



miracle cures pain fatigue dismay
suspicion uncertainty anxiety
problems stress
questions incomprehension
uncertainty anxiety
doubt dismay stress
fatigue doubt
pain problems stress
dismay suspicion uncertainty
doubt problems stress
uncertainty anxiety
fatigue stress
doubt problems stress
suspicion long journey
certainty doubt pro
acle cures anxiety long jo
erf questions incomprehens
blems anxiety stress
doubt long journey stress disbelief

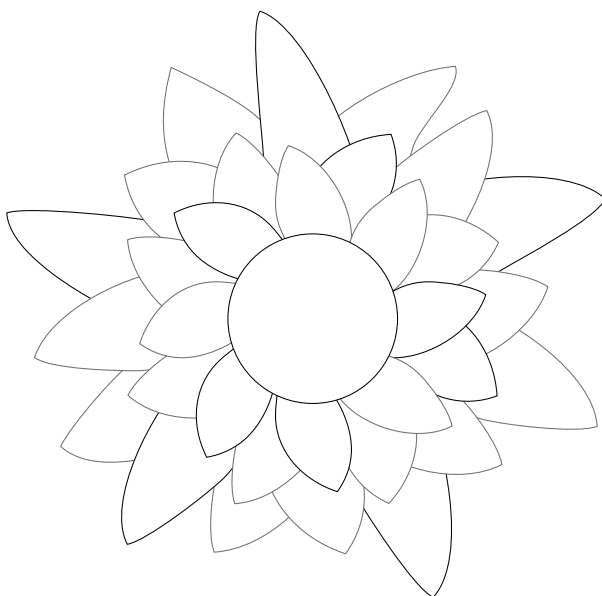


A BEGINNER'S GUIDE TO FIBROMYALGIA



adfm
fibromyalgia
awareness
association

Eguzkilore: From Basque, EGUZKI (*sun*) LORE (*flower*).



Authors

Scientific Committee of adfm (Fibromyalgia Awareness Association)

Dr Rafael Belenguer Prieto. Rheumatology.
9 de Octubre Hospital. Valencia.

Dr Ana Carbonell Baeza. Physical Activity and Sport Sciences.
University of Cádiz.

Dr Javier García Campayo. Psychiatry.
Miguel Servet Hospital. Zaragoza.

Dr Juan Vicente Luciano Devis. Research.
Sant Joan de Déu Health Complex. St. Boi de Llobregat.

Dr Ana María Martín Nogueras. Physiotherapy.
University of Salamanca.

Dr Manuel Martínez-Lavín. Rheumatology.
Manuel Chavez National Cardiology Institute. Mexico City, D.F.

Ms Esther Muñoz Espinalt. Nursing.
Del Mar Hospital. Barcelona.

Dr María Ángeles Pastor Mira. Psychology.
Miguel Hernández University.

Dr Cecilia Peñacoba Puente. Psychology.
Rey Juan Carlos University.

Dr Elena Pita Calandre. Clinical Pharmacology.
University of Granada.

Dr Javier Rivera Redondo. Rheumatology.
Gregorio Marañón Hospital. Madrid.

Dr Fernando Torre Mollinedo. Pain Unit.
Galdakao Hospital. Biscay.

Dr Eva Trillo Calvo. Family Medicine.
Aragón Health Service. Zaragoza.

Coordinator

Andoni Penacho Albisu.
adfm (Fibromyalgia Awareness Association).

Acknowledgements

To our scientific committee. Never has anyone had so many wonderful colleagues.
To those who have been with us from the start.
To those who have supported us up to now.
To those of you who are here with us now.

