

FIBROMYALGIA

PATIENT INFORMATION



FIBROMYALGIA

fibro-, "tissue", (latin)

μυώ, myo-, "muscle", (grekiska)

άλγος, algos-, "pain", (grekiska)

The Fibromyalgia Association

The Fibromyalgia Association was formed in 1998 with the aim of increasing understanding of fibromyalgia and thereby helping and supporting people affected by the disease.

People with fibromyalgia have long been met with distrust and ignorance. Therefore, the fibromyalgia association works for:

- To inform healthcare, insurance funds (Försäkringskassan), employers, schools and more to create a greater understanding of the disease.
- To influence political decisions that have importance for people with fibromyalgia.
- To produce more effective forms of treatment through increased research on fibromyalgia.
- To help and support the association's members.
- To work for everyone with fibromyalgia to have an increased quality of life.
- To teach people with fibromyalgia to live with their disease.

The Fibromyalgia Association
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WHAT IS FIBROMYALGIA?

The word fibromyalgia means pain in muscles and connective tissue. The condition has been known for a long time, but it was only in the 1980s that it was accepted as a diagnosis. Although fibromyalgia today is well known, it is still questioned in healthcare and by authorities. Fibromyalgia, abbreviated FM, is actually a syndrome with a collection of symptoms without clear biomarkers, which makes it difficult to diagnose. Fibromyalgia is a so-called criteria-based diagnosis. The most common is to follow the criteria according to ACR 1990 from the American College of Rheumatology. Fibromyalgia has the diagnosis code M79.7.

What causes the condition is still largely unknown. There are studies that show that people with fibromyalgia have changes in the muscle tissue, changes in pain regulation systems and that there is often psychological overload in connection with the disease.

The pain experience of a person with fibromyalgia is affected by the central nervous system (brain and spinal cord) "turning up the volume" on incoming nerve signals, this is called central sensitization. Today, this type of pain, which is due to changes in how nerve signals are processed, is called nociplastic pain.

That the nervous system becomes overprotective in this way is believed to be due, among other things, to the body's own pain inhibiting system not functioning optimally. This in turn may be due to biological, psychological and social factors that interact in a complex way. In some studies, for example, a different pattern of inflammatory substances in the body has been seen in fibromyalgia, compared to healthy subjects. However, whether it is a cause of, or a consequence of the pain and the stress that the pain can cause is unclear.

The development of long-term pain and the nervous system becoming overprotective appears to occur through the same processes used in learning (*Long Term Potentiation*, LPT). Just as it is difficult to erase a memory, it can be difficult to become pain free. However, learning more about the pain system and trying new, more flexible approaches and behaviors can create new learning, which in the long run can affect the pain experience.

Modern treatment methods largely aim to give the patient the opportunity for such new learning and to influence the vicious circles that easily arise, which also lead to more pain. Pain biologically leads, among other things, to anxiety, and it is common to feel sad and frustrated. Many people experience that their memory works worse and that their patience and energy fail, as well as that their sleep deteriorates. The result is that you don't really recognize yourself. Many feel that they cannot spend time with loved ones as much as before and that self-confidence is negatively affected. Unfortunately, this increases depression and the more anxious or depressed you become, the





more unpleasant the pain becomes and the harder it can be to stay active. Vicious circles can easily be created in this way and you can feel that you are stuck and unable to move forward.

The disease is currently not curable. Medicines that affect the nervous system can be helpful for some, but are rarely the whole solution. The treatment methods that research has shown work best are CBT (cognitive behavioral therapy), physical exercise and pain school. It can be an advantage if you receive these treatments in a coordinated so-called multimodal rehabilitation.

Treatment of fibromyalgia involves working with new approaches where, among other things, acceptance is an important part.

Acceptance means actively working on shifting perspectives and instead of fighting the pain, try to make peace with it and instead focus on what is important and valuable in life. The treatment consists of trying to live as rich and meaningful a life as possible.

Through change work, many people may eventually experience that the pain feels different when the nervous system has the opportunity to learn new things. Acceptance is not giving up, but on the contrary being brave and entering into an active process.

