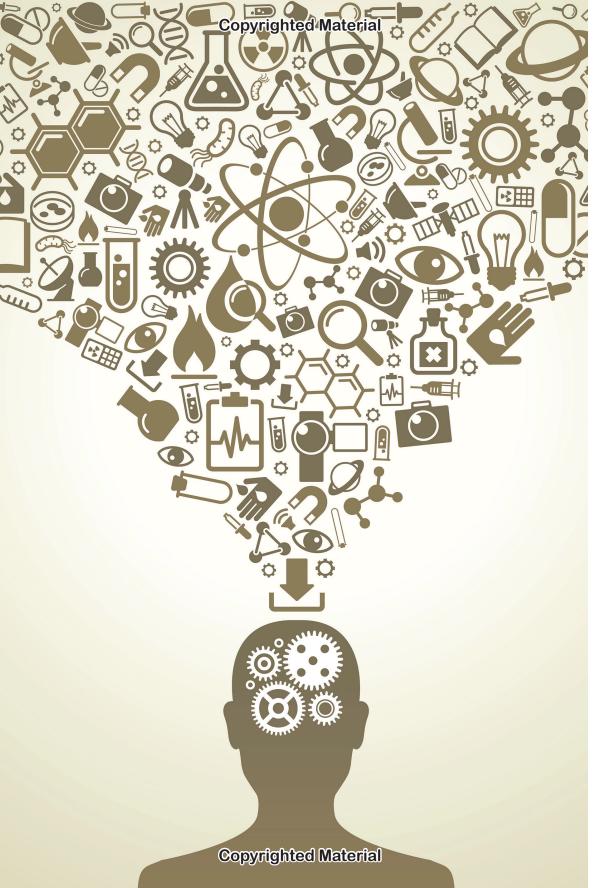
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DEDICATION

This book is dedicated to all the volunteers of Creative Healing for Youth in Pain (CHYP): past, present, and future. Your hard work, passion, and creativity are what fuel the organization and bring such powerful programs to our youth and families looking for help. Thank you for all that you do, not only for our team, but also for the community we serve together.

We give special recognition to the years of effort from Olivia, Laura, Sara, Shelley, Samantha, Liz, and Dana. CHYP would not be where it is today if it weren't for your generosity of time and spirit. We appreciate you and so do our families!



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Who are "we"?

"We" is used a lot in this book, so we want to introduce ourselves. To put it simply, we are three people working together to help children, teens, and young adults solve the mystery of chronic pain. We each stumbled into this world of childhood chronic pain from different directions, and this book is a compilation of our observations, experiences, and unique perspectives on this healing journey. We'll each tell you a bit about ourselves here, and if you want to learn more about us, look at our full bios in the back of the book.

I'm Georgia Weston, LCSW, a chronic pain survivor and advocate. I was diagnosed with chronic pain at age 14. My diagnosis came only after visiting more than 20 doctors, countless emergency rooms, and a very scary ambulance ride. Most people thought I was faking it—that I was making up the pain for attention. I even started to doubt myself and referred to it as my "fake pain." I thought I was going crazy!

The whole process was hard—harder than it had to be. But I was lucky enough to be going through it in the 21st century, in Los Angeles, with health insurance and parents who could take the time to drive me to all my appointments. I had never heard of chronic pain, and I didn't know anyone my age who had it. The journey was terrifying and difficult, and the worst part for me was feeling alone. That's why I've dedicated my life to helping others through this confusing and lonely chronic pain maze. A combination of art, Iyengar yoga, and hypnotherapy is what helped me—but creative healing means different things for each person. It is about finding what works best for you!

I'm Dr. Lonnie Zeltzer, a pediatric chronic pain physician. I've been treating children who suffer from chronic pain for more than forty

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years. Over the decades I've noticed a clear pattern in my patients. Almost everyone who walks into my office is bright, sensitive, observant ... and usually a perfectionist. My patients have creative, intellectual minds—which is a good thing, but also can be adding "fuel to the fire" when it comes to pain. The brain is a fascinating instrument that truly has a mind of its own. An explanation of how brains experience and learn from pain is the most empowering gift I can give these young people. My patients have seen multiple doctors, undergone numerous tests, and taken many medications with no end to their pain. It became clear to me that a better approach was needed.

