

Your Recovery Workbook

Part 2:

Managing Long Term Pain

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YOUR RECOVERY WORKBOOK PART 2: MANAGING LONG-TERM PAIN

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A Managing Pain Story: A young woman had a problem with back pain even after she healed from surgery. She wanted to take care of herself and her children without pain. She was tired of going to bed in pain every night and getting up every day in pain. She tried a back brace and many kinds of medicine that didn't help. Her doctor told her, “There is nothing more I can do. You have chronic pain. You have to learn to live with it.”

She didn't know how to do that until she went to a pain specialist. He said that some pain came from ignoring limits on what she should do. When she overdid it, she felt helpless and afraid to move because of the pain. They talked about her physical and emotional experience of pain and found some ways she could be more in control of it. She accepted some pain, and was able to manage it so she could still have a very good life. That was the beginning of her recovery from pain.

1. INTRODUCTION

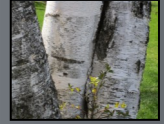


- Chronic or long-term pain lasts longer than six months and affects your life.
- It can be more physically and emotionally stressful than short-term (acute) pain.
- Constant pain can lead to anger and frustration after trying pain remedies and medicines with little relief.
- What you expect may not match what your health care team can really do for you – Not all pain can be completely resolved.
- Medications are not the only answer – Sometimes using strong pain medicine long-term can make it harder for you to live well.
- Find the right pieces to solve the pain “puzzle” - Be open to trying new things.
- Accepting pain and treating it (but not “fighting it” or letting it control you), can give you a better quality of life.
- Start by learning more about your pain and choosing some of the “tools” in this workbook to help achieve your recovery goals.
- Talk to your doctor or health care provider for any questions you have.

**"IT IS NO LONGER ACCEPTABLE THAT PAIN BE JUST
MANAGED: WE MUST EXPECT THAT IT CAN BE
TREATED, AND SUFFERERS CAN ALTER IT
THEMSELVES THROUGH EDUCATION."**

DR. DAVID BUTLER, FOUNDER OF THE NEURO ORTHOPAEDIC INSTITUTE

2. UNDERSTAND WHAT CHRONIC PAIN IS



Pain messages are danger signals sent from your body to your brain. Your body judges the messages and responds.

If your brain thinks you are in danger, many body systems are quickly called on to get you out of “trouble.” One way the body protects itself could be pain.

Being in pain for a long time can cause more problems because of the “fight or flight” response that occurs in response to a perceived harmful event, attack, or threat to survival. (*Mark the signs or symptoms of pain that you have*)

- Increased heart rate and higher blood pressure
- Sweating
- Muscle tension (Your body prepares itself to stay and fight or to run away.)
- Being more alert for danger and looking to protect yourself
- Having less appetite or more problems with digestion
- Using the body’s stored energy to fuel the muscles (higher blood sugar)
- Wanting to be away from other people
- Feeling the need to get help
- Being tired, low on energy, or getting sick easily from low immunity

Pain Q & A:

Is the pain all in my head? All pain comes from the brain, which decides whether or not the body’s danger signals should cause further pain messages and chronic pain. “No brain—no pain!” That is a new way to think of your pain.

Does that mean my pain is not real? No—All pain is real. Some providers don’t know some of the new science behind the brain and spinal cord processes.

When I am in pain, does it mean there is something bad happening? Not usually— Pain may be like the brain’s “self-check” that reminds you to be careful.

Butler, D. & Moseley, L. (2013). Explain pain. 2nd edition (Neuro Orthopedic Institute). Noigroup Publications: Adelaide, South Australia.

EXPLORING THE PAIN EXPERIENCE



Pain can have various meanings. (*Mark the ones you have experienced*)

- My body is being harmed physically
- I am suffering emotionally
- It changes the way I move and act
- I can only think about the pain, its cause and its remedy
- It's a spiritual reminder of mortality or a cultural test of strength and courage

Caudill, M. A. (2009). *Managing pain before it manages you*. Guilford Press: New York.