WHO IS AFFECTED?

Around 2–4% of the population is estimated to suffer from fibromyalgia. The majority of these are women (85–90%), but it is increasingly common for men to be diagnosed.

People of all ages can be affected, but the incidence increases with increasing age (up to 75 years). The most common patient presenting for fibromyalgia is a middle-aged woman.

Hereditary factor can affect

A genetic factor has been identified in fibromyalgia and this probably plays a greater role than previously thought. Studies show that daughters of people with fibromyalgia are at increased risk of developing the disease.

How do you develop fibromyalgia?

It is not yet known why some people develop fibromyalgia, but there are a number of factors that are thought to contribute to triggering the condition.

Prolonged local pain is the biggest risk factor. The generalized (widespread) pain has in more than 80% of fibromyalgia patients been preceded by long-term localized pain (for example, after a whiplash injury).

Other factors thought to be associated with illness include sleep difficulties, infections, physical/psychological trauma, catastrophizing thoughts about the pain and its consequences.

Prolonged stress is also a risk factor.



DIAGNOSIS

Criteria-based diagnosis

Current diagnostic criteria for fibromyalgia were established in 1990 by the American College of Rheumatology, ACR. According to these criteria, one must have had general pain in all four body quadrants for at least three months.

On the right and left side, upper and lower half of the body including cervical spine, front chest and/or lumbar spine. In addition to this, one must also feel pain when pressure is applied to at least 11 out of 18 specified places on the body, so-called *tender points*. The pressure should be relatively light.

Alternative diagnostic criteria

There are other criteria that can be used in diagnosing fibromyalgia. These were approved by the ACR in 2010 and are used to some extent today. In 2016, there was a revision of the criteria based on the assessment instrument Widespread Pain Index (WPI) and Symptom Severity Scale (SSS). In Sweden, the criteria from 1990 are still mostly used. The lack of laboratory tests or X-ray findings that can objectively support the diagnosis means that fibromyalgia is sometimes questioned.

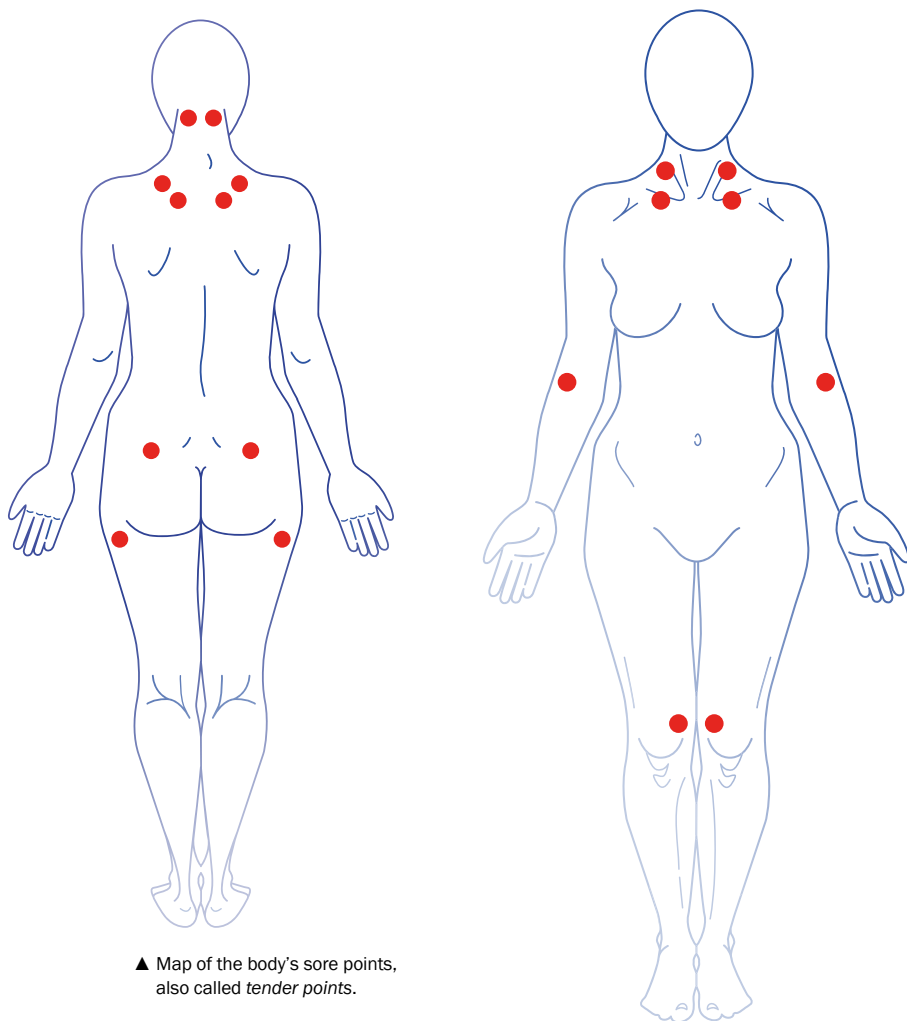
Differential diagnosis (diseases with similar symptoms)