Most physicians are <u>not</u> taught how to treat chronic pain. I've learned to encourage a "creative healing" approach involving education, non-traditional healing options, and a supportive social environment. This book is step one: *education*. You have to know and understand what is happening to both your brain and body. That takes work, and this book is a great start.

I'm Dr. Paul Zeltzer, and I found my way into the pediatric chronic pain field after decades of working with children and teens with cancer who have acute pain. I am a neuro-oncologist, educator, brain cancer researcher, author, and entrepreneur; my medical career spans 40 years. Most of my efforts had been in the field of cancer-related pain, but chronic pain is more complicated and has to be addressed in a different way. I love meeting and working with children and teens who develop resilience right before me. I find it invigorating, because once they overcome this pain *thing*, a much deeper understanding of the preciousness of health develops. These young people gain a real sense of value from their experience. It's a gratifying adventure for everyone involved ... even if you didn't want it.

This book will explain many concepts, including the bio-psycho-social model. Each topic is important, but your **focus** here is on things **you** (the reader) can control.

As a final thought, we thank you for being curious enough to read this. Being open to learning is a skill that will take you far in life. So, let your interest blossom, make your own judgements about our words, and then create your own solutions that fit into your life.

Chapter 1: The Smart Brain Pain Syndrome



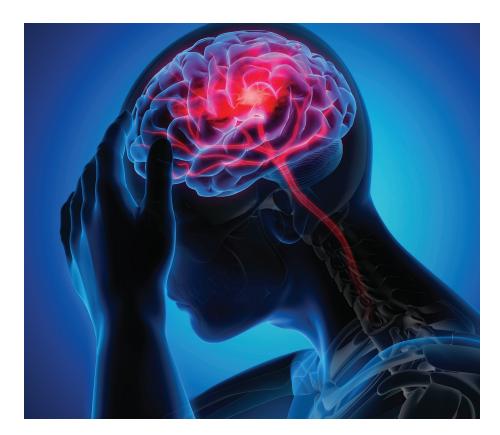
1a. Pain-How do we recognize it?

You know what it's like to feel pain. We've all had a paper cut or stubbed a toe, banged our "funny bone," or even held that hair dryer a little too close. We try to avoid it as best we can, but pain happens. It's a part of life.

Some people may wonder why we even need pain—who wants that kind of discomfort?

Well, believe it or not, from an evolutionary and survival perspective, pain *protects* us.

You may be wondering ... do we have to experience paper cuts? *Do we really need to be "protected" from paper?* Well, the simple answer is: yes.



When we get paper cuts, as tiny as they are, they damage our skin. That wound exposes us to hazards like bacteria. We don't want them inside our bodies because they can lead to infection. So, when the paper breaks through the surface of our skin, we feel pain. Our brains are reminding us to be more careful—let's not do that again.

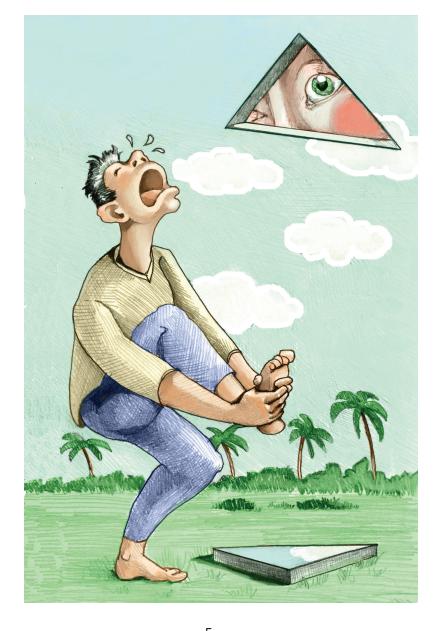
Obviously, a paper cut is a simple example, but we're just warming up here. Let's move it up a notch. Think about a time that you stubbed your toe. *It hurt*.

