

FIBROMYALGIA

THINGS YOU SHOULD KNOW



MAKING THESE INVISIBLE ILLNESSES VISIBLE

WWW.SOCIALBUTTERFLIESFOUNDATION.ORG



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WELCOME MESSAGE

Greetings,

We have put together some useful information for you. Whether you are wondering if you have lupus or fibromyalgia or are newly diagnosed, we want you to know that Social Butterflies Foundation is here for you. As an organization founded by a survivor, we understand your needs. Our motto is "Butterflies don't let each other fly alone."



CHASTITY CORBETT
FOUNDER & C.E.O.

ABOUT US

Social Butterflies Foundation was founded on October 5, 2018 by lupus survivor, Chastity Corbett. It is a grassroots organization dedicated to helping those battling with lupus and fibromyalgia, as well as their families and caregivers. Social Butterflies Foundation is the first and only non-profit located in Hampton Roads, Virginia devoted to providing real, direct assistance to survivors and their families living in Virginia and Maryland.





MISSION & VISION

OUR MISSION

Social Butterflies Foundation is dedicated to empowering and uplifting individuals living with lupus and fibromyalgia, as well as their families and caregivers. Our mission is to provide direct assistance, education, support services, and encouragement to help survivors face the challenges of these debilitating illnesses.

OUR VISION

Our vision is a world where no one suffering from lupus or fibromyalgia has to endure the challenges of these life-threatening illnesses alone. We envision a united community of survivors whose voices are heard and who receive the support they need. Together we will make these invisible illnesses visible.



OUR PROGRAMS & SERVICES

From educational resources to emotional support, we strive to empower our community and improve their quality of life. Explore our programs and services below to see how we can assist you on your journey toward health and wellness.

SUPPORT GROUP

1

The Social Butterflies Foundation's Lupus & Fibro Support Group provides a safe and understanding environment for both youth and adult survivors, their families, and caregivers to unite. Support Group meetings are held every 4th Saturday from 11AM-1PM at Sentara Careplex Hospital inside conference room D.

E.F.A. PROGRAM

2

Living with a chronic illness can also affect survivors financially. Social Butterflies Foundation created its Emergency Financial Assistance program to help provide assistance with medical bills, prescription costs, and utilities.

CARE OUTREACH

3

The Care Outreach Program is our way of showing that we care. We want survivors to know that they are not alone. We are there to help during the rough times as well as being there to celebrate the good times. We adopt families during the holidays.

OUR PROGRAMS & SERVICES

WIG OUTREACH

4

Many lupus and fibromyalgia survivors suffer from alopecia due to the illness or medications taken to treat the illness. Losing your hair can be devastating and traumatic. The Wig Outreach program aids survivors in obtaining wigs. The program also hosts workshops with guest speakers discussing hair, skin, and other beauty tips to focus on both inside and outside.

SUMMIT & HEALTH FAIR

5

Social Butterflies Foundation's Lupus and Fibromyalgia Summit and Health Fair is a step towards an awareness campaign to bring the medical community, survivors, and support services together. The summit establishes an open forum between medical professionals, patients, and their families while providing valuable resources.

SCHOLARSHIP

6

Social Butterflies Foundation aims to provide youth battling with lupus and/or fibromyalgia, as well as children of survivors, with college scholarship opportunities to help fulfill their aspirations for higher education.

Fibromyalgia

WHAT IS FIBROMYALGIA AND HOW IS IT DIAGNOSED?

The American College of Rheumatology states that fibromyalgia is defined by chronic widespread muscular pain and tenderness.

Fibromyalgia is difficult to diagnose because there is no definitive test. However, the combination of patient history, bloodwork, and X-rays makes a diagnosis possible.



HOW DOES FIBROMYALGIA MAKE YOU FEEL?