Although fibromyalgia is no longer considered a diagnosis of exclusion, there are a number of different conditions that can produce similar symptoms that also need to be investigated. It is important that other treatable diseases are not missed at the time of investigation.

It is important to distinguish which symptoms are due to which disease. This requires close contact with your doctor and frequent follow-ups, where your doctor can also diagnose and treat other treatable conditions such as rheumatic diseases, hypothyroidism and depression. Ehlers Danlos syndrome (EDS) and Myalgic Encephalomyalitis (ME/CFS) are syndromes which have many overlapping symptoms with fibromyalgia. It is not uncommon to meet criteria for more than one syndrome.

Often a long wait for a diagnosis

The disease fibromyalgia is difficult to diagnose. Several visits to



▲ Map of the body's sore points, also called *tender points*.

different doctors are often required. It can take several years before you get your diagnosis, which is of course psychologically stressful.

Forecast

Fibromyalgia is a long-term condition. There are occasional patients who recover completely, especially if the pain has not been there for a long time. Identification and treatment of symptoms makes it possible to learn an approach to the pain and fatigue without it taking over life completely. The disease is not progressive, which means that you usually do not get worse over time.

BEFORE YOUR DOCTOR'S VISIT

Prepare before seeing the doctor so that you can present your symptoms correctly. Consider the following:

- What are your symptoms and when did they start? Have you had them all the time or off and on?
- Have you discovered something that triggers your symptoms?
- How are your symptoms affecting you?
- How do you experience your pain? Is it sharp or muted?
- How do the symptoms affect your feelings? Does the pain make you depressed or anxious?
- How do the symptoms affect your work and personal life?
- What medicines, herbal remedies or supplements do you take?
- What surgeries have you had?
- What current treatments has another doctor or specialist prescribed?

Write a pain journal

The doctor may find it easier to understand you if you keep a daily pain journal of how you feel, even if it only spans a period of a few weeks. Note the pain intensity (on a scale from 0 to 10), activity and how you feel a few times per day. It will help both you and the doctor to be able to see your pain patterns.

On the Fibromyalgia Association's website there is a folder in which you can describe your pain. You can download it and fill it in before your doctor's appointment.

Find the right doctor

Your symptoms are real even though you may be told they are not. It is good if you find a doctor who is knowledgeable in chronic pain. If possible, request a longer time for your first visit. You have the right to change doctors if you feel that the chemistry between you is not right.

Get emotional support

It can be helpful to get support from a therapist or someone else you trust. Sometimes you need to know that you are not alone in your situation and then you can turn to a local fibromyalgia association for contact with others. It is also good to have someone outside to talk to who understands your situation.

SYMPTOMS OF FIBROMYALGIA CAN INCLUDE:

Pain and tenderness

The main symptom of fibromyalgia is long-term, widespread pain. Often the maximum painful area moves between different parts of the body and the intensity of the pain varies from day to day. Completely pain-free days rarely occur.

