
A Simple SURVIVAL GUIDE

**For Chronic Pain and
Fibromyalgia**

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Guest Speaker
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Ontario Fibromyalgia Association

“Caring is good medicine”

– Bill Moyers –

Dr. MacDonald has devoted his career to helping people with severe and disabling forms of chronic pain and fibromyalgia. He is well-known for his caring approach, his deep understanding of how chronic pain affects people’s lives and for his work as an expert witness in court.

Dr. MacDonald has written a recent book to help people in pain, *Unbelievable Pain Control: How to Heal and Recover from Chronic Pain and Fibromyalgia*

In this book, you will learn about:

- Pain control that is truly unbelievable
- Pain control without medications
- How to get doctors and insurance companies to believe in your pain
- How to gain control of your pain and your life
- New ways to reduce the stresses caused by your pain

For more information about Dr. MacDonald and this book, please go to www.unbelievablepaincontrol.com

Thank you

Dr. Michael MacDonald - A Simple Survival Guide

I come to you today bearing gifts, messages, hope – and ideas gathered from the thousands of people I have worked with over the past 25 years. Some of these people have been world renown scientists, medical specialists, psychologists and rehabilitation professionals. But, the best ideas, the deepest inspirations, have come from the people of all walks of life, who have suffered from chronic pain and fibromyalgia. Each day, I spend hour after hour listening and learning. I owe a deep debt of gratitude to you all.

I have been trained as a psychologist, in clinical health psychology, research, and rehabilitation. In the early part of my career, I worked on a physical medicine and rehabilitation ward at St. Joseph's Hospital. Part of my work involved helping people who had suffered from serious and disabling illnesses such as strokes, and amputations caused by diabetes or trauma. The other main part of my work involved helping people who suffered from chronic or long-term pain. I learned from these individuals – every one of them (and I am still learning). I try to understand what it is like to survive and cope with long-term physical pain and physical disability. I think this experience and background helps to provide a solid foundation for the work I do each day.

There was no doubt about the serious and physical nature of the strokes and amputations that people struggled with. Everyone knew and accepted that these were conditions that rocked the very foundations of individuals and their families. No one questioned why a psychologist was working there. It was understandable that such patients might need some help in coping with how their illnesses and disabilities have affected their lives. Who wouldn't need help in this kind of medical crisis?

I wish the situation could be so straightforward for people with fibromyalgia and chronic pain. These are serious problems. People in pain need help just as much as individuals with other kinds of serious physical problems. Much more could be accomplished, if doctors, lawyers, insurance companies, families, employers, and friends would just stop questioning the basic physical nature of chronic pain and agree to provide the necessary help and support.

I am a psychologist. I have been trained to look for psychological factors that relate to a person's illness or injury. But that is not my main job. My main job is to help people move forward in their lives, to make the best out of what has happened to them, to build a new life if necessary.

I do not get distracted with a search for psychological causes. There is no point. The research has been clear. My own experience in treating thousands of patients fits with what the research tells us. Fibromyalgia and the many other forms of chronic pain are physical conditions. Real. Complex. Sometimes mild. Overpowering at times. In some cases totally disabling. Definitely not a condition anyone would chose to have, despite what some lawyers and insurance companies might think.

Today, I will draw from my early days on the physical medicine floor, and talk about a simple common sense plan for coping with chronic pain and fibromyalgia. This is not rocket science, but I believe it will be useful. It is a practical plan for coping and adapting to any long-term medical condition. Here are some simple steps.

SAFETY FIRST

Put another way, you can't even start to get better until you stop getting worse; or even better, prevent yourself from getting worse. Let me repeat this.

You can't get better until you stop getting worse.

Like any health problems, stress will make your pain worse. And when I mean worse, I mean a physical aggravation of your core symptoms: pain, weakness, fatigue, memory difficulties, poor sleep, irritable bowel symptoms etc. This kind of worsening can happen if you are hit with serious and powerful stresses - such as a major loss or threat to the well being of your family. Loss of work and related financial stresses are very big stresses, for almost anyone.

Another common threat to safety occurs when a person's insurance benefits are cut-off. If you are out of work, you may have no income coming in. This is a panic situation and your stress levels can peak - instantly. All of a sudden, you may be in danger of having your debts escalate out of control and losing your home. Your body will soak up this stress like a sponge. A major pain flare-up may be triggered. It is almost impossible to get better, or make any progress, under these conditions.