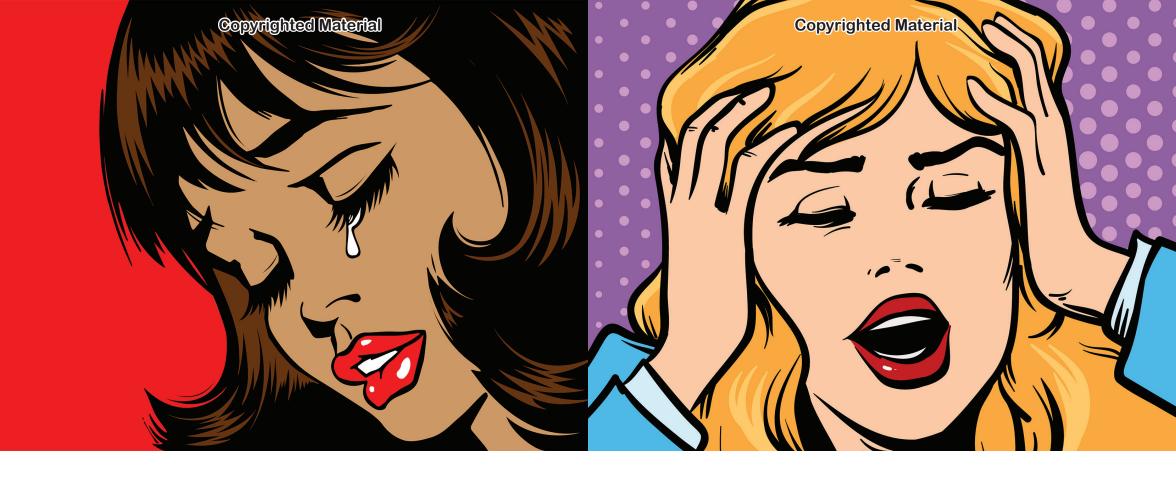
Again, the pain makes you think, "Let's not do that again." So, to avoid this same discomfort next time, your brain *learns*—walk a little slower, turn on the hallway light next time, or don't text while walking. Whichever reason your brain labels as "why" you stubbed your toe prior to the pain, it automatically makes a note that you don't want to repeat this behavior. It's a *Post-It* note in your brain—next time you'll avoid those actions and you won't stub your toe!

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Pain can get a little more complicated though. In fact, there are two types of pain: "acute" and "chronic."

The examples we gave before fall under the category of acute pain. An injury happens, it heals, and it goes away—something everyone deals with. Since we're comparing acute pain with chronic pain, let's use some more examples.





- a. <u>Acute pain</u> is our brain telling us that there's an injury or illness we need to be aware of—it's a warning.
 - i) Annie breaks her ankle playing soccer.
 - ii) She goes to see the doctor and gets an x-ray that shows her broken ankle.
 - iii) Annie gets a cast and stays off her ankle for six weeks.
 - iv) In six weeks, Annie's cast comes off.
 - v) Her injury has healed and her pain is gone.

- b. <u>Chronic pain</u> may or *may not* be our brain and body telling us there's an injury or illness. Chronic pain *stays* after the injury or illness has healed and **the pain no longer serves as a warning sign.**
 - i) Jenny breaks her ankle playing soccer.
 - ii) She goes to see the doctor and also gets an x-ray that shows her broken ankle.
 - iii) Jenny gets the same cast as Annie and stays off her ankle for six weeks.
 - iv) After six weeks, Jenny's cast comes off.
 - Her injury is healed, but she still feels pain.

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There is no more damage to either ankle—they both healed—but Jenny is now experiencing chronic pain. It comes in many different forms, and chronic pain is now recognized as a specific medical condition related to an overactive nervous system. The carpentry is fine, but the electrical system is off!

The first reaction of most doctors is to look at the ankle, because that is where Jenny experiences pain. *But*, that is not actually where the pain is—it is *occurring* in the brain. Even though it feels like there is pain in her ankle, **all pain is actually processed in the brain.** It's like a soldier with *phantom limb syndrome* insisting that his leg hurts even after it has been amputated. There's no physical leg there anymore, yet he feels pain in the limb. **That is because the part of the brain that controlled feeling in the leg is still active.**





Chronic pain is real and can last for months or years. It is more difficult to diagnose and treat than acute pain because the actual sources of pain are more complex. Whenever we experience pain, **pain receptors are activated.** They tell us we are in pain. For most people, when the injury is gone the pain receptors deactivate. That's acute pain. But, with chronic pain, the pain receptors in the brain **stay activated**—past the healing of the original pain.

How do we start to solve this puzzle? Have you ever worked on a jigsaw puzzle? Some people start picking out all the edges to make the border. Others group pieces together based on color. You may even recognize certain details from the picture on the box, so you'll have a general idea where those pieces belong.