Fibromyalgia patients often describe muscle pain, but they can also have pain in the joints. The pain worsens with muscle work, but pain also occurs at rest. You have less stamina and often move more slowly. As the pain usually worsens after physical activity or training, this can lead to inactivity and you can develop a fear of movement. It is important to remember that the pain in fibromyalgia is rarely dangerous, and that physical exercise is important for a positive prognosis. On the other hand, you may need to rethink training and try your way from a level that is low-intensity, but regular. Anything that can be made a daily habit is good, such as short walks.

In fibromyalgia, one has a generally increased sensitivity to pressure-triggered pain, which is therefore not only limited to the body's *tender points* or the muscles. Tenderness linked to a lowered pain threshold is characteristic of the disease. This can cause pain even with a mild pressure that usually does not cause any discomfort, for example pressure from clothes or a hug.

When something that normally shouldn't hurt becomes painful, this is called *allodynia*. Painful stimuli, such as a needle stick or stubbing the toe, can be experienced much stronger than in healthy people. It is called *hyperalgesia*.

Numbness, tingling and burning occur in more than half of the patients, without any nerve damage.

Morning stiffness

Stiffness in the morning is a common symptom and it may take time to go away. For some, the feeling of stiffness persists throughout the day.

Fatigue and sleep disturbances

About 70% of all fibromyalgia patients suffer from fatigue, which can be as disabling as the pain. The fatigue cannot be explained by external stress, and cannot be rested away. *Fatigue* is a term used to describe this type of exhaustion. Sleep disorders are part of the disease and affect approximately 70–90% of patients. Difficulty falling asleep and/or shallow, broken sleep is very common, and you rarely wake up refreshed.





When you're tired, it's easy to fall into sleep-depriving habits. You can therefore benefit from a sleep school and changing your bed routines. A stable circadian rhythm where you get up and go to bed at the same time every day, as well as reducing your time awake in bed, are the most important parts of such a treatment.

Psychiatric symptoms

In fibromyalgia, symptoms such as concentration difficulties, impaired memory and an increased sensitivity to stress are seen. Depression and anxiety are also common and it is important that this is treated.

Other symptoms

The following symptoms are common in fibromyalgia, but do occur also in other conditions:

- IBS (irritable bowel syndrome)
- Irritable bladder
- Impotence
- Problems with skin and mucous membranes
- Tension headache
- Indigestion and stomach pains
- Sound, light and smell sensitivity
- Numbness

Overlapping symptoms

Patients with fibromyalgia may exhibit combinations of symptoms that are also common in other diseases. These are called overlapping symptoms, i.e. the same symptoms are shared by one or more diseases. Examples of conditions with some common symptoms with fibromyalgia are ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome), MPS (myofascial pain syndrome), and RA (rheumatoid arthritis).

FACTORS THAT INFLUENCE

SOME THINGS CAN WORSEN FIBROMYALGIA SYMPTOMS

Physical overexertion

A sudden increase in physical activity can lead to such severe exercise pain that it is difficult to function normally for several days afterwards. One may even experience a kind of malaise. If you are inactive for several days, you get less benefit from your training. Exercising at a suitable level is, on the other hand, beneficial for fibromyalgia.

Inactivity

Inactivity can also make the pain worse. Our pain regulatory systems are probably negatively affected by inactivity. It can also lead to increased depression, anxiety and impaired night sleep.

Monotonous movements and static load

Monotonous and static movements can lead to overload, as the endurance of the muscles can be reduced. It can make carrying things more difficult and it can be a challenge to perform repetitive movements such as hanging laundry or unloading the dishwasher. However, you can cope with a lot if you think about taking short breaks and avoid tension in, for example, shoulders.

An occupational therapist can guide you on how to better cope with physically challenging activities.