There are many types of pain, and they are not all treated the same:

- **Musculoskeletal** – Pain that is felt in bones, joints, muscles, tendons, or ligaments related to injury, inflammation, strains, wear-and tear, or sometimes from no injury at all.
- **Visceral** – Pain inside the chest, or abdomen that may be from receptors that are sensitive to stretching, poor blood flow, inflammation or disease.
- **Neuropathic** - Pain from inflammation or processing errors in the nervous system. May include the brain, spinal cord, or nerves to the body tissues.

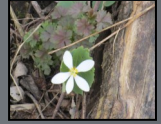
Not all providers are able to deal with all types of pain— Sometimes a specialist is needed.

Pain may also be from nerve recovery during healing, from weakened tissues, or from fear of movement.

- Inflammation is a way for the body to defend itself and start the healing process. Its swelling redness and pain after injury can be a good thing — It is how your body repairs itself.

Modified from Butler, D. & Moseley, L. (2013). *Explain pain*. 2nd edition (Neuro Orthopedic Institute). Noigroup Publications: Adelaide, South Australia.

PAIN IN THE NERVES



Nerve pain can be very distressing. (*Mark the kinds of nerve pain you have felt*)

- Pins and needles
- Burning pain
- Pain in bed, especially in hands and feet
- “Zings” – Unexpected, quick pain without warning
- Pain that gets much worse when you are feeling stressed
- Odd sensations “like string pulling, ants crawling, or prickling”
- Phantom limb pain that can include itching, tingling, or hurting even after losing an arm or leg. (There is pain memory, including “virtual limbs” mapped inside the brain.)

Painful nerves are sensitive ones. They may be responding to brain signals telling them to be more sensitive, even if they are not injured.

- People with damaged or compressed nerves may have no symptoms unless there is fear, pressure, or anxiety that add to the danger message to the brain.
- The spinal cord can sometimes magnify or distort the pain by telling the brain there is more danger in the tissues than what there really is.

Modified from Butler, D. & Moseley, L. (2013). Explain pain. 2nd edition (Neuro Orthopedic Institute). Noigroup Publications: Adelaide, South Australia.

Mirror therapy can be helpful for chronic pain in amputated or affected limbs.

Mannino, R. (2013). Using mirror therapy to reduce pain and improve movement: Re-establishing the connection. Retrieved from http://www.hss.edu/professional-conditions_using-mirror-therapy-to-reduce-pain-and-improve-movement.asp#.VS7oMkIo61s

PAIN IN THE BRAIN



Sometimes the pain experience is less about the tissues and more about the brain and its signals. (*Mark statements below that you identify with*)

- It started off so simply and now it has spread.
 - It gets worse when I think about it.
 - The pain seems to have a mind of its own.
 - I have been diagnosed with several different causes for the pain.
 - It gets better when I drink alcohol.
 - It follows a pattern or cycle (weekly, monthly, seasonally, other)
 - Treatments work for only a little while—Pills don't seem to help.
 - The pain moves around in my body.
- Your brain can adapt to pain messages by sending more chemicals to activate pain sensors, or sending fewer pain messages.
 - Changes in the brain can persist, like an orchestra that plays the same “pain tune” over and over.
 - If it can't play other songs, unhappy tunes may continue to affect your life.
 - We want your brain “orchestra” to play all of its tunes again.
 - You can start by learning more about the mind-body connection in pain.
 - The following book is recommended. Or, at least watch the video below.

Butler, D. & Moseley, L. (2013). Explain pain. 2nd edition (Neuro Orthopedic Institute). Noigroup Publications: Adelaide, South Australia.

Watch one of the following YouTube videos. Search Lorimer Moseley and choose, “Body in mind - the role of the brain in chronic pain” 24.11 minutes, TEDx “Why things hurt” 14.33 minutes or “Explain pain in less than 5 minutes” 5:00 minutes.

3. GET YOUR QUESTIONS ANSWERED



Lower your anxiety by finding out more. — Write down your answers:

What is happening in my body?

What do my test results show?

Do I need more therapy or testing?