Many people with fibromyalgia also experience additional symptoms such as fatigue, sleep disturbances, stiffness, cognitive and memory problems, and symptoms of depression and anxiety. More localized pain conditions often occur in patients with fibromyalgia, including migraine or tension headaches, temporomandibular disorder, irritable bowel syndrome, gastroesophageal reflux disorder, irritable bladder, and pelvic pain syndromes. The symptoms of fibromyalgia and associated conditions can vary in intensity and wax and wane over time. Stress often worsens these symptoms. It is often misunderstood and at times unrecognized.

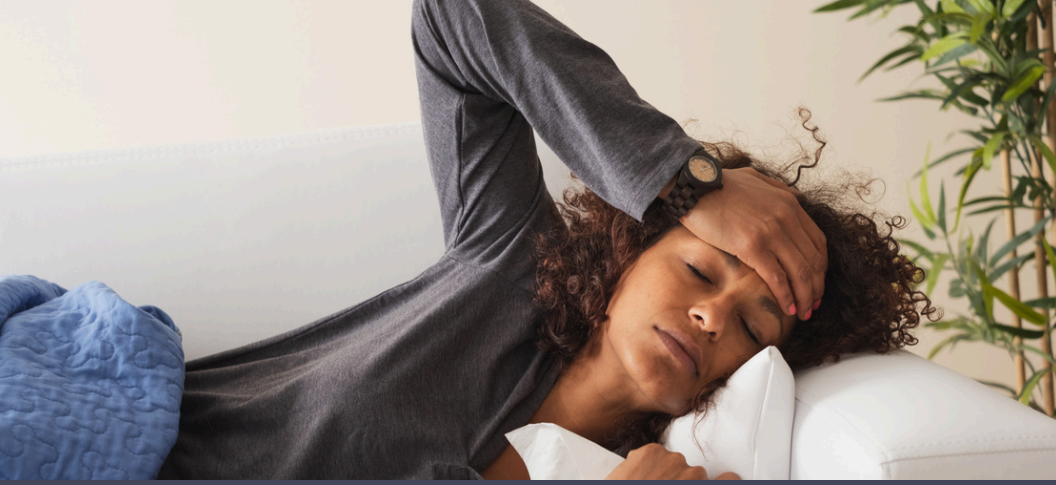


SYMPTOMS

Fibromyalgia has been described as a constellation of symptoms affecting various body parts and functions. From muscle pain to sleep disturbances and anxiety, here are some common symptoms.

Pain – Widespread musculoskeletal pain is the most common symptom of fibromyalgia. It generally occurs at multiple sites throughout the body, although it may start in one region, such as the shoulders, and later occur in other areas over time.

Fatigue – Most people with fibromyalgia have fatigue, decreased endurance or the kind of exhaustion felt with the flu or lack of sleep. Sometimes the fatigue is severe, and it can be a much greater problem than the pain.



SYMPTOMS

Sleep Disturbances – The problems with sleep vary from person to person. Some people have difficulty falling asleep; others sleep lightly and wake up frequently during the night.

Mood and Concentration Problems – Feeling sad or being down is common. People with fibromyalgia also may feel anxious and have difficulty concentrating or performing simple mental tasks. These problems tend to come and go and are often most prominent at times of extreme fatigue or anxiety. Some people with fibromyalgia have depression.

Other Problems – Headaches, jaw pain, abdominal or pelvic pain, dizziness, restless legs and numbness or tingling in hands and feet may occur.



MANAGING FIBRO FOG & STRESS

Manage fibro fog

Many people with fibro have “fibro fog” (feelings of confusion and memory loss).

Try these ideas to clear the fog:

- Focus on 1 task at a time.
- When someone tells you their name or an important piece of information, try repeating it out loud and writing it down.
- Before a doctor's appointment, write down your questions — and bring your medical diary so you can tell the doctor about your symptoms and side effects.
- Keep a calendar to record appointments and reminders.

Manage stress

For many people with fibromyalgia, stress can trigger your symptoms — or make them worse.