Stress

Our stress system exists, among other things, to enable us to cope with various challenges. It is fundamentally positive that we have the ability to "shift up" to cope with demanding things. However, constant stress is negative and can worsen pain and fatigue. We may have to think about what in everyday life we can change and above all give ourselves moments of relaxation. Then stress doesn't have to be a bad thing. Trying to avoid stress completely can lead to increased stress sensitivity and further anxiety and depression.

Anxiety and worry

Many people with fibromyalgia suffer from depression, worry and anxiety, which can depend on how they are treated. Research shows a strong link between depression and long-term pain.

Weather changes

Rain, cold and wind can cause increased pain. Most, but not all, feel better in heat. Sensitivity to both heat and cold is common.

TREATMENT FOR FIBROMYALGIA

Medical treatment

When you suffer from fibromyalgia, you naturally hope that medication will provide good pain relief. Unfortunately, this is often not the case. With research and increased knowledge about how the pain occurs, we can hopefully also get a better effect from drug treatment.

Traditional pain-relieving drugs such as Ipren and Alvedon can have a good effect on acute pain, but do not have the same good effect in fibromyalgia. This is because the mechanisms underlying the pain are different in fibromyalgia. In fibromyalgia there is an increased sensitivity in the sense of pain, *sensitization*, which has developed and become the most important pain mechanism.

Morphine preparations should be avoided as they cause a lot of side effects and lose their pain-relieving effect over time. These can even cause increased pain and side effects such as constipation, irritability and increased depression. Especially if they are used every day for long periods of time.

The drugs that can have some effect in fibromyalgia are medicines that affect our sense of pain. Some antidepressant drugs, such as SNRI preparations, can relieve both pain, fatigue and sleep problems in the short term because they affect the levels of serotonin and norepinephrine, substances that have an important function in the body's own pain-inhibiting system.

It is important to have realistic expectations if you are trying medications. Often you have to try your hand at different combinations of medication to see what works best. An individualized treatment is important, as the same treatment is not suitable for everyone. A common combination is pain relievers combined with low dose antidepressant medications.

Multimodal rehabilitation

The treatment methods described below are often coordinated in a so-called multimodal rehabilitation. This is often given in groups, which has proven to be good for the process.

School of pain

This is a fundamental part of care that is sometimes neglected.

Several studies have reported that education in pain physiology not only helps relieve symptoms, but also leads to better functioning and disease management, as well as prevents the development of catastrophizing. It thus helps to understand more about how the sense of pain works and how to develop an overprotective sense of pain.



CBT and ACT

People with fibromyalgia (as well as others who suffer from chronic pain) have a tendency to develop unfavorable ways of thinking and acting, which can lead to the worsening of their symptoms. One can easily end up in vicious circles with increased depression and anxiety. CBT (Cognitive Behavioral Therapy), and ACT (Acceptance Commitment Therapy), offer different techniques and methods to become aware of and change these, often unconscious, ways of thinking and acting. Through CBT and ACT, new behavior patterns are supported.

Physical activity

Exercise is a treatment that research has shown has a good effect. Therefore, it is good to get help to start training your strength and endurance carefully and in the right dose. It can be difficult to find the right level at first, but physical activity helps in the long run.

Many feel good from exercising in warm water. It is also important not to underestimate the gains of everyday activity!

HERE ARE SOME SUGGESTIONS ON WHAT YOU CAN EXERCISE:

- Water gymnastics in a well-heated pool
- Walks
- Cycling
- Weight Training
- Yoga
- Tai chi

All exercise in fibromyalgia should start at a low intensity with a careful, gradual increase. Preferably with the support of a physio therapist.



Treatment against fatigue

Pain, fatigue and sleep problems are connected and affect each other. Depending on the type of sleep disorder you have, different treatments are recommended.

As a first step, you can cut back on caffeine, alcohol and smoking. These substances have a negative impact on sleep. Also try to get yourself a good sleep routine. 24-hour rhythm is important and it is best stabilized by trying to get up at roughly the same time every day. You should also avoid going to bed too early if you are awake for long periods during the night. Keep cell phones and tablets switched off during the night. You are easily disturbed by the ringing, even if you are not fully aware of it. Buy a normal alarm clock instead.