Just like every mind approaches puzzles differently, the same can be said for the approach to pain. There is no single right or wrong way to complete a puzzle. Similarly, our brains organize some pain as "chronic" instead of "acute." So, let's think of another way to solve the puzzle. Easier said than done, we know.



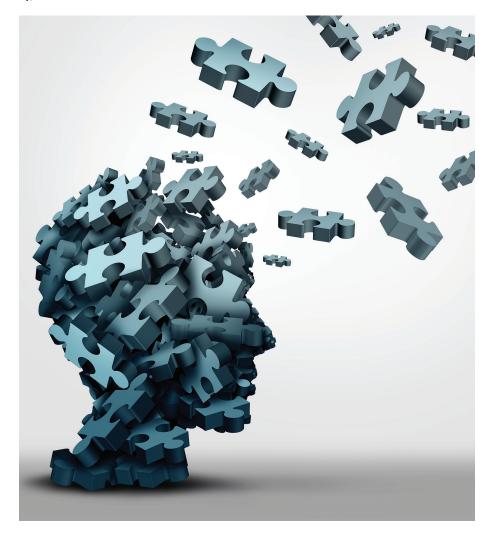
Maybe, instead of looking at the colors, you should try grouping by patterns or focus on the edges. Trying a new method means that you're already on the right path (even if you may not know it yet). Experiment with different ways to find what's right for you, because you won't know until it either works out or doesn't.

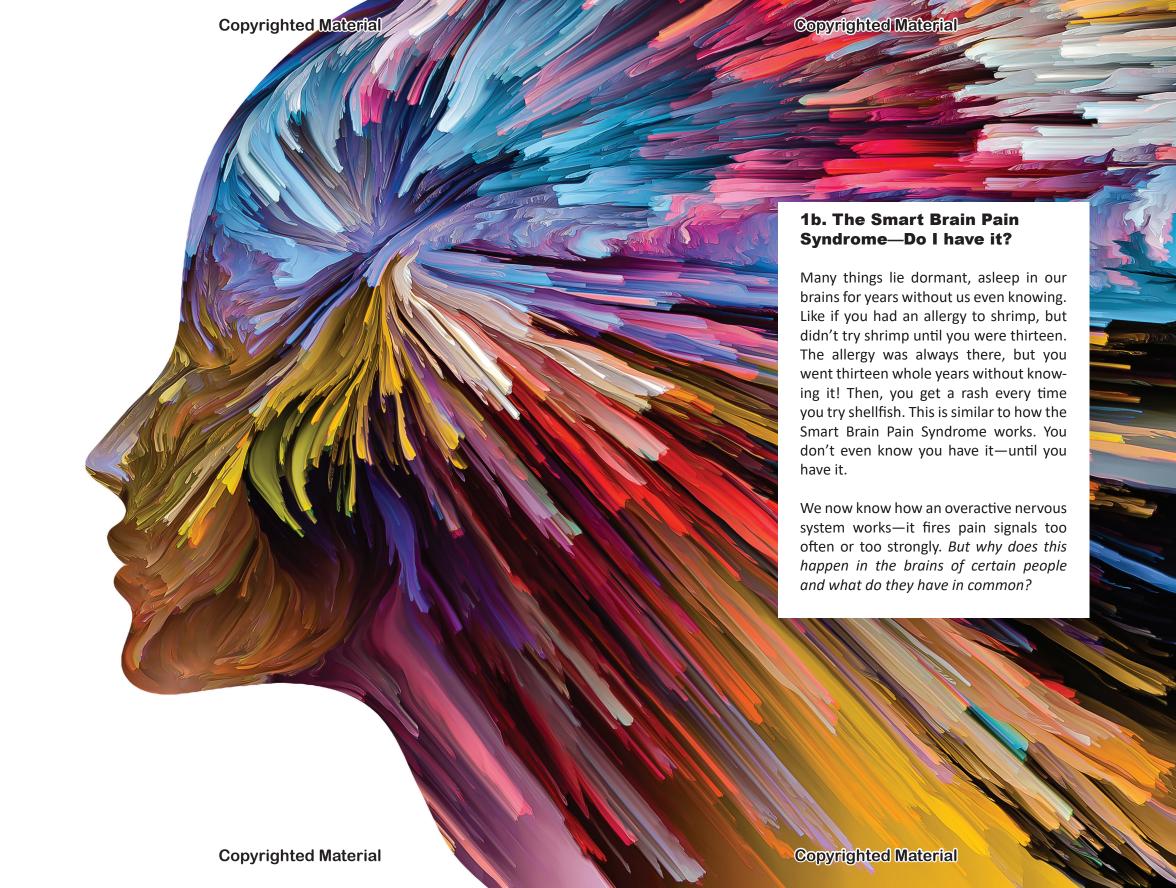
But sometimes things are misplaced. What if you lose the puzzle box and can't use it as a reference to see if you got it right? Sometimes you remember what the picture looked like; sometimes you can't.