In memory of

Dr Jesús Acín Urzainqui

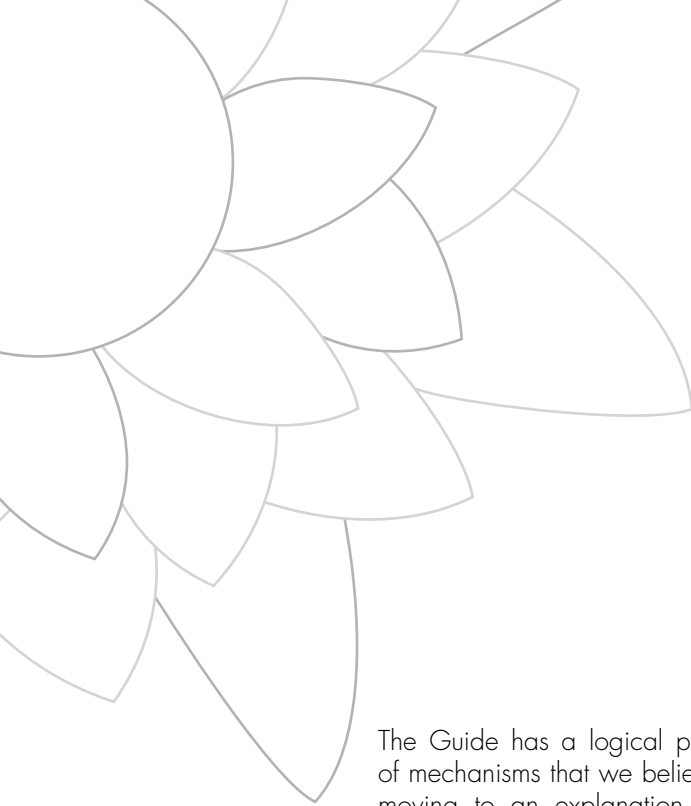
Dr Juan Carlos Vesga Carasa



PREFACE

For so many years fibromyalgia has been a Cinderella condition: patients often not believed and required to endure suffering in silence, the health community sceptical of the existence of illness without any clinical measurement, and researchers grappling with the understanding of cause and mechanisms. In this first quarter of the 21st century, much has changed. There is global acceptance that fibromyalgia is indeed a valid condition, there have been tremendous advances in understanding the mechanisms at play, and clinicians now appreciate that each individual experiences this condition in a unique way with a diversity of symptoms and a spectrum of severity. Fibromyalgia is therefore the epitome of a condition that requires a good partnership between the patient and the healthcare team in order to achieve the best outcome. To this end patient engagement and empowerment is a crucial first step, beginning with a global knowledge of the condition.

It is therefore timely that a reliable, easy to understand and informative document should be available to help patients and their families have a better understanding of fibromyalgia. A Beginner's Guide to Fibromyalgia is exactly what is needed and fills the gap perfectly. Developed as a collaborative project by healthcare professionals with diverse expertise, this comprehensive Guide provides up to date and useful information, and can be recommended as an excellent reference for those eager to have a better knowledge of fibromyalgia.



The Guide has a logical progression, beginning with an explanation of mechanisms that we believe are operative in fibromyalgia, thereafter moving to an explanation of how fibromyalgia is diagnosed, and culminating in the body of the work that provides useful practical advice and self-management tips about the many facets of living with this condition. Most importantly there is an excellent description of relevant questions that are probably asked by most patients at some time. A thorough reading of this Guide will provide many tools that can be used to promote health and well-being.

The authors can be justly proud of a superb work that will have meaningful value for our patients and families. By facilitating the education of patients and families, the partnership of patient and healthcare team will be nurtured and the wellbeing of patients will be improved. This excellent reference manual should have a special place in the home library of every person with fibromyalgia. "Knowledge is power", a statement from over half a century ago is meaningful today.

Mary-Ann Fitzcharles, MB, ChB, FRCPC

Rheumatologist and Pain Physician

INTRODUCTION


If a doctor has just told you that you have fibromyalgia, this Guide is for you. I'm not going to try to pass myself off as a clairvoyant but my guess is that you're a woman about forty years old. I could be wrong, as it also affects men and other age groups, but I've got a head start here. The available statistical information also tells me that you've had years of going round and round in circles, undergoing inconclusive diagnostic tests and consulting several different doctors.

You've probably endured a long journey full of doubts and fears. That's why we wanted to produce this Guide to give you some clear concepts to help you in your everyday life and be your new travelling companion. One thing is certain: you're in a better position today than you were yesterday. Now you're not wrestling with a ghost, now you have something concrete to deal with; our experts will help you and tell you how to do this.

What you need to know is that you're facing a chronic illness, so the sooner you deal with it and control the symptoms, the sooner you'll start feeling better.

The information given by our scientific committee (who have written and revised the Guide) comes from many different disciplines and is based on scientific evidence. All the techniques, therapies and products mentioned here have been proved effective.

This Guide can never, however, be a substitute for healthcare professionals, who should always be consulted.



Never forget how important it is for you to take responsibility for your own health. This means that, when necessary, you should trust qualified, experienced healthcare professionals and follow their advice because they are the only people with the clinical training to ensure you get appropriate, reliable treatment.

It's understandable that we, as patients, look for solutions to our disorder, but we should be very cautious when offered miracle cures or products by people taking advantage of our illness, since their unproven effects can endanger our health and self-esteem.

I'm sure that you will be able to find a local fibromyalgia association that will be really helpful. Please seize the opportunity to find out more about it, by contacting them for more information on their activities.