How long will it take to get better?

What treatments might help me?

What won't help me?

What can I do to help myself feel better?

Write your other questions and answers below:

4. FIND OUT WHAT YOUR BODY WANTS



Pain is not **all** bad. It can guide you to the best healing behaviors:

- Get support and a sense of control
- Use self-care and soothing
- Add movement and activity
- Balance your activity and rest
- Learn to cope with pain
- Use your pain “tools”

Pain is very personal. Listen to your body and discover the unique comfort “recipe” that is only yours.

Accept that you have pain for the time being. — However, that doesn’t mean you don’t keep trying to make things better.

“PAIN SELF MANAGEMENT IS ABOUT LEARNING NEW (OR USING OLD) SKILLS, TRYING THEM OUT AND SEE WHAT WORKS FOR YOU... ACCEPTANCE IS NOT ABOUT GIVING UP BUT RECOGNIZING THAT THIS IS YOUR PAIN TO MANAGE AND YOU NEED TO TAKE MORE CONTROL. ACCEPTANCE IS ALSO A BIT LIKE OPENING A DOOR ... BE WILLING TO USE IT AND TRY AND DO THINGS DIFFERENTLY.”

Pete Moore, from Pain Toolkit. Retrieved from Squire, P., Williamson, O., Lau, B., Gromala, D. & Pearson, N. (2011). Treatment options for pain – Beyond medications, surgery and injections. Retrieved from <http://www.cirpd.org/painmanagement/healthyliving/documents/thepaintoolboxnov2011.pdf>

5. GET SUPPORT AND A SENSE OF CONTROL



Be an active member of your health care team— Tell them how you feel.

- Express yourself openly and honestly.— Pretending things are OK adds stress and is not fair to others who want to help.
- Set goals and plans according to what you think is important **to you**—Share them with your health care team.
- Learn more about your pain patterns— Try keeping a pain and fatigue log or diary for a few weeks (See page 12) to have insight into what is happening.

Get the right kind of support:

- Let your family members and friends help you. You don't have to go through this alone.
- Use community resources if needed. — Find out how to get help with food, housing, finances, healthcare, counseling, or other problems online by checking www.resourcehouse.org or by calling a local helpline, such as 211.
- Anxiety, depression, anger and fear can be treated with individual or group therapy if needed. Changing the way you think can change the way you feel.
- Some people decide to stop using opioids and use other treatments. They may decide they are not able to live a normal life even with higher and higher doses, or may have too many side effects.
- While slowly decreasing the amount used (under medical care to avoid withdrawal symptoms) you can learn to manage chronic pain in other ways.

CHRONIC PAIN IS OVERWHELMING. LET OTHERS HELP YOU, AND TAKE ONE STEP AT A TIME.

DECIDE TO TREAT YOUR PAIN



Don't let myths and fears keep you in pain. (*Mark those that you were thinking*)

- I don't want to be a complainer.*** You have the right to ask for pain relief. Everyone should talk about their pain. It is easier to control pain in its early stages, before it becomes severe.)
- I don't want to lose control.*** Most people don't lose control when they take pain medications the way they were prescribed.
- I want to save the pain medicine for later.*** Pain medicine doesn't lose its effect, but sometimes the dose needs to be higher to get the same relief. It helps to add other kinds of pain treatment.
- I'm afraid of being addicted.*** When pain medicine is used in the right way, people rarely become addicted. By slowly lowering the amount you take, the body adjusts.

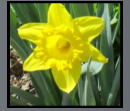
University Hospital, Newark, NJ. (2013). A patient's brief guide to pain control. Retrieved from <http://www.uhnj.org/patients/pain.htm>

If you are addicted, your body and mind depend on a drug. There are state and federal laws against doctors giving opioids or narcotic drugs if they show any of the signs below. (*Mark which are true for you*)

- I have little or no control over drug use.
- I take more than I am supposed to.
- I have prescriptions filled at more than one place.
- I crave the drug even when I know it can harm me.
- I forged prescriptions, or had "lost" or "stolen" prescriptions replaced.
- I borrow or share drugs with others.

