19 Signs You Grew Up With Fibromyalgia

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Growing Up With Fibromyalgia

Many stories told by those with fibromyalgia starts with a very clear date, or time period and when it first started. Often, they know the exact car accident or virus that triggered the chronic pain and fatigue that is fibro.

But I don't have that kind of story. Like many others that have had fibromyalgia since childhood, it is difficult to pinpoint precisely when it started.

Reading the experiences of others with childhood fibromyalgia, or juvenile primary fibromyalgia syndrome (JPFS), has shown me that my personal experience is not all that unique.

The Facts About Juvenile Primary Fibromyalgia Syndrome

Diagnosis and treatment of JPFS are still in development now, but much progress has been made in the last 10-15 years. Of course, for those of us growing up in the 90s or before, very little was known about JPFS and many of us went undiagnosed.

It is estimated that six percent of children in the United States have JPFS, it is most commonly seen in girls, ages 13-15. But it has been seen in boys, and it has been diagnosed at younger ages.

The most common symptoms of JPFS are:

- Widespread pain
- Multiple tender points
- Fatigue
- Joint stiffness
- Skin tenderness
- Post-exertional pain
- Sleep disturbance
- Irritable bowel symptoms
- Poor memory
- Tension headaches
- Dizziness
- Fluid retention
- Paraesthesia - numbness, itching, tingling for no apparent reason
- Restless legs
- Bruising
- Raynaud phenomenon - numbness and feeling cold in your hands and/or feet
- Chronic anxiety

Treatment for Juvenile Primary Fibromyalgia Syndrome

Once a child or teenager has been diagnosed with JPFS the question is what do you do about it? There is no one treatment plan, but there are a number of options that can bring great relief:

- Medication
- Cognitive behavioral therapy (CBT)
- Reducing stress
- Getting more sleep
- Regular exercise
- Pacing activities
- Healthy eating habits

The sooner a young one is diagnosed and given a treatment protocol, the soon they can find what helps them cope with fibromyalgia. Once they know how to cope successfully, they will be better prepared for living with fibromyalgia and will be able to live a better and fuller life.

What Juvenile Primary Fibromyalgia Syndrome Feels Like

Fibromyalgia is different for everyone, so my experience may be a little different from yours or your child's, but this is what it was like for me:

1. It was being different from all the other kids.
2. It was hurting more then you should when you fell down or got hit by a ball.
3. It was avoiding activities that caused pain, like running or playing sports.
4. It was getting sick, a lot, way more than any of the other kids.
5. It was lying in bed awake, long after you should have been asleep.
6. It was laying in bed crying while you writhed in pain. And then being told “It’s just growing pains. It’s normal.”
7. It thought it was normal to hurt if you sat in the same position for too long.
8. It was being called a crybaby because everything hurt you.
9. It was being labeled dramatic because things hurt you that shouldn’t have.
10. It was being called a faker because you couldn’t possibly be in as much pain as you said you were.
11. It was being called a hypochondriac because you couldn’t possibly be as sick as you said you were.
12. It was thinking it was normal to feel completely drained after being in the heat.
13. It thought it was normal to feel dizzy every time you stood up.
14. It was feeling tired and lethargic when all the other teenagers had endless amounts of energy.
15. It was feeling exhausted no matter how long you slept.
16. It was being called lazy when you said you were too tired to do something.
17. It was thinking it was normal to be in excruciating pain for days after exercising.
18. It was feeling like you were going crazy.
19. It was feeling like you were dying.

Growing up with fibromyalgia is rough, especially when no one understands what is wrong or even that there really is something wrong with you. But guess what? If you did grow up with fibromyalgia that means you are a survivor–and if you can survive that then you can survive almost anything else life throws at you.

If you have a child or teenager in your life that has some of these symptoms, please talk to a doctor about it. Help them get answers now before things get worse. Please support them, show them compassion, patience, and most of all, believe them!