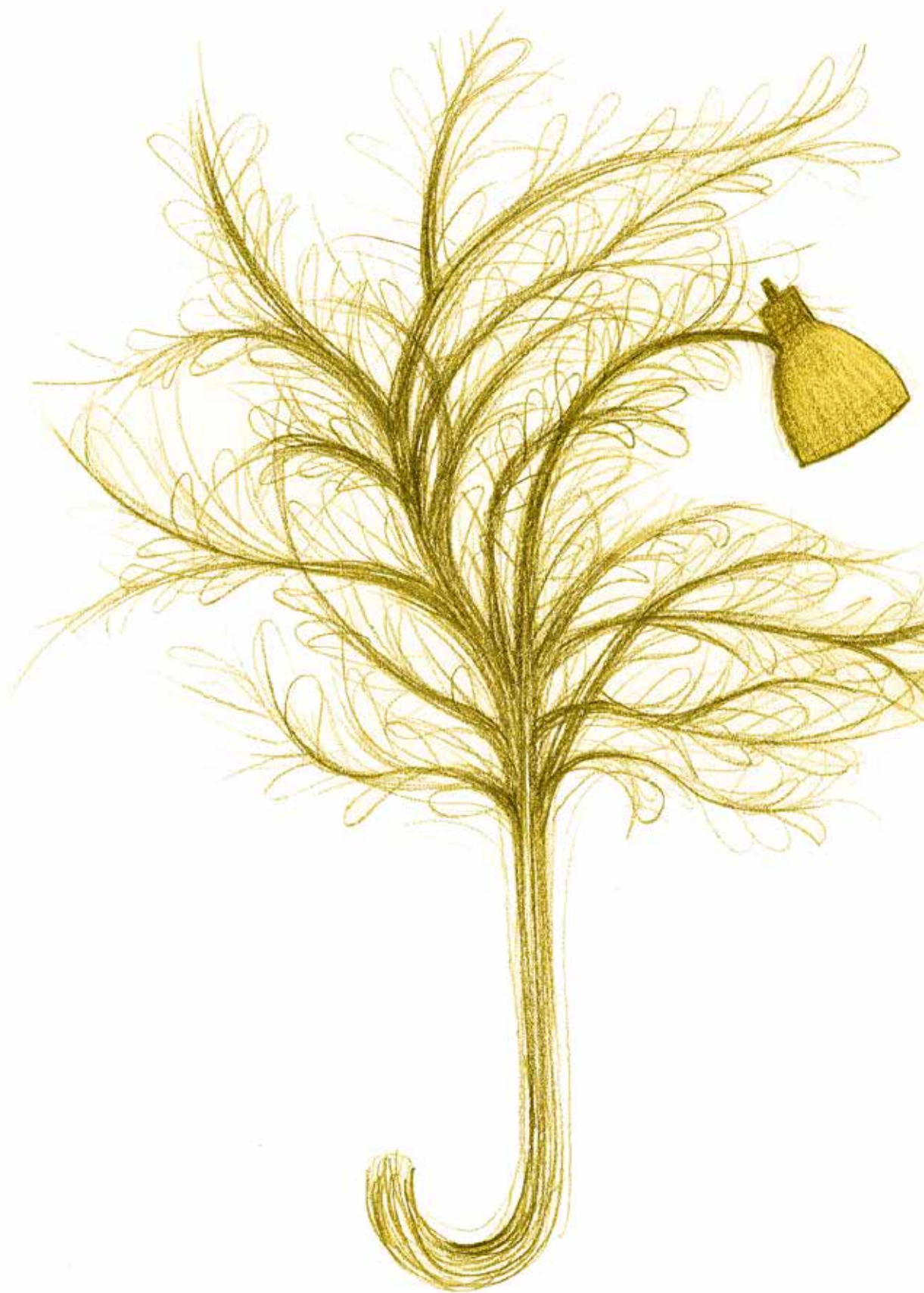
We hope you find this Guide useful, because we have produced it for you.

Andoni

CONTENTS

What is fibromyalgia?	13
Primary care	23
Psychological treatment	29
Physical activity	35
Physiotherapy	51
Healthy habits	55
Relationships with family and friends	67
The future and the current state of research	73
FAQs	79

This Guide has been written by various specialists who work in the National Health System in Spain. Its content reflects some of the peculiarities of the Spanish health system, which may not match those of other countries. It therefore cannot be extrapolated to other healthcare systems.



WHAT IS FIBROMYALGIA?

“También a mí me dan miedo las estrellas y todas esas cosas que no se abarcan o no se acaban nunca...”

“I am also afraid of the stars, and of all these things we cannot fathom, or which never end...”

Miguel Delibes

Fibromyalgia is a common illness characterised by many different symptoms that occur all at once. The cardinal symptom is widespread musculoskeletal pain (affecting the muscles, ligaments and joints); symptoms also include profound fatigue, sleep problems, lack of concentration, memory loss, anxiety and feeling sad, among others (Table 1).

Fibromyalgia is characterised by many symptoms that occur all at once

Other symptoms, such as headache, digestive disorders, dizziness, muscle spasms, chills, low-grade fever, ringing in the ears, dry mouth and eyes or widespread itching,

are less common and not all patients experience them, although they may appear at any time during the course of the condition.

Table 1. Common symptoms at the time of diagnosis

- Widespread pain
- Fatigue
- Sleep problems
- Cognitive disturbances (concentration, memory)
- Altered mood (anxiety, depression)

The features of these symptoms are very similar in most people with fibromyalgia; what really matters is the number and variety of symptoms that occur at once. Clearly, the greater the number of symptoms, the greater their impact on the patient's life.

You have probably already seen a number of doctors and specialists, who may have made various different diagnoses (**Table 2**), and you may be undergoing a number of treatments. We hope that, after reading this Guide, you will have learnt that many of the diagnoses you have received are simply clinical manifestations of fibromyalgia. This knowledge may also help you come off some medicines once you have started treatment for fibromyalgia.

Table 2. Other diagnoses common in patients with fibromyalgia

- Irritable bowel syndrome
- Headache
- Muscle spasms
- Subclinical hypothyroidism
- Restless leg syndrome
- Vertigo or dizziness
- Mixed anxiety-depressive disorder

You should also be aware that fibromyalgia has a fluctuating course, with periods of improvement and flare-ups, which depend on many different circumstances and are distinct in each patient. This will help you understand that an especially rough patch is often followed by a better period.

How fibromyalgia develops

The latest research has found that fibromyalgia involves changes in the body's neurotransmitters – the substances that allow nerve cells to communicate with one another.