Sometimes opioid contracts or agreements are needed that limit the amount you can use — They usually include random drug testing.

GATHER A "TEAM" FOR SUPPORT



***Write down who supports you in each part of this worksheet.
If you don't have anyone to write in, try to find someone
who can help you in that way.***

EXPLORE YOUR PAIN PATTERNS



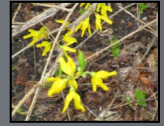
Recognize how much your pain affects your life. *(Write down some ways you want to take control in each category below)*

- Work:
- Relationships, friends and family:
- Hobbies and sports:
- Thoughts and emotions:

Pain or Fatigue Diary—Keep track for a few days to explore your patterns

When (date & time)	What was I doing, where, for how long?	Describe your pain or fatigue	Emotions (frustrated, angry, sad, scared, etc.)	Thoughts (What was I thinking about? What upset me?)	What is a healthier response (a more helpful way of looking at it?)

6. USE SELF-CARE AND SOOTHING



- Balance mind, body, and spirit — Take walks and connect to nature whenever you can. Enjoy time with pets.
- Use natural comforts like a dim, quiet room, soft music, cold or warm packs, meditation, yoga, deep breathing, or massage to loosen tight muscles and relax you.
- A few drops of essential oils from plants can help balance your body—The smell triggers parts of the brain that deals with mood, emotion, or memory, and may help promote sleep, decrease pain, nausea or anxiety.
- Eat balanced, healthy meals, quit smoking, and be mindful (more aware of body sensations without over-reacting to them).
- Focus on wellness— **Be kind and gentle to yourself.**

I often felt betrayed by my body. It was always breaking down, leaving me frustrated and bitter. No one else seemed to have as many problems and pain as I had . . . When I found myself trying to heal my chronic lower back pain, I was disappointed to hear the old “poor me, why me?” thoughts in my head. I asked my body, “What are you trying to tell me?” And here was my body’s soft, small answer. “I’m not trying to betray you. But I have needs, too. I try to let you know but you’re too busy. . . . Sometimes I have to scream at you for you to hear me.” I remembered nights when I ignored my body’s need for sleep, eating sugar until I had throbbing headaches, forgetting to drink water, punishing workouts that I pushed through in agony. I am not suggesting that all sickness or pain is created by lack of awareness or the ill treatment of our bodies. However, each moment we are in chronic pain or illness, we can choose our attitude toward it.

Rouillon, T. (2013). Body betrayal: How to cope with chronic pain and illness. Retrieved from <http://tinybuddha.com/blog/body-betrayal-how-to-cope-with-chronic-pain-and-illness/>

7. ADD MOVEMENT AND ACTIVITY



Pain can cause changes in behavior, posture, and movement patterns that can be hard to change back.

For example, if the brain makes you “splint” or hold the muscles tighter, that muscle tension habit can continue even after the other pain gets better.

Expecting or fearing pain can also cause it to continue. If you don’t move enough, and your tissues weaken, they can become even more sensitive.

Acid can build up in the tissues from a lack of movement or from something that causes pressure. Movement can help by flushing out the acids.

(Mark some of the ways movement can be helpful to decrease your pain)

- Changing positions when sitting or lying down too long.
- Making muscles around your joints stronger to support bones and tendons.
- Keeping your bones strong.
- Loosening stiff, painful joints and becoming more flexible.
- Losing weight if you are overweight to decrease pressure on joints.
- Improving your sense of well-being.
- Sleeping better after being active.
- Being more active and having more energy.

Modified from Mayo Clinic. (2015). Exercise helps ease arthritis pain and stiffness. Retrieved from <http://www.mayoclinic.org/diseases-conditions/arthritis/in-depth/arthritis/art-20047971?pg=1>

You may need to adapt and change the way you do things.— Focus on doing the things that are important to you and your family.