People with chronic pain often feel lost and confused—like someone who has lost the top of their puzzle box. Their life may not have been perfect before (whatever that means), but with pain it's now more complicated than ever. In their time of need—when they really need help putting all their puzzle pieces back together—they can't find the box and can't remember where all the pieces are supposed to go. What do you do with all of the pieces?

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The entire point of a puzzle is to fit the pieces back together in exactly the same way so that it looks just like the image on the box. It's a kind of *mosaic*. (If you don't know what a mosaic is, look it up on Google—they are really cool!) Every piece is arranged to make up a great and beautiful whole. Now, since we don't have our puzzle box picture and we've got all these pieces, why don't we expand our thinking? Instead of trying to force all the pieces back in the same old way that just isn't working, why don't we create a mosaic from them—our very own, new image? This is how problem-solving becomes more than just an activity, but an art form!







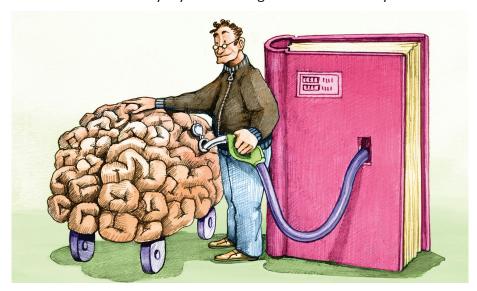
Bright ... Creative ... Sensitive ... Observant ... Perfectionist. Sound like vou?

This is true of most people with persistent pain. These are all great qualities that make you special and unique, but they also make you susceptible to chronic pain! Your brain learns so quickly and so intensely that sometimes it becomes too aware, and it gets stuck (which impacts your body)! We'll get more into the nitty-gritty of this later, but it is important to understand that even though your smart brain is complicating things, your smart brain is also your key to success.

When people have ongoing pain, they are usually stressed. Your body can start to fall apart—it's a lot to handle, day in and day out! Have you ever ridden in an older car? The car is doing its best to get you where you want to go, but it's a long way! Even though the car is driving and working, over time it's not working as efficiently. It may start leaking oil or overheating more quickly, and eventually, it may break down. Maybe it won't break down completely but, while at the beginning of your trip you got 30 miles to the gallon, now you only get 10 miles per gallon. It'll cost you a lot more to go the same distance. This is the idea behind what's going on with your body. The constant pain, tension, and stress are making it more difficult for you to get out of bed, go to

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school, and meet with friends. You may be able to keep going, but the strain can lead to everyday tasks taking a lot more out of you.



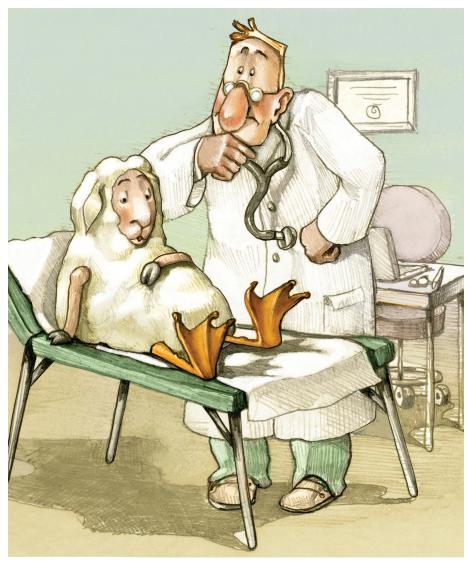
Let's look at stomachaches. What happens when your stomach hurts? You bend over and hold your tummy. If that ache doesn't go away, after a while that tension adds up. Gradually, the muscles on the outside of your belly tense up. This causes more pain, and then more tension, and even more pain. Pain + tension --> more pain + more tension ... it creates a kind of cycle.