When produced in adequate amounts and at the right times, neurotransmitters – such as serotonin, noradrenaline, adrenaline, dopamine and many others – ensure proper functioning of the circuitry of the nervous system. When the production of neurotransmitters is altered, the circuits that depend on these substances malfunction, which produces symptoms.

This is precisely what happens in your pain pathways: malfunctions in these neurotransmitters lead to a situation in which some stimuli are perceived more strongly than usual, thus producing the characteristic, widespread aches and pains of fibromyalgia.



Neurotransmitters are responsible not only for pain pathways, but also for the proper operation of other circuits. So, when they fail, other symptoms appear as a result of abnormal function in these other pathways. Sleep problems, headaches, fatigue, changes in digestion, cognitive disturbances and even symptoms of anxiety and depression are believed to originate through this mechanism.

The specific causes of fibromyalgia are unknown

The specific causes of fibromyalgia are unknown (Figure 1). Many possible causes have been studied, including viral infections, hormonal disorders, muscle conditions and exposure to toxic substances in the environment. However, we still don't have the answer to what causes fibromyalgia.

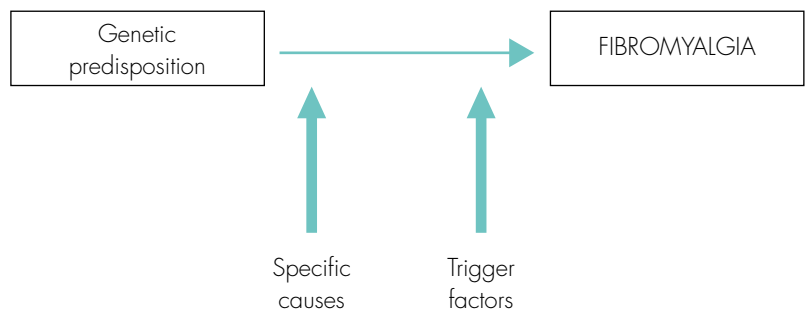


Figure 1. **How fibromyalgia develops**

Genes play an important role in one's predisposition to developing fibromyalgia. The number of affected individuals in the same family is often greater than expected, which suggests that genetics are involved. In fact, some studies have already reported that certain genes are associated with fibromyalgia.

Triggers cannot be considered a cause of fibromyalgia, but, as their name implies, they can trigger the start of clinical manifestations, especially in people who are genetically predisposed. Indeed, any stressful life event can act as a trigger: an accident, an operation, being assaulted, menopause, problems at home or work may trigger a flare-up or increase symptoms. Of course, the greater the duration and intensity of the triggering event, the greater its influence on your life.

In short, these trigger factors end up breaking down your body's stress response mechanisms, and the symptoms of fibromyalgia start to appear.

How fibromyalgia is diagnosed

The diagnosis is based on your clinical manifestations. A wide range of the aforementioned symptoms, occurring at the same time and often quite severely, should raise suspicion of fibromyalgia (Table 3).

A diagnosis of fibromyalgia is not reached by ruling out other diseases; it is established because your set of symptoms is consistent with the diagnosis.

Physical examination does not contribute much relevant information to the diagnosis. Nevertheless, it may reveal the presence of hyperalgesia (pain and tenderness greater than expected when pressure is applied) or allodynia (pain in response to stimuli that shouldn't be painful), which are highly characteristic signs observed in some people with fibromyalgia. Physical examination can also rule out other conditions, such as inflammation of the joints.

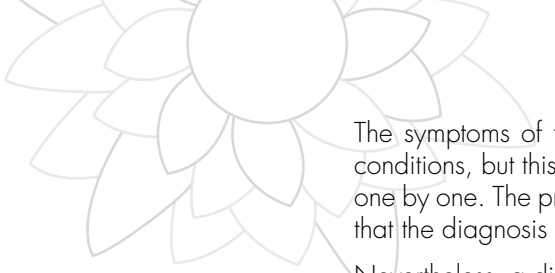
Until recently, much importance was given to pain and tenderness from applying pressure to specific points on the body (known as 'tender points'), and these were considered essential for a diagnosis of fibromyalgia. However, over time, studies have proven that tender points are not specific to fibromyalgia, and increasing importance is now being given to the other symptoms. In fact, tender points are no longer a necessary criterion for a diagnosis of fibromyalgia.

A diagnosis of fibromyalgia is not reached by ruling out other diseases; it is established because your set of symptoms is consistent with the diagnosis

Table 3. Diagnosis of fibromyalgia

- Based on symptoms, not on ruling out other diseases
- Physical examination does not provide additional information
- No lab tests or other tests are needed
- The presence of fibromyalgia does not rule out other diseases
- The presence of other diseases does not rule out fibromyalgia

There are no laboratory tests or imaging studies that confirm or rule out the diagnosis. An MRI scan of any painful area of the body, for instance, will not provide any information to help diagnose fibromyalgia, as the changes caused by the illness are not located in the tender area, but rather in the body's pain transmission pathways. Furthermore, these changes occur at a molecular level and are impossible to detect with scans.



The symptoms of fibromyalgia are common and very frequent in other conditions, but this doesn't mean that other diseases have to be ruled out one by one. The presentation of symptoms in fibromyalgia is so distinctive that the diagnosis is usually quite straightforward.

Nevertheless, a diagnosis of fibromyalgia does not rule out the presence of other diseases; in some cases, tests may have to be performed to determine whether you have other illnesses as well.