A so-called sleep school is training in how you can manage your sleep problems yourself and is the treatment that has the best effect on sleep disorders. You can keep a diary of your sleeping habits and receive practical tips and advice on how to improve your sleep.

At fibromyalgiportalen.se you will find a sleep school adapted for you with fibromyalgia.

There is sometimes reason to talk to your doctor about your sleep. This applies, for example, if you are bothered by restless legs or if you snore a lot. In the case of snoring, it may be necessary to rule out that you have nocturnal breathing breaks that cause great fatigue during the day. There is treatment for this.

Medical treatment

Antidepressant SNRI preparations can relieve both pain, fatigue and sleep problems in the short term. Medicines for sleep should be used with caution.

Vocational rehabilitation interventions

People with long-term sick leave or recurring shorter periods of sick leave due to fibromyalgia should be offered occupational rehabilitation interventions after assessment of work ability and establishment of an individual rehabilitation plan.

Inform your employer and co-workers about your situation and how you feel. Get help reviewing what you can change regarding routines and your workplace. Get help from an occupational therapist. You have the right to receive work aids.

If you cannot continue to work in your place, you have the right to relocation if this is possible. Consider going through



different solutions with the insurance fund (Försäkringskassan) and doctor before you agree to reduce working hours.

Physiotherapist and physiotherapist

A physiotherapist has a wide range of knowledge and can help you with optimal training and suggestions for relaxation techniques. The physiotherapist can also offer pain-relieving treatment such as TENS (*Transcutaneous Electrical Nerve stimulation*, a pain relief method that stimulates the nerves) and acupuncture.

You do not need a referral to see a physiotherapist.

Occupational therapist

You can get support from an occupational therapist to increase valuable activities in everyday life. It could be getting help with changes to, for example, habits or routines. It could also be to adapt the environment you live in, or to find new strategies in what you do, so that everyday life works better for you.

Other forms of treatment

In this section everyone gets to try things out after what works.

Milder forms of massage can have a positive effect for many.

Treatment options that may be considered are; TENS, yoga, movement-increasing treatment and acupuncture.

Methods such as yoga, mindfulness and meditation can help reduce your stress and thus your pain.

LEARNING TO LIVE WITH FIBROMYALGIA

Living with long-term pain places great demands on adjustment and changed behaviour. How well you succeed depends on your personality as well as your family relationships and social circumstances. It also depends on any other illnesses, injuries, physical condition and how understanding your surroundings are. Support and understanding from healthcare is very important.

Most people eventually find a way of life that makes the balance between activity and rest work.

Practice finding a balance between overactivity and inactivity.

Help yourself to an easier everyday life

When you have fibromyalgia, every day is a new challenge. What can you do yourself to make everyday life easier?

Divide activities into sessions with breaks in between. This is called *Pacing*, and is something that everyone with fibromyalgia does more or less unconsciously, but which can be good to practice. For example, household chores can be done at a slower pace where you think about doing one thing at a time and avoid "crashing" afterwards (which can also steal a lot of time). Map your energy account. Respect what you can do during the day and try to stay within those limits, even if you are doing something that you think is fun. This way you save your energy.

Activities can conceivably cost energy, but can also provide energy if you find a sustainable way to carry them out. Prioritize what you put your energy into. Keep in mind that it can be important to think about what gives pleasure and joy and to prioritize it over more demanding activities.

- Start the day with a hot shower. Heat relieves pain and softens stiff muscles.
- Move! Inactivity leads to stiffness and fear of movement.
- Activity is good, even though it can hurt.
- The pain is not dangerous!
- Daily exercise is important. Take the stairs, stretch during the break, stand and work sometimes, cycle to the shop. Above all; avoid long periods of sitting still.
- Do something that you find fun. Maybe you have a special hobby. Getting involved in something you enjoy makes you focus



on what is important in life and divert your attention from the pain for a moment.