8. BALANCE MOVEMENT AND REST



- **Get enough sleep** – Try to fix sleep problems like sleep apnea, snoring, restless legs or jerking limbs. Improve poor sleeping habits and treat chronic pain so you can be more comfortable during the night.
- **Know your limits** – Listen to your health care provider if they tell you some activities to avoid.
- If your provider suggests using a cane, walker or brace, do this to give your joints a little break from the weight they have to bear.
- **Make your goals realistic** so they don't add too much pain. You can ask your health care provider or therapist to help set a goal you want to meet.
- **Pace your activity** – Don't over-do it when you are feeling well and do not under-do it when you are feeling unwell. The old saying "Slow and steady wins the race" is true when you are working to reduce pain.
- **Solve problems** – Follow medical advice, using pain treatments as scheduled and as needed. Don't wait until it feels unbearable because the pain "roller coaster" can make you more dependent on medicine rather than less.
- **Relax** – There is a connection between pain, physical tension, and emotional anxiety. They create a vicious cycle. Relaxation skills can help you get better control over your pain. Deep breathing, guided imagery, and gentle stretching can be helpful.
- Avoid "tug-of-war" struggles with anxiety or pain. **You can be in charge.**

Q & A

Should you use "No pain, no gain" as your guide? No—Some pain is probably going to be there as you recover, but don't over-do it to try to push into or through a "pain barrier" unless your health care provider suggests it.

Should you fear pain? No—Understand pain rather than fear it. Be as active as possible, letting it be your guide.

9. LEARN TO COPE WITH PAIN



Coping takes personal strength.— People use different ways of coping at different times in their lives. You have already learned to use some coping skills.

Active coping is healthy. (*Mark the ones you have been doing*)

- Try to understand the problem with courage, acceptance, and honesty
- Explore different ways to be active and to do things
- Don't try to totally avoid pain. And don't try to beat it by pushing yourself, over-doing it until pain stops you, so all you can do is rest.
- Stay positive — Going through hard times can give you insight and personal growth
- Make goals and plans— Gradually move toward them
- Be patient with yourself as you work from small toward bigger goals

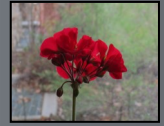
Passive coping is not as healthy. (*Mark the ones you have been doing*)

- Avoid activity and anything that might be painful
- Do nothing but rest
- Wait for something or someone to change your situation

You are the person to change your health by learning more about your pain, talking to your health care provider, and trying new ways of self-care.

YOU CAN DETACH PAIN FROM YOUR EMOTIONS TO AVOID HAVING A RESPONSE OF ANGER OR ANXIETY.

KNOW THE “THREATS” YOUR BRAIN SEES



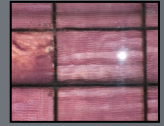
Your brain wants to protect you from anything it sees as a danger— Even small threats can maintain pain (because your brain messages are automatic).

(Mark what your brain may fear as a threat)

- Having pain or certain movements that hurt
- Not knowing if there is a serious cause for pain
- Not being believed
- Not having a steady income or job, needing help, or getting old
- Repeating an injury or making it worse
- Not being able to play with the kids, or your friends or family
- Not being able to take care of people or pets you are responsible for
- Not being able to do the housework
- Too much anxiety (not able to cope)
- Looking worse or gaining too much weight
- Losing important relationships or being unable to start new ones
- Not being able to drive, needing a wheelchair or cane
- Having surgery, therapy or injections that don't help
- Drug addiction
- Other

Butler, D. & Moseley, L. (2013). Explain pain. 2nd edition (Neuro Orthopedic Institute). Noigroup Publications: Adelaide, South Australia.

CLARIFY THE PROBLEM



What happens to let you know you have a problem?

Have you tried to change this problem in the past?

Now, think about what could be different:

Why do you want to change right now?

What would keep you from changing?

What are the barriers today that keep you from changing?

What might help you overcome whatever holds you back?

What things (people, programs or behaviors) have helped you in the past?

What do you think you need to learn about so you can change?

Modified from Miller, W.R. & Rollnick, S. (1991). *Motivational interviewing: Preparing people to change addictive behavior*. New York: Guilford Press (p. 191-202).