Conversely, when someone is diagnosed with any other disease, this does not necessarily rule out the presence of fibromyalgia. In many patients, fibromyalgia first appears alongside other illnesses, which can even mask or hide its symptoms. In such cases, the symptoms of fibromyalgia can be interpreted as manifestations of the other disease or even as a lack of response to treatment, which often leads to unnecessary, erroneous increases in medicine doses or changes in treatment strategy.

A diagnosis of fibromyalgia is important

It is very important, both for you and for your doctor, to establish the diagnosis of fibromyalgia as early as possible. For you, this means that your symptoms are part of a recognised condition and not figments of your imagination, as you may have been led to believe. Knowing you have fibromyalgia will allow you to focus on treatments that have the greatest chance of success and gives you a better long-term prognosis or control of your condition.

From your doctor's point of view, making the diagnosis of fibromyalgia can provide a satisfactory explanation of your symptoms and allow you to start proper treatment within currently-available options.

When patients are given a diagnosis, they can stop looking for other possibilities through never-ending tests and doctors' appointments. This brings the added benefit of no longer having to undergo multiple treatments, most of which are useless and costly.

How it's treated

You should bear in mind that there is no curative treatment for fibromyalgia. You should focus your expectations on improving your overall state of health and preventing your condition from getting worse over time.

Proper treatment can improve your condition to the point where you can lead a normal life and manage your illness, just as patients diagnosed with other chronic diseases are able to live with their illnesses.

You should also be aware of which treatments can provide benefit and which can actually be harmful. **Table 4** provides a list of treatment measures that have been proven useful through scientific research.

Table 4. Evidence-supported treatments for fibromyalgia

- Information and education
- Regular exercise
- Some types of psychotherapy
- Some medicines

Medicines

Proper treatment of fibromyalgia does not mean taking medicine for each and every one of your symptoms. That would require many different medicines and you would soon start to notice unwanted side effects, which would actually make your condition worse. It is worth noting that many people with fibromyalgia are exceptionally sensitive to medicines, which means their side effects may be even worse.

Pharmacological treatment should focus on addressing the mechanisms that are believed to cause fibromyalgia. This means taking medicines that act on the nervous system – especially antidepressants and anticonvulsants. Many scientific studies have shown that these medicines have a clearly beneficial effect in fibromyalgia; at present they are the only medicines that have been approved by the health authorities to treat this condition.

These medicines act simultaneously on the different symptoms of fibromyalgia. As well as improving mood and relieving anxiety (the main indications for which they are usually prescribed), they can induce sleep, reduce fatigue, improve functional capacity and lessen pain severity, among other effects. So, a single medicine can improve many symptoms of fibromyalgia in one go.

There are many types of antidepressants and anticonvulsants, with different effects in each patient; trial and error is the only way to find out which is best for you.

You should also know that sleep medicines are not effective in the long term. It has been widely proven that, over time, these drugs lose the ability to improve sleep, but their unwanted side effects remain. Most importantly, you may become addicted to these substances and develop withdrawal symptoms when you try to give them up.

Proper treatment of fibromyalgia does not mean taking medicine for each and every one of your symptoms



There is no advantage to using any other medicines - apart from anti-depressants and anticonvulsants - to treat sleep disorders. A good sleep routine can be very helpful in improving this symptom.

There is no single medicine that can relieve fatigue. The only way to treat this symptom is to address the other clinical manifestations and improve your fitness so that you only feel tired later on in the day.

Painkillers or analgesics, such as paracetamol, will reduce your pain. This is the medicine you should take as soon as you start feeling pain. Again, you should be aware that painkillers can only reduce your pain; they will not make it go away. You should also be aware that once you have reached the recommended dose, you shouldn't take any more, because the painkilling effect will be the same, but the risk of unwanted side effects will be much higher.

Taking stronger painkillers doesn't help much in fibromyalgia. Drugs such as morphine or transdermal patches are contraindicated, as their use can cause very dangerous unwanted side effects.

Since fibromyalgia follows a fluctuating course, it is a good idea to come off as many medicines as possible when you're feeling a bit better. The reasoning behind this is that, when you have another flare-up that requires medication, you'll have a better response to treatment. Otherwise, the only option when you have a flare-up will be to increase your dosage, which also increases the risk of side effects.

In short, we know that some medicines can help relieve your symptoms, but you must be aware of the risk of unwanted side effects that could worsen your condition. Therefore, you should only take medicines that you find really improve your symptoms, and you should avoid prolonged treatment whenever possible.

Alternative treatments

Your family, friends and acquaintances will probably advise you to try alternative treatments such as acupuncture, homeopathy, chiropractic, herbal products, electromagnetic therapy, ozone therapy and many others. These are rarely recommended by doctors.

Such therapies are also not provided within our health system in Spain, mainly because so many studies have found no clear evidence of their effectiveness in improving the symptoms of fibromyalgia.

Most of these therapies lack major side effects, but their alleged benefits are also unlikely to be better than a placebo or sugar pill treatment.

In this Guide, we advise you to talk to your doctor whenever you are recommended any alternative treatment. Your doctor can give you accurate information on research that has been done into the effectiveness of these therapies for your condition.