You need protection – with whatever benefits are available to you. These could be from short-term or long-term disability policies offered from your

workplace. Automobile insurance benefits should be available to victims of car crashes. You may be entitled to worker's compensation if you were injured at work. (I hope you all know that worker's compensation does recognize fibromyalgia and chronic pain as legitimate types of work-related injury). Other types of benefits may also be open to you such as government disability support plans.

To have your application for these benefits accepted, you will need to understand a very important distinction. No benefits are available to a person just because they are in pain or have a serious injury or illness. This is shocking for many people. It is true, though, not only for painful injuries, but for any medical condition.

To protect yourself, two parts are necessary for success at obtaining benefits. One is a serious impairment, meaning an illness or injury. The other is the presence of limitations related to the impairment. For example, if you are unable to work because of your chronic neck pain and are applying for benefits, you will need documentation to back up your neck injury diagnosis **and** explanations of how your injury and pain actually limit your ability to work.

Think, for a moment, of standing on the bank of a river. You are on one side and where you need to go is on the other side of the river. The waters are murky and you are not sure of how deep or dangerous the water is. You need a bridge to get you to the other side - a bridge to where you want to be.

To reach your goal of receiving benefits, you will also need a bridge - a bridge of communication. This bridge is really a way to help the decision maker understand how your illness limits your ability to work. This person, at an insurance company, for instance, needs an answer to a very important question before she can say yes to benefits for you. And she needs to have that answer documented, so that when her files are audited by the claims manager, she won't be at risk for losing her job.

The question goes like this. I believe this person has fibromyalgia (or severe migraines or multiple sclerosis, as examples). All the doctors' reports confirm this. But some people with fibromyalgia can work. I need an explanation of how this person's fibromyalgia limits them from working. To answer this question, many people try to describe how severe their symptoms are, or explain how much they are suffering. This is not really answering the question, though. It is like trying to speak louder, without offering any new information.

What is needed are details regarding the limitations caused by your fibromyalgia. This is the bridge of communication we are talking about. Some examples of limitations related to fibromyalgia are: limited walking, sitting or standing, low endurance, reduced tolerance for stress, inconsistent activity levels, etc. For some of you, a return to work may be dangerous to your health. For example, serious escalations of pain and insomnia may be triggered. Or a clinical depression may follow if you can't cope with the increased pain and stresses at work. If these circumstances are true for you, it would help for your doctors to put this in writing and send it to your insurance company, worker's compensation case worker or to your lawyer.

It is essential for you to win these battles, not just for your financial health, but also for your physical and emotional health. If even one source of major stress can be reduced, you will start to experience less pain, fewer limitations, and more life. We will return to this important issuer later. For now, though, **remember safety first.**

BE SURE ABOUT A CURE

This is a really a very obvious step and one that I'm sure you have all pursued. Who would want a diagnosis of a chronic condition of there were any other choice. I don't have to convince you of this.

Yet, it is important that you be sure, not just about your diagnosis, but also about all the symptoms involved. Fibromyalgia, for example, is a complicated condition made up of many varied symptoms. Are you sure that each symptom is actually caused by your fibromyalgia and not some independent condition?

What if you have headache pain, or insomnia, or constipation? Some of these problems seem like they may be related to your fibromyalgia. But are you sure? Is your doctor sure? Maybe they are caused by something that could be fixed: like unwanted side effects from a medication that could be changed.

When you go to your doctor, ask questions, and have them written down so she can see them. This will help the visits be more productive for both of you. Some of my patients treat their appointments like a business meeting. They have notes, even a clipboard. Some have an agenda prepared. I like that; we get a lot done this way.

There will come a time when you have asked all of your questions. A time when it seems clear that you have fibromyalgia and that your doctor has done all he can do. There is no cure yet. You understand this. You don't like it, but after all you have learned, it seems that that is the way it is. Then the time comes to move on. You can try to reduce your doctor visits, to become more involved with your family and community, and to focus on your future.

There is no set time for every person; each person becomes ready at his or her own pace. Even if that time has not come for you, watch for it. You may see some early warning signs. Pay attention, nurture them. For some people, an early sign is that they are sick and tired of seeing doctors. At this point, you can start to think of alternatives, such as support groups or learning from others who have similar experiences. Another sign is that you may feel like reaching out to others in pain.

