FIBROMYALGIA ASSOCIATION CANADA

Fact Sheet Fibromyalgia in Children and Youth

What is it called?

Fibromyalgia in children and youth have different names that all refer to the same condition. Juvenile Fibromyalgia (JFM) = Widespread Pain Syndrome = Diffuse Myofascial Pain Syndrome = Amplified Musculoskeletal Pain Syndrome. Chronic primary pain such as JFM is a disease entity as recognized by the International Classification of Disease (ICD) – ICD 11[1].

How common is it?

It is more common than statistics indicate. This is because it goes by so many different names, the criteria doctors use to diagnose it are old and need updating, and many people, including health care providers, are not aware it exists.

Chronic musculoskeletal pain is present in 4-40% of children and youth. It is estimated that 1-6% meet the criteria to diagnose juvenile fibromyalgia. Studies indicate that over 80% of individuals who meet the criteria for JFM continue to experience symptoms into adulthood. In comparison, approximately 50% of those who do not meet the criteria still report experiencing some symptoms in adulthood.

Diagnostic uncertainty is common and negatively impacts recovery. A lack of diagnosis can lead to feelings that one has missed something, searching for an alternative diagnosis and an overall mistrust in the medical system. We know that being given a diagnosis validates the pain, leads to lower rates of depression and catastrophizing (feelings of pain spiraling downwards). A diagnosis leads to less fear about the pain and better functioning.

When a doctor is considering possible diagnoses that explain signs and symptoms, it is important to rule out other conditions that share some of the same signs with fibromyalgia. It is important to close the page on investigations in order to focus time and energy on fibromyalgia management.

[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4450869/

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What are the symptoms?

Symptoms may include migratory pain in muscles and joints, fatigue, sleep difficulties, hypersensitivity to touch, irritable bowel syndrome, poor concentration/focus, chronic tension headaches, depression, anxiety, Postural Orthostatic Tachycardia Syndrome (POTS), interstitial cystitis and pelvic or chest myofascial pain.

What can increase the pain?

Anxiety, worry, depression, dehydration, poor nutrition and lack of sleep can increase the pain but is not the cause of pain.

What can decrease the pain?

Distraction, relaxation, positive emotions, physical exercise, hydration, good quality sleep and good nutrition can cause a decrease in the pain.

Diagnosis Criteria

While the diagnosis criteria need updating, there are certain criteria that need to be met to make a diagnosis.

Major Criteria:

1. Generalized musculoskeletal pain for 3 months or more
2. No underlying medical conditions, like Lyme disease, thyroid issues, etc.
3. Normal bloodwork

Minor Criteria: *(presence of 3)*

1. Chronic anxiety or tension
2. Fatigue
3. Poor sleep
4. Chronic headaches
5. Irritable bowel syndrome
6. Subjective soft tissue swelling
7. Numbness
8. Exercising can increase pain
9. Weather factors can increase pain
10. Anxiety or stress can increase pain

What are possible risk and precipitating factors?

Eighty percent (80%) of youth with chronic pain will have one parent living with chronic pain.

Fibromyalgia is more common in females as hormonal factors play a role. Fibromyalgia diagnosis in males can often be overlooked.

Precipitation factors include a prior viral infection (e.g. mononucleosis, influenza, parainfluenza), hypermobility of the joints, connective tissue diseases, small fiber neuropathy, an inflammatory process or a genetic syndrome.

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Fibromyalgia involves the myofascial system in both children, youths, and adults

Fascia is the connective tissue layer that is over all joints, bones, muscles, organs and the brain. It is there to support and connect the body and to absorb and transport mechanical energy. It contains a high amount of nerves and blood supply. It is "like a spiderman suit under the skin." Fascia has a memory in itself that is influenced by physical and psychological trauma, stress, posture, dehydration and aging. Fascial meridians correspond to Chinese medicine knowledge and that is why acupuncture, shiatsu massage, yin yoga and Qigong all help in juvenile fibromyalgia. The myofascial system is affected by hydration, so improving hydration and nutrition can help as well.

How is Juvenile Fibromyalgia treated?

Treatment includes a combination of self-management strategies, physical therapies (movement), psychological therapies, medications, and learning to pace activities. Education for parents is needed, including training on how to coach their child to manage and cope with pain more effectively.

Physical approaches include a graded aerobic exercise program (start low and go slow), stretching and strengthening exercises. Mind-body activities that target the myofascial system include restorative yoga, Qigong or Tai Chi.

Psychological approaches include Cognitive Behaviour Therapy (CBT) that focuses on thinking differently about pain. Treating underlying or coexisting mental health conditions and reducing stress at home, school, friends and environment will help control the symptoms of fibromyalgia.

Pharmacological approaches may include magnesium, vitamin D or iron supplements if iron levels are low. Folic acid, B12 and magnesium all help improve the myofascial system.

Doctors/nurse practitioners may prescribe pregabalin or gabapentin, amitriptyline or nortriptyline, duloxetine, tramadol, muscle relaxants, or topical creams. Opioids are not helpful, and NSAIDs alone are not very effective. A 30-50% decrease in pain is a realistic goal with pain medications. There always must be a balance between pain relief and increased function versus adverse side effects of the medication. Eventually, an increase in function will decrease the pain. The primary objective is to increase function, pain relief is the secondary goal. Anything that decreases function should be reassessed.

Who can help?

Family doctors can support this condition and more complex cases can be referred to a specialized Pediatric Chronic Pain Program for detailed management.

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Summary from Dr. Christine Lamontagne's presentation:

- *Validate the pain experience of children and teens: they are so often dismissed because there's no medical diagnosis to explain their pain. Chronic pain Syndromes are diseases in their own right.*
- *Understand and be able to explain central sensitization. It is the Diagnosis!*
- *Don't get hooked up on terminology. It does not matter what was the inital trigger. Treatment is the same for all diffuse myofascial pain syndrome.*
- *Integrate phamacological, active physical and psychological approaches that target the myofascial system and the mind-body connection.*
- *Treat associated conditions like depression (30%), anxiety (60%) undiagnosed learing disorders, POTS*
- *Early intervention is key to avoid persistent disability. Outpatient/inpatient pain rehabilitation combining neuromuscular exercise and CBT based approach seems promising to reduce disability and reduce pain.*

Resources

Helpful Apps include:

MindShift, Headspace and Smiling Mind

Recommended Readings include:

- "The chronic pain and illness workbook for teens: CBT and mindfulness-based practices to turn the volume down on pain" by Rachel Zoffnes (https://fibrocanada.ca/book/chronic-pain-and-illness-worbook-for-teens)
- When your child hurts. Effective strategies to increase comfort, reduce stress and break the cycle of chronic pain" by Rachael Coakley (https://fibrocanada.ca/book/when-your-child-hurts)

Helpful Websites:

- Solution for Kids in Pain (SKIP) – Improving Children's Pain Management
- Power Over Pain Portal for Youth

Helpful Video:

- What is pain - Be pain smart

This Fact Sheet is adapted from the May 9, 2024 presentation by Dr. Christine Lamontagne, Medical Director of Chronic Pain Services at Children's Hospital of Eastern Ontario in Ottawa, Canada.

You may view the presentation on FAC's website at https://fibrocanada.ca/facs-presentations

This Fact Sheet was kindly reviewed by Dr. Christine Lamontagne, MD