Impact of fibromyalgia

One of your first questions is likely to be whether fibromyalgia will progress to the point where it shortens your life. This can never happen, because fibromyalgia is not a progressive or degenerative disease that gets worse over time.

Nevertheless, as a chronic condition, it can have a series of negative consequences on different aspects of your life. This is known as disease 'impact'.

Anxiety and a lack of physical activity, for instance, can make you overweight and suffer metabolic changes, such as high blood sugar or high cholesterol levels, which, in turn, make it easier for high blood pressure to develop. All these changes can lead to a series of complications that have further negative consequences on your health and the course of your illness.

As a chronic condition, fibromyalgia can have a series of negative consequences on different aspects of your life. This is known as disease 'impact'.

The impact of fibromyalgia is not limited to health; it can also affect other areas of your life.

Fibromyalgia can have a very big impact on personal aspects of your life – your family life, your relationship with your spouse or partner, children and friends. It has long been known that all of these aspects are impaired in people with fibromyalgia and contribute heavily to a perception of poor quality of life.

The impact of fibromyalgia on work is considerable. Difficulty carrying out normal daily activities often translates into poorer job performance and many work hours lost. People with fibromyalgia miss work, are off sick and need incapacity benefits much more than average. As a whole, the percentage of people with fibromyalgia who stop working for any reason is considerably higher than among people without this illness.

The immediate consequence of this impact on your work is of a financial nature. Loss of income is often an added problem.







We are well aware of the challenges of continuing to work, but you should be aware that patients who quit work as a consequence of their condition are precisely those who experience the worst course of illness. Maintaining an active lifestyle is likely to help you stay healthier, as it will make you strive to be in the best possible shape every day.

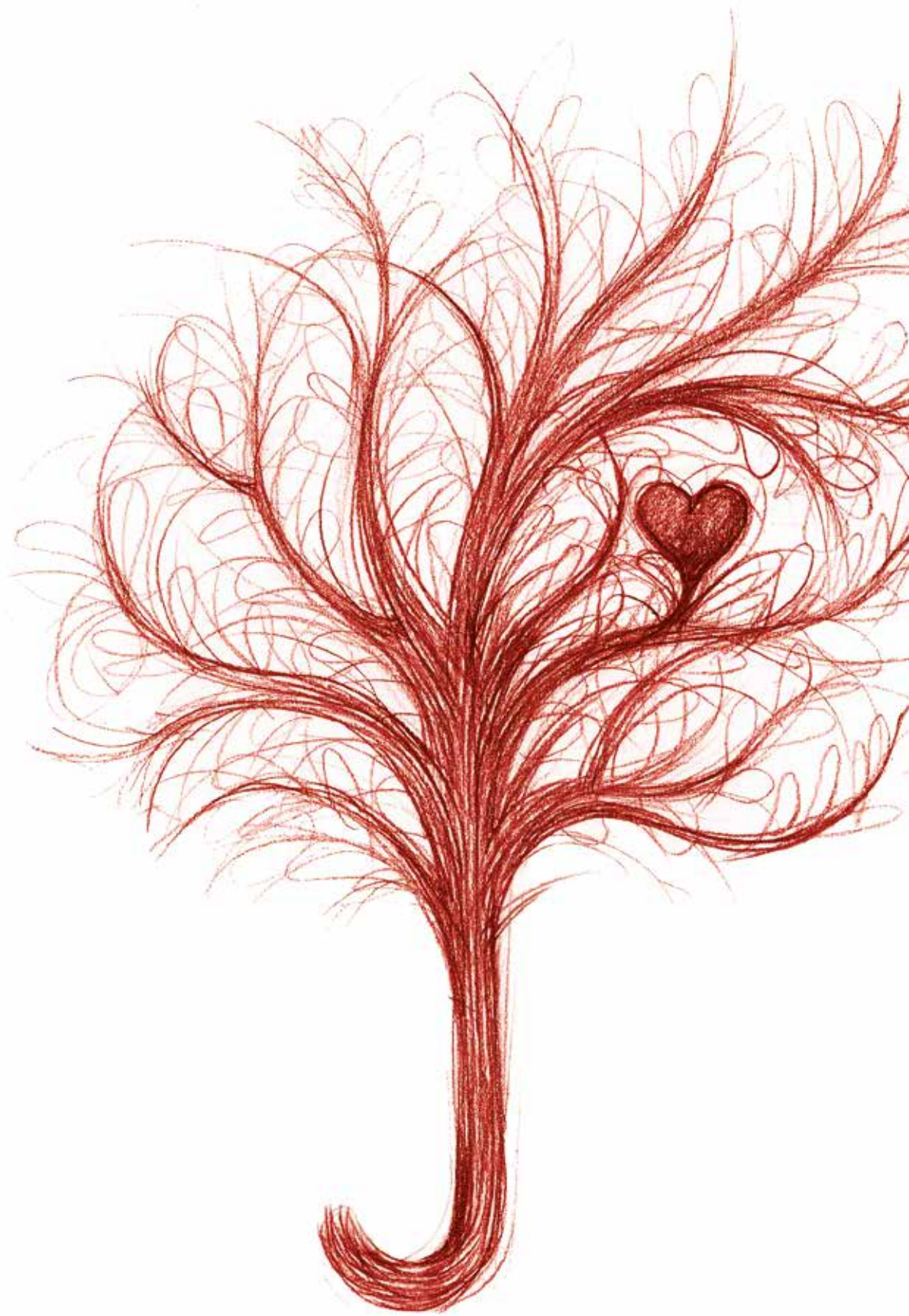
In this Guide, we advise that, before deciding to quit work definitively, you should at least try to make changes in your job to adapt. When your condition improves, you will then have the opportunity to resume your full duties.