I do not want you to give up hope, though. Many people do benefit from a reduction of their symptoms, less suffering and a more manageable life over time. But at the same time, I do not want you to spend your life searching for a cure that doesn't yet exist. I see this from time to time in some patients. One person was so obsessed with finding a cure that she was planning to go the Dead Sea in search of their healing waters. She was a very unhappy person – suffering from deep feelings of grief related to her ongoing pain and limitations. Searching, endlessly, was a terrible waste of a life for her. And, indirectly, it added to her suffering and losses.

FOCUS ON STRATEGIES FOR SMART CONTROL

Earlier on, I gave you some of my deep wisdom by saying that you cannot get better until you stop getting worse. After about 20 minutes of talking, I still think this is true.

Unfortunately, sometimes the getting worse is actually caused by an individual's own attempts to get better. Sometimes people fight too hard, rest too much, and take too much medication. They are trying to get better, trying to deal with their pain, trying to overcome their limitations. But their solutions become part of the problem. This is understandable in many cases, but it is still counterproductive.

Most people are not planning to cause themselves more problems. Sometimes they are just experimenting. As Martha Stewart would say, *this is a good thing*. Sometimes people get stuck, though, and keep repeating patterns that are not working. You are not to blame. In fact, often it is the pain that is to blame. Pain makes people act in ways that surprise even them.

One example is what I call the Xena Reflex. You all have heard about Xena the Warrior Princess, on television. It was quite a few years ago. She was a warrior, dressed in armour, who swung a huge sword to strike down evil wherever she found it. If anyone dared to get in her way, they were in for big trouble.

Pain, especially in the form of sudden flare-ups, can make people feel they are being attacked. The pain is hurting them, causing them to suffer and interfering with their life. Pain is telling you to slow down, to stop what you are doing. It seems that it wants you to give in and do what it is telling you to do: to submit to its' power. And people react in different ways to this attack.

For some individuals, the Xena Reflex kicks in. It makes them want to fight back. They do not want to let the pain win. They don't like feeling controlled or pressured. So they fight. Their pain seems to be telling them that they can't do the vacuuming today. *Well, they feel, I will just show the pain who is really in control. I will do the vacuuming if I feel like it. I am no wimp. It's only pain.* And so, the stronger their pain gets the harder they resist.

A person, I was seeing last year, was just like Xena. She hurt her back at work, trying to catch a heavy box that had slipped off a table. Her back pain continued for several years, causing her sleep problems, a loss of her job, conflicts with the worker's compensation board and serious financial strains. She was subsequently diagnosed with fibromyalgia and experienced frequent and severe flare-ups of pain. And what pain did to her was to make her very angry. It was an automatic reaction, almost like a reflex. She didn't plan to get angry, and didn't like herself when she felt this way. That was how pain made her feel though. For others it makes them feel fear or sadness. For Xena, it was anger, almost a fury. And when she felt this way, she got busy. She had always coped with the stresses in her life by becoming busy, through exercise, housekeeping, work – even bodybuilding, which was a hobby for her and her husband. This time she decided to catch up on all the chores that had been getting behind in her home.

As she became more active, her pain increased. Then she reacted with more anger, which made her work all the harder. She started to feel that the pain was winning. She fought with even greater drive. More activity, more tension. What pain did to her was that it made her want to go to war with her body and with her pain. She hated the feeling of being overpowered. She reacted by showing her pain who was boss. **Unfortunately, when you go to war with pain, pain always wins.** It is like doing battle with your own body. How could you ever win a fight like this? Whatever happens, your body suffers, which means you suffer. For Xena, the war triggered more pain, more fury and then even more pain until she was forced to collapse in bed, defeated.

I have purposely exaggerated this example to make a simple point. Control doesn't come from fighting harder, it comes from fighting smarter. Pushing yourself when you are in pain is important to do. Sometimes, it is important to push really hard, even to the point of triggering a flare-up. But these should be saved for special occasions.

When people tell me that they overdid it, I always ask them if it was worth it. To me, that is how you should decide. If you are prepared to pay the price of increased pain and increased limitation, then by all means, go for it. Do whatever is important to you. If afterward, when the pain hits, you still feel that it was worth it, you know you made the right decision.