The longer you are in pain, the more your brain is trained ("conditioned") to be in that state. When we talk about "rewiring the brain," that refers to deconditioning. You can actually decondition your brain to your pain signals through gradual exposure to things that make you feel good, instead of focusing on negative feelings like pain and stress. You have to teach your brain that your body is okay, by showing it new and better ways to respond to those triggers: pain, stress, and fear. How do we do that?

We can't know if everyone reading this book *has* Smart Brain Pain Syndrome or not; it would be impossible to say. **But regardless of a label or diagnosis, the concepts and skills that we will talk about in this book are tools that you can use for the rest of your life.** So, why not keep reading and exploring all you can about the Smart Brain Pain Syndrome?

1c. Why haven't 14 doctors been able to diagnose my pain?

Doctors are traditionally taught a "biomedical model" of care. This means they look at a bunch of your symptoms and put them together to create a "differential diagnosis" (meaning all the possible medical problems that this cluster of symptoms fits into). Sometimes they do more tests to narrow down the actual diagnosis. This is a great method for diagnosing many health issues, but chronic pain demands a very different approach that some doctors don't understand.



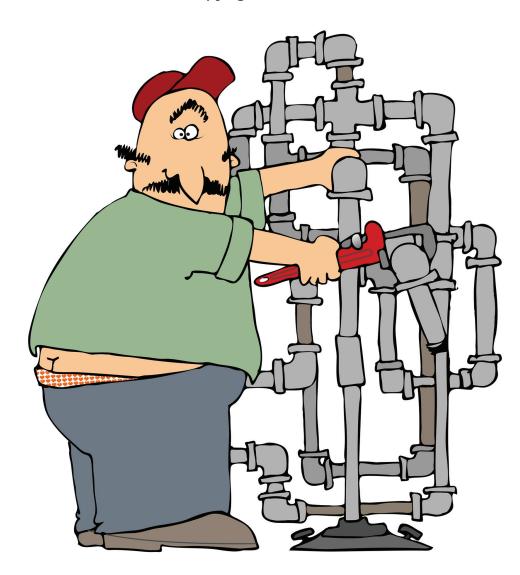
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Diagnosing and treating chronic pain is like peeling back the many layers of an onion, because you have to look at the many factors influencing the whole you. We are not simple creatures; we have a lot going on. In addition to pain, we have bothersome siblings, peer pressure, parents telling us what to do—and what NOT to do. We have homework to complete and chores to be done. We have sports, hobbies, and activities that take our time and attention. And don't even get us started on navigating friends and a social life!



If the onion represents chronic pain, every time you peel a layer it may expose another layer of issues that need to be addressed. It's not quick or easy. It takes time, and even if some doctors have an understanding of chronic pain, most of them don't have the time to peel your onion and deal with all its different elements. It's very difficult for a doctor to truly understand you in the ten minutes they are actually with you face-to-face. This is not an excuse for them—it's an explanation for why you've seen many doctors who were unsuccessful in treating your pain.



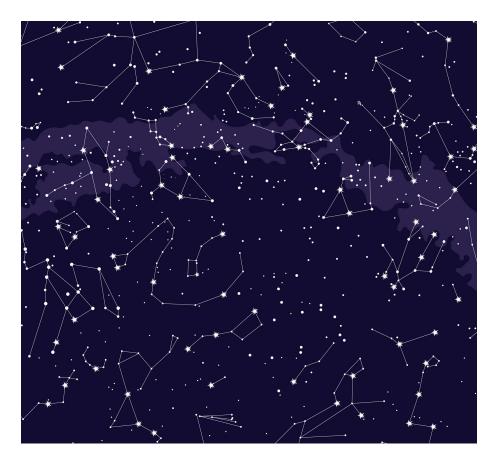
If you have stomach pain, you've probably seen at least one gastroenterologist (the "plumbers").

If you have muscular or bone pain, you may have seen an orthopedic surgeon or two (the "carpenters").

Plumbers and carpenters are great at their crafts, but they may not be what you need. Instead of just looking at the pipes and woodwork, we encourage you to explore your electrical circuits.



That's how we see our role—the "electricians" of the body. What messages are traveling through your wires? What do your circuits look like? There's more to a structure than just lumber and nails, just like there is more to a body than organs and bones.