Use these tips to manage everyday stress:

- Plan ahead for how you're going to use your time — decide what's most important and do that task first.
- Ask for help when you need it.
- Make time for fun, relaxing activities.
- Try not to sweat it if you don't get everything done or have to cancel plans — remember, your health comes first.

Manage pain

Most people with fibro have joint pain, muscle pain, or headaches. Always check with your doctors before trying new ways to manage your pain

Smoking can trigger fibro symptoms and make them worse. If you smoke, make a plan to quit.

FAST FACTS



What are the complications of fibromyalgia?

- More hospitalizations — Those with fibromyalgia are twice as likely to be hospitalized as those without fibromyalgia.
 - Lower quality of life — Women with fibromyalgia may experience a lower quality of life.
 - Higher rates of major depression — Adults with fibromyalgia are 3 times more likely to have major depression than adults without it.
 - Higher death rates from suicide and injuries — Death rates from suicide and injuries are higher among fibromyalgia patients, but overall mortality among adults with fibromyalgia is similar to the general population.
 - Higher rates of other rheumatic conditions — Fibromyalgia often co-occurs with other types of arthritis such as osteoarthritis, rheumatoid arthritis, systemic fibro erythematosus, and ankylosing spondylitis
- Fibromyalgia affects 2-4% of the population, predominantly women.
 - Fibromyalgia is diagnosed based on patient symptoms and physical examination.
 - There is no laboratory, radiographic, or other diagnostic test, but these tests can be used to exclude other conditions.
 - Medication, while important, is not the only treatment. Patient education, exercise, self-management skills and alternative therapies help treat fibromyalgia symptoms.
 - Furthermore, according to the Arthritis Foundation, people with rheumatoid arthritis, lupus or ankylosing spondylitis, and other rheumatic diseases are also more likely to develop fibromyalgia.
 - Symptoms usually appear between ages 30 and 55.
 - Though more common in adults, children (especially adolescent girls) may develop fibromyalgia.



TREATING FIBROMYALGIA

Treating fibromyalgia usually involves a multi-faceted approach that includes medication, non-drug therapies, and self-management. It may take some trial and error to find an effective combination of treatments.

- Medications are prescribed to relieve pain and improve sleep. There are 3 medications approved specifically to treat fibromyalgia symptoms. Other medications, mainly antidepressants, are used off-label to treat symptoms. Over-the-counter and prescribed pain relievers and anti-inflammatory medications may also be used for pain relief. (Learn more about medications for fibromyalgia at arthritis.org/drug-guide.)
- Non-drug therapies may include biofeedback, acupuncture, cognitive behavioral therapy, stress management or hydrotherapy.



MANAGING FIBROMYALGIA



Take time for yourself



While it is important to learn as much as you can about fibromyalgia, it's also important to take a break from focusing on your disease when you need to. Living well with fibro often involves making some changes within your family, your profession, and your social circle.

But even though fibro may affect many different areas of your life, it's important to remember that this disease does not define you. Taking time to do activities you enjoy will help you reconnect with yourself.



Talk about what fibromyalgia is

- Fibromyalgia is a chronic disease – people who develop fibro will have it for the rest of their lives
- Explain that fibromyalgia is unpredictable. Symptoms can appear, disappear, and change. Knowing this may help other people understand your ups and downs, and also the changes that you may have to make in your life.

Make adjustments as a family

Good communication is important for helping your family adjust to your diagnosis. You'll want to make sure you share details of your symptoms and treatment with your family – keeping them informed can lessen their concerns. It'll also help them understand why you may sometimes say “no” to activities.

Use these tips can also help your family adjust:

- Maintain a manageable schedule with time for breaks.
- Reassign household responsibilities as needed.
- Ask friends or extended family members to help around the house when possible.
- If you have children, talk to them about your it and how it may affect life at home.

FIBROMYALGIA & WORK



Manage work with fibromyalgia

Many people with fibro can continue to work, although they may need to make changes in their work environment. Depending on what your symptoms are like and what kind of job you have, you may be able to work with your employer to make adjustments so you can stick with your current career.