KEY POINTS

Fibromyalgia is characterised by:

-  Widespread pain, with various other symptoms occurring at the same time.
-  A fluctuating course, with alternating periods of improvement and flare-ups.
-  No test is able to confirm the diagnosis.
-  A diagnosis of fibromyalgia does not rule out other diseases.
-  Physical exercise, psychotherapy and some medicines are the three pillars of treatment.
-  Antidepressants, anticonvulsants and basic painkillers have shown the most effectiveness.





PRIMARY CARE

“En cada amanecer hay un vivo poema de esperanza, y al acostarnos, pensemos que amanecerá”.

“Every dawn is a living poem of hope; at dusk, remember another dawn will come.”

Noel Clarasó

As general practitioners, we are the gateway into the Health Services, and therefore, your first port of call. Primary care is very accessible and provides an immediate solution to many health problems, while ensuring continuity of care throughout your life.

This is especially important in chronic conditions such as yours. Chronic conditions require constant monitoring over a long period of time and also normally affect physical, mental and social aspects. Continuity of care allows us to identify any progress in your condition, quickly detect flare-ups and take early action. This is why the diagnosis, differential diagnosis and treatment can and should begin in primary care, to ensure fast, comprehensive care.

The differential diagnosis and treatment can and should begin in primary care to ensure fast, comprehensive care

As general practitioners, we sometimes find it difficult to give you all the information you need. People who are just starting out their journey with fibromyalgia usually have complex symptoms, many uncertainties and questions, and are looking for answers. In addition, the media - the Internet, magazines, television, etc. - are a dubious source of information, which can confuse people because they sometimes make unscientific or inaccurate assertions.

We usually recommend you involve your family in this process if you wish to do so. Your partner will be key here. The initial information you



receive, everything you learn and the joint decisions you make, play an essential part in managing your fibromyalgia.

As your illness has a chronic course, it is our job to reassess you from time to time in order to identify changes in your symptoms and any deterioration or lack of response to the treatment. Your general practitioner may suggest increasing your treatment or refer you to an appropriate specialist while coordinating your care. There may also be periods of marked improvement, when you may be able to reduce any medicines you're taking or even stop them completely.

We usually recommend you involve your family in this process if you wish to do so. Your partner will be key here.

We recommend that one doctor should coordinate everything and guide you at all times. That is where your general practitioner comes in. It is very important to avoid constantly switching from one specialist to another without a specific purpose and not to have further tests or repeat tests without a good reason. Achieving the right risk/benefit balance for you is essential.

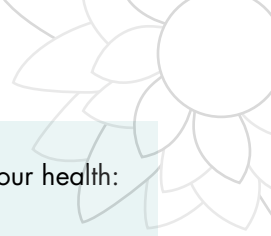
Preparing for your visits to the doctor is an important aspect of your new doctor-patient relationship.



visiting the doctor

Before attending your appointment, it is important that you **prepare for it and think of everything you need to cover**. If necessary, make a note of everything you want to discuss with your doctor:

- Main reason for your visit.
- Worries about the reason for your visit.
- Questions you would like answered.
- Your expectations of the visit (things you hope your doctor will offer you, such as medicines, lab tests, etc.). You should bear in mind that no blood tests or other diagnostic tests are able to confirm or rule out fibromyalgia.
- New or changed symptoms. Remember that your doctor already knows your usual symptoms so you need only to highlight any changes in those symptoms and report new ones.



You might find it useful to keep a folder with all the **information about your health**:

- Possible food or drug allergies.
- Results of previous tests.
- Reports from other doctors.
- List of all the healthcare professionals you are seeing and what action and/or treatment you have started.
- List of your usual medicines, or failing that, the empty medicine cartons. Make a note of which medicines have been effective, and which haven't, or if you have had any notable side effects.

Sometimes visits can be complicated because it is difficult to understand what the doctor is saying to you and because you may forget what you've been told, or because you are worried about asking too many questions. Remember:

- Ask all the questions you want, even if you think they sound silly, as they may help alleviate your anxiety and avoid misunderstandings. Tell your doctor about everything that worries you and report any changes in your state of health.
- If you don't understand the answer, ask again. If the doctor uses technical terms you don't understand, ask him or her to explain them to you with simpler words.
- Take notes during the conversation, because you might forget some of what the doctor has said to you. You can also ask someone to accompany you, especially if you find it hard to explain things or understand the details.
- Start by talking about what is most important to you.
- Speak clearly and concisely. Unfortunately, the consultation time is limited.
- Speak frankly, without being embarrassed about what you want to say. Your doctor will not judge you and will treat the information with complete confidentiality.
- To report a particular symptom, specify the following details:
 - When it began (how many hours, days or weeks ago).
 - If it gets worse at a certain time of day or when doing a certain activity.
 - If you have taken any measures to resolve it, e.g., taking medication, changes in posture.
- If your doctor decides to prescribe some medicine, ask:
 - What type of medicine it is.
 - Why you will be taking it and what it does.
 - When and how you have to take it, for how long and at what dosage.
 - If it will interact with other medicines you are taking.