These everyday decisions are a necessary part of managing the stresses that come with all types of chronic pain. Protecting yourself is one strategy for managing stress with the goal of trying to avoid getting worse. Making hour-by-hour decisions about what activities you should, or should not, do is another way of managing yourself: another way of finding more control in your life.

Stress is a big problem for people in pain. One reason for this is that for most illnesses and injuries, stress can aggravate the disease itself. Heart disease, high blood pressure and diabetes are examples of illnesses that can be significantly worsened by stress.

The main reason that stress is such a big problem for chronic pain sufferers is that the pain symptoms themselves cause a lot of the stress, strain and suffering. Pain, fatigue, and poor sleep, as examples, can cause you direct and instant suffering. These are symptoms that are "in your face", day after day, week after week. Chronic pain can also lead to physical and psychological

limitations that disrupt your life. Limitations to your capacity to work, and care for your home and family, these are all types of significant stress.

The long-term nature of chronic pain is also highly stressful. Most people can handle even severe pain for short periods of time, like during childbirth, or following surgery. It is the long-term pain that wears you down. The disruption to your life also can build over time. This whole package of pain and stress can be truly overwhelming. I don't need to tell you this, of course - you live it.

Now, here is the kicker. Not only does chronic pain cause direct stress itself, but the stress it causes can also aggravate your illness. This is a basic two-step dance. Pain causes stress. That is step one. Then the stress causes more pain. That is step two. Then the pattern can keep going, and building. More pain. More stress. Then even more pain. Huge pain flare-ups can result.

Lets consider a simple example. Let us say that your chronic back pain becomes so severe that you can no longer do your job. The loss of your job is now a major stress for you and your family. Then this high stress triggers a significant aggravation of your injuries and pain. Now you have to cope with your chronic back pain, plus the emotional stress of losing your job, plus the fact that now you are out of work with no income, plus your back pain that is even higher now. No wonder chronic pain can get so complicated and hard to control.

If you focus only on your increased pain, your success will be very limited: limited because the stresses that are aggravating your symptoms are still there, working hard to keep your pain at a high level. You will be like a dog chasing its tail.

Some people try to chase their pain, in this type of situation, by taking more and more pain medication. This approach is doomed to failure. It can also set you up for a serious addiction problem.

What does work is to work with your health care team and attack each of the problems the best way you can. This attack should address your immediate symptoms of increased pain, fatigue and worsened sleep. You need to obtain and protect your income by securing income replacement benefits. Remember safety first. Decisions about returning to work, going on light duties or getting retrained need to be reviewed with your doctors, lawyer and family. These are just some simple examples.

The basic idea, here, is that somehow, some way, with all the help you can find, you need to reduce the stresses that are aggravating your chronic pain.

Often this involves asking questions, finding out the necessary information, and making very practical decisions like I discussed in the previous examples.

In general, decisions are a very helpful way to reduce stress. Much of the stress following long-term illness comes in the form of uncertainty about your future. What happens if my pain doesn't go away? What happens if I can't go back to work? What happens if I can't do everything for my family like they need me to do? In the darkness of these uncertainties, anxiety and stress will grow and multiply. And you injured body will soak it up, leading to more pain..

EMOTIONAL HEALING

In the early stages of your injury, most of the things I will talk about today will be very difficult for you. You will be more prone to fight too hard, rest too little, resist slowing down, and still be plagued with a million questions about why this pain can't be cured. Pacing will be a four-letter word to you.

Chronic pain is real and physical. But, like any long-term illness, or injury, there is a lot of emotional healing to do. If your pain is severe and has caused significant losses and disruption to your life, there is even more healing to do. Powerful feelings of grief, anger, and fear are very common, not just in relation to your pain, but also in terms of how your life has been changed. Early on, you may struggle to find even the finest threads of hope.

For any type of long-term illness or injury, there are losses and forced life changes to confront. This takes time: sometimes a long time. Counseling is helpful for some people. The support of family is vital. And for this reason, it is often very helpful to have family members attend with you to your doctor visits and support group meetings.

One of the most helpful steps involves coming to a clear view of how your life has changed. Again, reducing uncertainty is so important. This means trying to understand how your body has changed; learning what are the temporary changes such as flare-ups and what are the more permanent changes? This means trying to learn about your limitations and how much you can realistically expect your body to be able to do.