A PAIN MANAGEMENT STORY



I had pain in my right knee for over a year. I tried massage (which helped in the past with other pain problems), essential oils, and wearing a knee sleeve. I took anti-inflammatory pills and herbal remedies, but they didn't help enough. I had a cortisone injection in my knee that helped for a few weeks. I was afraid because my pain seemed worse than the mild osteoarthritis the x-ray showed.

I wasn't able to bend my knee much and my balance was poor. I tried to be careful how I moved my knee, and couldn't be as active as I wanted to. Exercise was important to me because I was trying to maintain weight loss that came from years of diet and exercise. I knew that gaining weight added even more pressure to my knee joints. After a group exercise class one day, my knee felt much worse. I was limping and could barely go up and down stairs when the nearly constant pain flared up. I started worrying if I would even be able to do my laundry anymore.

My doctor said I had tendonitis and suggested Physical Therapy. The therapist checked my joint and muscle movement and saw which positions caused the most pain. He thought the knee joint and leg muscles were too weak to keep the loosened knee joint from moving wrong (causing the tendon inflammation). When I knew what the pain was from, I felt more in control. I had home exercises to do with slowly increasing weight. My therapist said to ice my knee 3 times a day and use a cane for a few weeks to give the knee some relief for healing. At first, I was too embarrassed. Then I decided to use my walking stick when going to and from the parking lot at work. I also used elevators instead of the stairs. When people saw my gnarled hiking stick, I joked that I felt like a gnome. Someone said it was like a wizard's stick, which was even better to joke about.

Soon, I started feeling better. There were setbacks after walking on steep hills, but I learned to keep the "pain in my brain" calm. I went to Physical Therapy about every 2 weeks for 2 months, stopped using a cane, and cut down on pain pills. I used stairs again after being shown the best way. The home exercises changed as my ability changed. I was surprised that I actually felt better when using an exercise bike. Later, my fitness and weight loss goals were back on track.

There is still pain, but not every day, and only for short times. I don't over-react or worry about it like I did before. I know my limits and listen to what my body is telling me. I ice my knee and take an extra pain pill if needed. My strength, balance, and flexibility are better with the help of a fitness trainer. I was also able to go back to some group exercise classes, modifying what I do and avoiding one-legged exercises. I have recovered to the point that I can do the things I want to do again, like hiking, a little tennis, and dancing. The long-term pain may continue to get better, but even if it doesn't go away, I know I can still have a good life.

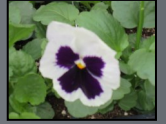
10. USE YOUR PAIN “TOOLS”



Mark the treatments or “tools” you want to try: if it is OK with your doctor or provider:

Cold packs or warm packs	Massage	Position changes	Listen to music
Yoga or gentle stretching	Essential oils	Acupuncture or chiropractic care	Creative arts
Physical therapy	Use pain medicine as needed	Deep breathing	Meditation
Eat healthy, balanced meals	Pace yourself and rest when needed	Joint supports, skin cream, ointment, or gel if it helps	Avoid over-reacting to pain with activity
Communicate more with health care team/family	Talk to a pain specialist	Be more active physically and socially	Be kind to yourself
Find community resources if needed	Use relaxation skills	Be more involved in goal setting with your treatment team	Build on your support network

EXPRESS YOURSELF AS YOU RECOVER



Draw a picture, write a poem, or pen a story about getting out of “poor-me land”.

AS LONG AS YOU MAKE AN IDENTITY FOR YOURSELF
OUT OF PAIN, YOU CANNOT BE FREE OF IT.

—ECKHART TOLLE



ABOUT THE AUTHOR

Mary B. Knutson is a Registered Nurse with a Master's Degree as a Nurse Educator. She has worked to improve education resources in academic settings, research, long-term care facilities, hospitals (including psychiatric units), and community health care agencies with the goal of empowering people and helping them toward better self-care. A collection of health education resources can be found online at www.healthvista.net.

Visit healthvista.net for more recovery resources.

Cover photo by Joan
Doucet of Surprise, AZ

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