On average, most of our patients have seen 14 doctors before they see us (the record is 42). That's a lot of waiting rooms and assessment questionnaires, a ton of repeating your story and hoping each time will be different. *The answer has to be somewhere!*

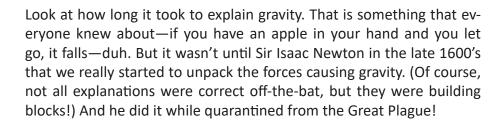
We need to order additional tests for only one out of ten patients we see. That means most of the answers have already been discovered; your history and tests just haven't been interpreted in a useful way.

Looking at the big picture (using a holistic approach) is a special type of medicine that not all doctors can do. Diagnoses are like constellations—beautifully complex and haphazard at times. You can look at a massive sky full of seemingly random stars and slowly start to connect those dots.

Chronic pain can feel like a mystery novel. There is an unsolved problem, and you have many people following clues to explain the mystery. There are wrong turns and trips down rabbit holes. It takes a good detective, whether it be Sherlock Holmes, Nancy Drew, or Scooby Doo, to notice what is obvious, hidden, or hidden-in-plainsight. The best detectives do not stop until the mystery is solved. There is an answer out there—there always is. Sometimes that involves a combination of answers, but you will know when it's right.

It will take time, but all problems have solutions—they're just not the easiest or most obvious. It is equally important to recognize that not all solutions can or need to be explained at once. This means that if it makes you feel good to sing proudly in the shower, or thoughtlessly finger-paint a "mess-terpiece," that's great! Keep that! Hold onto that action and feeling. Just because your neighbor may not appreciate you belting out tunes or your cousin disses your art, so what? It makes you feel good. Explanations, to yourself or to others, don't matter. When it's time for you or them or us to understand, we will.





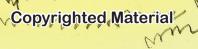
It's interesting how Newton is often described as "discovering" gravity. He didn't "discover" it—humans knew about it long before he came around. What he did was try to *explain* it. And now we have the term "gravity" when we want to describe that constant pull.

It doesn't mean that gravity didn't exist before the term was created. The scientific explanation just hadn't joined our language yet. When you experience something, like the peace you may feel sitting under an oak tree or the energy you connect with as you dance, you don't always have to label it in order to acknowledge its power. Creation of words and definitions don't change what things are, and neither will placing a label on your pain or experience.

It is horrible to feel misunderstood. How can something like gravity (or your pain) have gone unrecognized and unexplained for so long? We don't have a great answer for that, and the answer, honestly, doesn't really matter. They are both palpable forces that affect everything around them. Geniuses like Galileo, Brahe, Kepler, Newton, Einstein, and others built off each other's ideas to develop our knowledge of "gravity."

There will also be many people with ideas that you will build upon and put your own spin on until you have the explanation that is right for you. Just like what eventually happened with gravity, you will solve your own mystery in time.

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"Who knew it can be so much fun of learning about chronic pain and helping yourself to heal at the same time? The authors in this outstanding short book use humor and metaphors to talk directly to teenagers in pain (and their parents) introducing proven strategies to improve function, decrease pain and returning to normal life."

Stefan J. Friedrichsdorf, MD, FAAP, Professor in Pediatrics, University of California at San Francisco, Medical Director, Stad Center of Pediatric Pain, Palliative and Integrative Medicine, UCSF Benioff Children's Hospitals

"The Drs. Zeltzer and Ms. Weston bring years of clinical, research, and lived experience to the area of chronic pain and it is evident in this little volume. This book speaks directly to teens in a language that they can understand, filled to the brim with metaphors which aid in the understanding of this complex topic and practical ideas that are immediately usable to address it. Smart Brain Pain Syndrome uniquely emphasizes creative healing and surely will help many adolescents whose daily lives are now limited by chronic pain."

Neil L. Schechter, MD, Director, Chronic Pain Clinic, Boston Children's Hospital/Harvard Medical School, Boston, MA

"In the Smart Brain Pain Syndrome the Zeltzers and Weston take the mystery and fear out of chronic pain and replace it with vivid, playful analogies and comforting assurances that readers have the power within themselves to overcome their pain. The authors encourage readers to explore their creative resources, engage in the activities that bring them joy and foster the supportive relationships in their lives in order to "rewire" and redirect their brains and nervous systems away from their pain. Smart Brain Pain Syndrome is a hopeful and empowering introduction to successfully conquering chronic pain."

Cindy Steinberg, National Director of Policy and Advocacy, U.S. Pain Foundation