



# Understanding Your Lupus Pain Management Options

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## Lupus Pain Management Options

Getting in and out of the car in one swift, graceful motion is what you would expect of a 20-year-old. It's a time of great movement in one's life, when the path ahead has more opportunity, mystery, and possibility than ever before.

Unfortunately, the movement I was focusing on was the short distance from the car seat to the pavement, the bottom of the porch steps to the door, or the achingly slow climb over the lip of the bathtub.

I was 20, but my body felt aged, worn, and weighted down by the arthritic pain that can come with a lupus diagnosis.

In the last 15 years, the physical pain and the resulting emotional stress I have experienced have taught me that managing chronic pain goes beyond addressing physical symptoms. As lupus patients, we also need to understand the emotional and psychological aspects of pain in order to take control and ownership of our lupus pain management.

## What is Pain?

The International Association for the Study of Pain (IASP) defines it as: "An unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage." This means that pain is subjective and depends on a person's description.

For this reason, it is important for lupus patients to learn how to describe their pain to their rheumatologist. This will help ensure a more concise treatment plan.

## Pain Diary: Describing Your Lupus Pain

Keeping a pain diary will strengthen your ability to articulate how your body is feeling and it will encourage habitual body awareness. According to Health.com, the "LOCATES" memory aid is a great way to structure your pain diary entries:

- **L:** Location of the pain and whether it travels to other body parts.
- **O:** Other associated symptoms such as nausea, numbness, or weakness.
- **C:** Character of the pain, whether it is throbbing, sharp, dull, or burning.
- **A:** Aggravating and alleviating factors. What makes the pain better or worse?
- **T:** Timing of the pain, how long it lasts, is it constant or intermittent?
- **E:** Environment where the pain occurs, for example, while working or at home.
- **S:** Severity of the pain. Use a 0-to-10 pain scale from no pain to worst ever.

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## Medication

Now that you have described your pain effectively, your rheumatologist can suggest different pain management options.

The following medications are most common in treating lupus. Each medication has a different way of targeting inflammation in the body, which is what causes most lupus-related pain:

- Non-steroidal anti-inflammatories (NSAIDs), such as naproxen, and ibuprofen
- Antimalarial medicines, such as hydroxychloroquine
- Corticosteroids, such as prednisone
- Immunosuppressants, such as azathioprine and cyclophosphamide
- Biologics, such as rituximab and abatacept

Taking medication when needed is an important part of your health plan, but it is in your interest to seek alternative therapies that will complement your medical treatment. This could help shorten how long a medication is taken, thus decreasing any resulting side effects that could occur with prolonged use.

## Massage

The S.L.E Foundation states that massage increases pain-relieving endorphins (the feel-good hormones) and reduces inflammation and soreness. As a result, you will experience less of the exhaustion and physical pain of lupus.

If possible, seek out a licensed massage therapist who not only delivers excellent services, but with whom you also connect personally. I've been going to my massage therapist for the last 11 years and her care helped me decrease the pain I feel on a daily basis.

If you are uninsured, look up your local massage therapy schools. Most offer massages at low prices in order to provide students with hands-on experience during their studies.

## Acupuncture

Although it is unproven by science, many people have claimed that acupuncture for lupus has aided in alleviating pain. This traditional Chinese medicine involves an extremely thin needle, which is inserted into your skin at strategic points in your body as a way to re-balance your energy flow, and thus decreases pain.

A more Western interpretation is that the needles stimulate nerves, muscles, and connective tissue, which boosts your natural painkillers and increases blood flow. This treatment can be expensive, but if you have an insurance plan, it could be an option to explore.

## Occupational Therapist

An occupational therapist's job is to help a person with physical or mental illness regain control over their lives through the performance of activities required in daily life. Since lupus can prevent us from doing some of the simplest of daily tasks, an occupational therapist has valuable insight into what we can do to make our lives easier in the midst of pain management.

An occupational therapist is able to provide aids and appliances like long-handled shoehorns, adjustable tables, dressing aids, toilet aids, support rails, etc. OTs can also assist in work and home adaptations and the fitting of mobility aids like walkers, wheelchairs, perching stools, and sprung cushions.

*Next page: stretching, heat, and more lupus pain management options.*

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## **Stretching**

Stretching, however slow or small the movement, is an effective, easy, cost-free way to address your lupus-related pain. Stretches can be done in your office chair, in your bed, standing at the bus stop, or lying on your living room floor.

If your mobility is severely affected due to pain, start small with movements like moving your head slowly from side to side, letting your eyes lead, gazing further beyond your shoulder each time. If you cannot lift your limbs, start by stretching your hands or doing slow circles with your ankles.

Work your way up to fuller, slow-paced stretches like restoration yoga or Tai Chi. If you cannot afford to take a class, there are a variety of free YouTube videos you can move along to.

## **Envelope Yourself in Moist Heat**

Moist heat is recommended, as apposed to dry heat, to soothe aching joints. Relax in a hot tub or sauna, lie under a moist heated towel, or my lupus pain management go-to, take a hot shower.

## **Take a Breath**

The next time you experience physical pain, notice what happens to your breath. Your breathing becomes shallow and your body tenses, adding to the pain that you are already feeling.

By deepening our breath, we relax our bodies almost immediately.

Close your eyes, take a deep breath through your nose over five slow counts, then exhale through your mouth on another five counts. You can imagine you are breathing into the affected area, filling it with healing air, and then breathing out the toxins and pain.

Never underestimate the power our breath and mind can have in both increasing and decreasing the pain we are feeling.

## **Mindfulness Meditation**

Once you have tried different breathing techniques, you can choose to take it to the next level and explore meditation for lupus. Mindfulness meditation has been shown in clinical trials to reduce chronic pain by 57% and accomplished meditators can reduce it by 90%.

Learning to meditate can feel intimidating, so start with something simple you can fit into your everyday routine. There are different ways you can meditate beyond sitting on the floor cross-legged.

You can choose to give yourself five minutes of quiet each day where you turn everything off: the radio, the television, your cell phone, your computer, etc. If you cannot just sit motionless for those five minutes, give yourself a task like washing dishes, a crossword, or tackling a page in a coloring book.

It does not matter what you do, as long as you are present. If you are coloring, concentrate on that task only, and let all other thoughts or sensations wash over you.

Gradually you can increase the amount of “quiet time” you give yourself.

You can also do walking meditations, where you can focus on one sound you hear or one sensation you feel, like the wind on your skin. Taking time to be mindful will train your mind to become less emotionally invested and distracted by your physical pain.

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## **Become a Food Detective**

Start monitoring how you feel when you eat certain foods. Do you feel more pain when you eat some foods than others?

Take that food out of your diet for three months and then re-introduce it to discover its effects. Remember to only eliminate one food at a time.

Take stock of what is in your fridge and pantry. Load up on anti-inflammatory leafy greens and avoid processed food and sugar.

## **Talk It Out**

Being in physical pain can often alienate us from others. Feelings of loneliness and anger can only exacerbate the symptoms you are experiencing.

Talking to a psychologist, social worker, lupus support group (online or in person), or a good friend is a good way to work through how you are feeling about your health. If you are not ready to talk quite yet, buy a journal to store your thoughts and questions.

## **Celebrate the Small Victories**

Walking an extra block, climbing that extra stair, being able to lift your arm to reach that cup — it's important to celebrate these small victories in the life long process of lupus pain management.

If we make a commitment to recognize our limits without viewing them as weaknesses, to do what we can to understand what our body is telling us, and to give ourselves permission to voice our feelings about the pain we are feeling, we lay the foundation for a life of increased quality of health and happiness.