It is also important to learn about how your life has been affected. What

have you lost? For some people, this list can be quite long.

Loss of Independence – often the most upsetting, forced dependence on family members, spouse, insurance company.

Changes at Work – loss of your job, job security, seniority, income, pension.

Diminished Roles and Identity Changes – your role as wife, husband, parent, provider, identity and pride with a specific career.

These are just some highlights to consider. Most of you will have a much longer list.

One of my patients developed chronic back pain and fibromyalgia and was not able to work as a bus mechanic anymore. This was a huge loss for him. He called me one night, overwhelmed with grief and sadness. An old friend had called him out of the blue. When my patient picked up the phone, he heard his friend say “MacGyver?”. A chill went down his spine. MacGyver was the nickname they used to call him at work, (like the main character’s name, in the television show by that name). Whenever a bus would break down out on the highway, they would send for him. He had a knack for knowing how to get the bus running again when the other mechanics couldn’t. After he was injured, he could no longer work. And this call was a vivid reminder of how much he and his life had changed over the previous two years. He wasn’t MacGyver anymore. And his grief was overwhelming.

These are the kinds of losses that are often not well recognized by others. Sometimes they are invisible because they are too painful to tell others about. At other times, friends, family members, or employers are too busy trying to understand just what chronic pain is to pay attention to the million other details. Some, unfortunately, are so busy challenging you about the reality of your long-term pain, that they aren’t even listening.

In the early stages, it is very difficult to be realistic about these life changes and to be realistic about your future. Over time, and with the help of a lot of people, if necessary, you want to move away from the overwhelming emotions of fear and grief and to move toward some clear reasoning about how you are going to live the rest of your life. This is no easy task. Yet, it does seem to get easier with time. As your grief gradually becomes less intense, you can see more clearly and start to do some detailed planning.

BUILD UP YOUR TOLERANCES

Over time, it is important to try and build up your physical and emotional endurance. This is a long distance race. You may be exposed to tremendous pressures and adversity. Exercise and activity are not cures, even though some doctors and lawyers would like to think so. But they do help.

Some people like to do their exercise in the gym or at physiotherapy. Others do it at home with exercises they learned in treatment and with walking around their neighbourhood. Many people find it too discouraging, though, to continue, week after week. They are looking for the relief that they may have been promised. Frankly, I have never met anyone with chronic pain or fibromyalgia that experienced less pain with exercise. I have seen many people, though, get stronger and become able to do more with the same amount of pain.

It is an odd thing, though. When a person doesn't feel better – their pain levels are the same, or even a bit higher – they become convinced that they are not progressing. The increases in their capacity to do more are often invisible. Even if you are doing your exercises in a gym and are measuring your progress with each exercise, your gains may still not be apparent. That is because the amount that you are able to do at the gym is also affected by how active you have been in doing other things that same day. Maybe your gains will show up more in your ability to keep up at home or at work.

I love playing hockey. My wife even thinks I am obsessed with it at times. Over the past year, I have tried to increase my endurance by running a few times per week. I thought that if I was in better condition, I should be able to play hockey better: you know skate faster, last longer. But when I first looked at my hockey playing, I could not see much of a difference in my playing. I was tired before at the end of each game and I am still tired. Yet, I know that my running must be helping somehow, some way.

The problem was that I was looking for evidence of improvement in the wrong place. I was hoping to feel less tired when I was playing and less tired at the end of the game. But if I always pushed myself to maximum, I would always feel tired, no matter how much I improved in my conditioning. The real measures of my conditioning could be found by keeping records of my running,

like how far or how fast I could run. Or by looking at my performance during hockey games. I was able to score more goals so this was one measure. The best one, though, came from a compliment I received from one of my teammates.

In my work, I am always looking for two kinds of improvement. One is how my patients feel. But to me, the more important type of improvement involves people being able to do more with the same amount of pain. To me, this means they are getting stronger, experiencing fewer limitations, and hopefully less disruption and loss in their lives. Down the road, I believe this will pay off in terms of less life disruption and less ongoing aggravation of their pain and injury.

Exercise and day-to-day activity are just two ways to increase your tolerances and endurance. Other ways include learning strategies for improving your sleep, reducing flare-ups, irritability and depression, and learning new skills to reduce fear and avoidance of pain.