Use these tips:

- Make small changes to your workstation – like getting a more comfortable desk chair (sometimes called ergonomic chairs).
- Request a different or more flexible work schedule – for example, you could work from home on certain days or start your workday later.
- Get help from a vocational rehabilitation counselor (job coach for people with disabilities) to find work that's more manageable.

If the physical or mental demands of your job become overwhelming, you might benefit from changing jobs or switching to part-time hours. In some cases, not working at all may be the best choice for your health. You can learn about disability benefits from your company's human resources office or from the Social Security Administration (SSA).

If you're concerned about what will happen if you tell your employer you have fibromyalgia, remember that people with long-term health problems like fibromyalgia are protected by the Americans with Disabilities Act (ADA). The ADA says that employers must offer accommodations to help a person to meet the requirements for their job.





FIBROMYALGIA & SCHOOL

To do well in the classroom while keeping your fibro in check, make sure you:

- Don't overload your schedule — try to leave time for relaxation.
- Communicate with the school about your fibromyalgia — make sure you register with the school accessibility office and consider telling roommates, your academic advisor, professors, and staff at the student health center about your fibro.
- Learn about financial assistance opportunities — you might be eligible for federal financial aid and a number of scholarship programs.
- Think about accommodations you might need — if you expect to miss class sometimes or think you may need extra time on tests, make sure you talk to your professors or other staff members.

Manage school with fibromyalgia

Many people who have fibromyalgia are successful at school while preparing to pursue their dreams. School at any level can be demanding, so you'll want to make sure you're prepared to balance tests and homework with the need to take care of your health.

Find the support you need

Staying connected socially can help you put fibromyalgia in perspective and build a support system. Make sure you spend time doing activities you enjoy with other people, and identify family members and friends you can turn to when you need to talk to someone.

In addition to sharing with your family and friends, there are other ways you can find support:

- Individual therapy can help you cope with issues like depression and anxiety.
- Couples therapy can help you and your partner communicate as you both adjust to your diagnosis.
- An online support group can help you engage with other people affected by fibromyalgia and learn tips from people dealing with similar experiences.



LIVING WITH FIBROMYALGIA

Eat healthy and be physically active

Healthy living is good for everyone. Good nutrition and physical activity can help you feel better.

Use these tips to help you eat healthy and be active:

- Eat lots of fruits, vegetables, and whole grains.
- Always check with your doctors before taking any herbs, vitamins, or dietary supplements — they can affect the medicines used to treat fibro or make your condition worse.
- Choose healthy protein foods — like lean meats, poultry, and seafood.
- For bone health, eat foods with lots of calcium — like spinach and dairy.
- For heart health, eat foods with Omega-3 fatty acids — like salmon and walnuts.
- Try walking, swimming, or biking — these low-impact activities help your bones and muscles without hurting your joints.
- Try gentle yoga to relieve stress and loosen tight muscles — ask your treatment team what kind of yoga is best for you.
-

Manage fatigue

Most people with fibromyalgia have fatigue (feel tired often).

Try these tips to beat fatigue:

- Get enough sleep — aim for at least 7 hours each night.
- Take breaks during the day to rest and recover — there's no shame in needing a nap.
- Make changes to your daily routine when you need to.



American College of Rheumatology

<https://rheumatology.org/patients/fibromyalgia>

Arthritis Foundation

<https://www.arthritis.org/diseases/fibromyalgia>

Centers for Disease Control and Prevention

<https://www.cdc.gov/arthritis/basics/fibromyalgia.htm>

Johns Hopkins Medicine

<https://www.hopkinsmedicine.org/health/conditions-and-diseases/fibromyalgia>

United States Social Security Administration

<https://www.ssa.gov/>

U.S Equal Employment Opportunity Commission

<https://www.eeoc.gov/>



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