- Don't say no to something in advance for fear of not being able to attend. Make a decision on the day it applies. Often you feel better having done something that you might enjoy.
- A good night's sleep is very important. Improve the sleeping environment with a comfortable bed, blackout curtains or whatever makes you feel good.
- If possible, wear clothes that are easy to put on and take off.
- Learn relaxation! Relaxation can help you improve sleep quality and give your body more time for healing and recovery. At fibromyalgiportalen.se you can get help with mindfulness and meditation.
- Take one day at a time. The disease comes and goes, that is, worse days alternate with better ones. Give yourself permission to feel a little worse sometimes without despair.
- Try to accept that the pain is there but that it should not prevent you from living a meaningful and rich life. Find strategies to cope with this mentally and practically instead.
- Lower the demands on yourself. Take breaks and vary your movement pattern -Often!

MEN WITH FIBROMYALGIA

Just because fibromyalgia mainly affects women, one should not forget that men are also affected. The very fact that fibromyalgia is seen as a "woman's disease" makes it more difficult for men to get the correct diagnosis when they see a doctor for their problems. It is quite possible that there are hidden statistics for men with fibromyalgia because they are often given another diagnosis, such as wear and tear damage, herniated disc or burnout.

Fibromyalgia symptoms in men

The symptom picture in men differs from that seen in women. Research shows that men often experience milder symptoms than women, and they usually describe fewer tender points, less fatigue, morning stiffness and less IBS.

Social expectations

The traditional gender roles mean that the man is expected to be strong and resilient, although this has started to change to some extent. Some men base their self-esteem on their ability to work and to be able to take care of their family. When men suffer from fibromyalgia, they often cannot live up to their expectations and can then experience a sense of failure, which can lead to mental illness.

Contact with other men

Because fibromyalgia mostly affects women, men can feel extra alone in their illness. The association has its own Facebook page intended for you as a man.





When children and young people receive a fibromyalgia diagnosis, the loss of a normal life is extremely great. You want nothing more than to be one of the gang and be able to go out and play, go to the disco or play football. This can be difficult when the fatigue and pain set limits.

Questions that can be raised are: What will I be able to cope with? What will my life look like? Will I be able to do what I want?

Onset of symptoms

Fibromyalgia in young people often begins around puberty, when the child is 11–15 years old, but can also affect younger children. More girls than boys are affected, but the gap does not appear to be as large as in adults. The symptoms are the same as for adults with constant or almost constant pain and fatigue. During puberty, the pain is unfortunately often explained away as “growing pains”, it is therefore important to stand your ground and demand a thorough medical examination.

Family and school

The whole family is affected by all the visits and examinations that have to be done with doctors, school health care and counsellors/psychologists. For the child, of course, the whole life is turned upside down. It is then important that the family tries to live as normally as possible.

There is a risk that the child/youth ends up in negative circles with increased pain, impaired function and increased anxiety and depression if everyday activities such as school and leisure interests are avoided. However, this risk needs to be balanced with empathy and opportunities for adaptation, where activities are not avoided but can be adapted based on needs. The teachers should get





information about the disease and how they can support and improve the conditions for completing schooling. This may, for example, mean ergonomic adaptation, space for rest breaks or sitting in a certain place in the classroom.

More favorable prognosis

The good news regarding fibromyalgia in children and adolescents is that it is more treatable, and that the prognosis for the disease is more favorable than for adults. Some studies have shown that the disease improves faster in children than in adults and that in some cases it can even go away.

In terms of treatment, it has been seen that CBT and physical exercise are beneficial, just like for adults. One can therefore assume that pain school should also be of value, even if there is a lack of major studies in this regard. A young person has a young and malleable nervous system that is receptive to new knowledge.

It is of course important to rule out other treatable causes of pain such as rheumatism. Equally important is to pay attention to whether the young person is about to develop avoidance behaviors and may need professional help in the form of a doctor, physiotherapist and psychologist.

The Fibromyalgia Association has published a brochure specifically aimed at children and young people with fibromyalgia, and there is also a brochure aimed at school staff. You can download the brochures from the association's website: fibromyalgi.se.