SEARCH FOR INDEPENDENCE

Insurance companies like to think that people enjoy receiving disability benefits. Boy are they wrong. Most people hate it – and for good reasons. One obvious reason is that there is a lot of hassle involved: paperwork for you and your doctors, private investigators following you around, and never knowing when you may be cut off, as examples.

An even more compelling reason, however, is that most people hate being in a situation where they are forced to be dependent on others for their livelihood. In this circumstance, individuals feel that they have little control over their lives. This is highly stressful and very difficult to endure – especially as the years roll on.

I encourage people to talk with their lawyers and if at all possible, to arrange for the insurance companies to buy them out. This involves a lump settlement. Then they are free of the tentacles of the insurance company forever. For people injured at work, this does happen as part of the structure built into the system. Although this can take many years, individuals gradually move through the system. They end up back at work, end up in a new career or are given a permanent pension. For seriously injured workers, a permanent

pension can be a useful form of independence, because the pension provides security and it is permanent.

Whenever there is a chance to increase your independence, take it. Independence means greater control over your life, less stress, and less overall aggravation of your pain. Control is an important part of anyone's quality of life. Sometimes this involves trying to reduce the demands on you by reducing your debts, or moving to a smaller home with less cleaning and yard work. Any control that you can gain will be well worth it, especially in the long run.

A PLACE TO FIT IN

This last idea is more of a long-term plan, although it wouldn't hurt to be thinking about it as you move along. It is important for all of us to feel that we are making a difference in others' lives. Most of us accomplish this through family and work. However, when these parts of our lives are disrupted or lost, we need to find a new way to fit in. One person may chose to look for a type of work that is more compatible with his or her injuries and limitations. Others may look to volunteer work to achieve that feeling of worth. Still, others may try to make the most of the additional time they have with their children.

One of my favourite examples is a single woman in her thirties who developed chronic back pain. She used to work for a university in the public relations department. After a falling off a ladder, she hurt her back and could no longer work for a living. It took her a few years to come to terms with this major loss, understandably. Work had been the main source of her financial security and a central part of her identity and self-worth. She has no family, work was it for her.

After much soul-searching, she decided to offer her talents on a very limited basis to a local non-profit agency. They were thrilled when she approached them. It turned out to be a lifesaver for her and a win win situation for her and the agency. They got talent that they could never have afforded. She got to feel creative again: to develop new projects and have total control over her schedule and the demands placed on her. It turned out that she could only put in about two hours, maybe two to three times per week. But even when resting at home, she was excited to be thinking up new ideas and feeling, at least a little, like she was worthwhile again.

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Remember hard driving Xena? She was trying to find a way to fit in. Fortunately, she has been able to work out a retraining program with worker's compensation. She is hoping to be able to return to lighter work as a safety inspector in the near future.

Remember MacGyver? He has had a difficult time adapting to the limitations from his chronic back pain and the loss of his capacity to work. He has been given a permanent pension. It took some time, but now he is more settled on a renewed commitment to being a single father to his two teenage boys. It is very important for him to get out to his boys' many sporting events, whenever he can. He pays a high price, but it is worth it to him and his boys.

There is no one best way to survive chronic pain or fibromyalgia. Each person needs to find his or her own path. When I first started practicing in this field, I relied heavily on all the books that tell you "this is the way". And you will still get this mentality, sometimes, from professionals of all types. I encourage you to listen carefully and always keep learning. Remember, you are always the boss of your own body and your own life. You get to choose how to recover. The professionals are there to provide you with advice and options. Your injuries have already reduced your independence – you don't want any more to slip away.

There is an advertisement that used to run in magazines, several years ago, from the makers of Saab cars. It showed a drawing of someone driving on this pleasant country road that had many twists and turns. Underneath the picture was their slogan. **Find your own road.** I like that. As I keep learning from people – learning examples of methods and choices they have made I keep this slogan in mind. Find your own road.



This article may be printed/distributed freely as long as the entire article and the following bio are included.

Dr. Michael MacDonald is the author of the book, *Unbelievable Pain Control: How to Heal and Recover from Chronic Pain and Fibromyalgia.*

He has also created a detailed website about pain that can be found at www.unbelievablepaincontrol.com

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