



NATIONWIDE CHILDREN'S
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Helping Hand™

Health Education for Patients and Families

Juvenile Fibromyalgia Syndrome (JFS)

Juvenile Fibromyalgia Syndrome (JOO ve Nile fi bro my AL ja SIN drome) is a chronic pain condition characterized by widespread musculoskeletal pain. This means symptoms are present for more than 3 months. The symptoms begin in childhood or adolescence. JFS can run in families.

Cause

An over-sensitive nervous system causes JFS. It begins gradually, triggered by illness, injury, or an emotional event. It most common in girls between the ages of 13 and 15 years. You can feel pain from JFS anywhere in your body – or everywhere in the body.

Signs and symptoms

- Sleep disturbances
- Headaches
- Fatigue and restlessness
- Pain both above and below the waist, on both sides of the body
- Depression and anxiety
- Abdominal pain
- Cognitive “fog”

JFS and pain

Pain is like an alarm that helps us sense when we are in danger. When our body becomes more sensitive to pain, as in JFS, the volume of the “alarm” gets turned up high. So, the longer the pain continues, the more it hurts.

This means that even the lightest touch can cause discomfort.

Treatment at the clinic

At the **Comprehensive Pain Clinic**, you will learn how to manage your pain, as well as other symptoms of JFS. A team of medical professionals will show you how to help yourself.

- The **physician (doctor)** will:
 - Answer questions about your condition
 - Write prescriptions for medicine when needed
 - Watch over your care
- The **physical therapist** will:
 - Teach you safe exercises
 - Give you recommendations for physical activity
 - Give you a home exercise program
- The **psychologist** will:
 - Teach you to understand triggers of your pain
 - Give you ways to manage stress and pain in different places
 - Instruct you on how to relax
- The **acupuncturist** of **massage therapist** will focus on:
 - Decreasing muscle tightness
 - Improving sleep
 - Relaxation
- The **social worker** will help:
 - Provide appropriate school accommodations
 - With transportation issues
 - Identify other barriers to treatment

Treatment at home

Between clinic visits, there are everyday things you can do to feel and function better.

- **Stay active:** Appropriate exercise will help. People with JFS who do not exercise are more tired and have more pain. Physical activity is very important for your well-being.

Activities that you enjoy such as swimming, walking, biking, hiking, dancing, doing yoga, and sports are some of the ways you can stay active. It is important to find something active that you will stick with and enjoy regularly.

Your physical therapist can recommend safe exercise that will help you feel better so you can stay active.

- **Learn ways to relax and manage your stress:** Thoughts and feelings can influence your pain. When you are stressed, nervous or sad, your pain may be worse. When you are busy and not focused on pain, it may seem less intense. Hanging out with friends, going to school, watching movies and listening to music can help take your mind off the pain. Deep breathing, massage and acupuncture are also examples of things that may help you to relax.

Your pain psychologist will teach you ways to manage your pain and stress.

- **Get enough good quality sleep:** Getting good sleep is important when you are dealing with chronic pain. Your pain may seem worse if you are not sleeping well. When you are tired, you may not have the energy to do things you like to do. It is important to get good quality sleep to feel rested.
- **Take your medicines as prescribed:** Different medicines may be prescribed by your doctor to help decrease your pain. Keep in mind that some medicines take more time to work. It could take weeks before you notice a change in how you feel. Make taking your medicines part of your routine. It may be helpful to set a daily alarm to help you remember.

Talk with your doctor if you have questions about your medicines.

- **Go to school:** It is possible to have special arrangements at school such as having a second set of books at home or extra travel time between classes.

These types of accommodations can be made with your school under special learning plans called an Individual Education Plan (IEP) or 504 Plan. You and your parents can talk to your school about whether one of these plans can help you learn better. Our program can help you work with your school.

Frequently asked questions about exercise

Is it safe for me to exercise?

Yes! Research studies show that exercise is safe for patients with JFS. Patients who did not exercise were **more** tired and had more pain. So, physical activity is very important for your well-being!

How would exercise help me?

- There are many benefits of exercising regularly, such as increasing or improving:
 - energy levels
 - mood
 - bone strength
 - muscle strength
 - joint range of motion
 - endurance
 - sleep
- Exercise may also help decrease:
 - pain intensity
 - how many areas are in pain
 - anxiety or stress

What kinds of exercises should I do?

- **Low-impact aerobic exercise:** Find an activity you enjoy doing! Some examples are dancing, walking, biking, Tai Chi, swimming, yoga or Pilates.
- **General strengthening:** Your physical therapist (PT) will give you a home exercise program (HEP) to do at home. This will give you some ideas about safe exercises you can do to strengthen your muscles.
- **General stretching:** It is important to stretch before and after activity. Movement and stretching can be painful at first, but most people with JFS feel that regular, gentle movement helps decrease pain.

Frequency (how often): Your goal should be to exercise 3 to 5 days every week.

Intensity: You should be exercising at a moderate intensity. A moderate intensity means it should be hard, but not impossible to have a conversation with a friend. This also means that you should experience an increase in:

- breathing rate
- heart beat
- sweating

Time (how long): Your goal should be 30 minutes. At first you may need to exercise a shorter time and increase bit by bit.

When will I see improvements from exercise: Everybody will progress at a different rate. It is hard to predict when you will see improvements but exercising regularly at the recommended frequency and intensity will help you improve your function faster than not being active.

When should I not exercise?

- If you have a fever
- If you have a really hard time breathing

What if I am having a hard time exercising regularly?

- Problem solve.
 - Identify what is keeping you from exercising.
 - Figure out a way to solve the problem.

For example, if you are busy with schoolwork, find out a way to make exercise part of your daily routine.

 - Write it in your planner.
 - Do half of your home exercise program exercises on one day and half another day.
- Make exercise fun.
 - Listen to music while you exercise.
 - Do activities you enjoy.
- Find a workout buddy.
 - Invite a family member or friend along.
- Set personal fitness goals.
 - An example of a goal is: take your dog on a walk for 15 minutes, at least 3 times each week.
 - When you meet that goal, the time could increase to 20 minutes.
 - You should be proud of yourself when you meet a goal! It is a huge accomplishment and one step toward a healthier you!

Community and social support

After completing your program here, continuing physical activity in your daily life is an important part of continuing your journey.

Here are resources in the Central Ohio area to get you started:

Recreational activity:

- www.columbus.gov/recreationandparks/programs/Find-a-Program/
 - “Get Active” fitness centers
 - Aquatic programs
 - Community recreation centers
- <https://ymcacolumbus.org/youth-activities>
 - Youth sports and swimming
 - Teen programs

Tai Chi:

- Bodhi in Motion
- Beginner Tai Chi at Franklin Park Conservatory
- Central Ohio Martial Arts
- Schiller Park Community Recreation Center

Educational resources

For more information about Juvenile Fibromyalgia, check out:

- <http://healthlibrary.nationwidechildrens.org/Library/Encyclopedia/90,P01716>