THE DISEASE AFFECTS

Not being believed is a big problem for those suffering from fibromyalgia. As the disease is not visible on the outside, doctors, insurance funds, family, friends and colleagues may question the pain and fatigue you feel.

This is frustrating and difficult and can also lead to you having to see several doctors to find someone who really listens and takes you and your illness seriously. You have the right to a knowledgeable doctor who understands what problems the disease poses for you and who can help you with the symptom relief you need.

Inform family, friends and colleagues

Make sure to collect as much information as possible about sick-the judgment, for example brochures, articles and websites. Try to be straight and honest about how you feel. Trying to hide the fact that you are unwell only makes the situation worse.

Contact with other people living with fibromyalgia is important

It is nice to know that you are not alone in your illness. You should make sure you connect with others who have fibromyalgia and who understand your situation. By joining one of our local associations or registering at *fibromyalgiportalen.se*, you can get to know others with fibromyalgia. Together you can support and encourage each other. Of course you can also share your experiences. For many, membership of an association and participation in association activities has given them back their joy and zest for life.

Tips for you who are relatives

It is nearly impossible for people who have never experienced long-term pain to understand someone living with a chronic pain condition. You just can't take in what it's like to be in constant pain, never be full of energy, never sleep a full night, never wake up groggy, know that the constant pain will be there for the rest of your life and deal with it.

The pain often comes in flares with alternating better and worse periods. It may happen that you have to cancel things you intended to do and instead have to focus on dealing with the pain. In these situations, it is especially important that you do not blame your partner. A flexible approach, however, does not mean that you should abandon yourself and adapt your entire life and your life together based on the pain. On the other hand, it means that you have to reevaluate your view of quality of life and recognize the pain as part of your life, and to which you must relate.





**Things you should NOT say
to those who have fibromyalgia:**

- You're just imagining things.
- But it can't be that bad anyway.
- You will see that it passes.
- Try to have a more positive attitude.
- It must be wonderful to be free.
- It could have been worse.

Relationship tips for fibromyalgia

- Communicate. Finding ways to talk openly about challenges leads to effective problem solving and closeness. Remember you are playing on the same team!
- Relieve stressful feelings. Feelings of sadness and anxiety are normal reactions to a chronic illness. Find strategies to help each other when it feels difficult.
- Consider counseling. Couples can go to therapy together, or each separately, with a therapist, priest or psychologist.
- Watch out for depression. Grief is a normal response to chronic illness, but clinical depression is not.
- -Seek care in time!
- Inform your surroundings about your needs. The affected person can give double messages. The person wants to do things themselves, but may also feel offended when others do not help. The balance in the relationship changes. The healthy partner may feel taken advantage of. Be clear in your messages and be honest with feelings.
- The supporting party should pay attention to their own physical and mental health. There may be a risk of burning out. Pay attention to warning signs!
- Strengthen social connections. A chronic illness can be isolating. Strong friendships are a buffer against depression. The healthy partner must feel free to be social on their own even if the sufferer cannot bear to socialize with others.
- Address financial stressors. Money can be a strain on any couple, and chronic pain can take a huge financial toll. Planning and budget then become extra important.

THE FIBROMYALGIA PORTAL

The fibromyalgia portal is part of the project Feel good with fibromyalgia, where the Fibromyalgia Association launches a completely new concept for self-care in fibromyalgia.

The portal is an interactive digital platform that offers knowledge and tools that can lead to better disease control and increased quality of life.

OUR VISION WITH THE PORTAL IS TO:

- Help as many people with fibromyalgia feel better as possible.
- The portal should function as a relief for the healthcare system.
- The portal should be a gathering place on the internet for that which is relevant to self-care in fibromyalgia.
- The platform should be user-friendly and easily accessible.
- With a focus on inherent resources, we highlight the healthy choices and what you can actually do.

WWW.FIBROMYALGIORTALEN.SE





**DARE TO FEEL GOOD!
FIND THE BALANCE!**

FIBROMYALGIFÖRBUNDET

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