- If you should take precautions, such as not drinking alcohol, avoiding sun exposure or not driving.
- How you can tell if it is working.
- What you should do if you miss a dose.
- Its side effects.
- If you don't feel it's right for you, because of how or when you have to take it, because of the cost or anything else, ask if there are any alternatives

Before the end of the visit, make sure you understand all the instructions you have been given. Finally, ask how and when you can get in touch with your doctor if you have any questions. Also ask the doctor whether you can see another person, such as your nurse, when the doctor is unable to see you personally.





KEY POINTS



General practitioners can solve many of your health problems, quickly detect flare-ups and take early action.



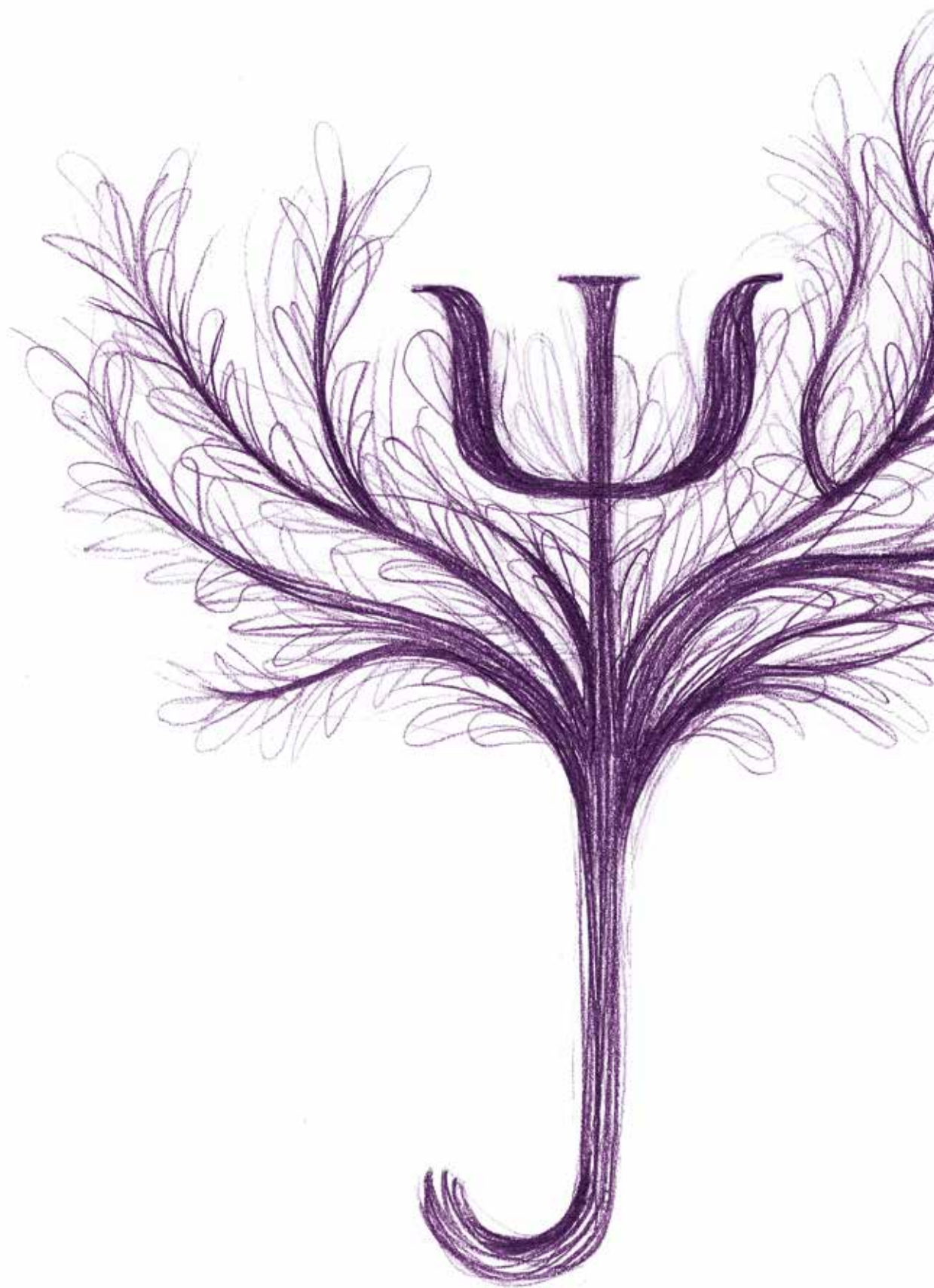
General practitioners can coordinate everything and give you guidance, without referring you to specialists unless there is a specific need.



Prepare for your visits to the doctor and think of everything you need to cover at your appointment. You might find it useful to keep a folder with all your health information.



Make sure you understand all the instructions you have been given. Ask how and when you can get in touch with your doctor if you have any questions.





PSYCHOLOGICAL TREATMENT

“No existe nada bueno ni malo; es el pensamiento humano el que lo hace así”.

“There is nothing either good or bad, but thinking makes it so.”

William Shakespeare

After diagnosing fibromyalgia, your doctor may also recommend psychological treatment. You might think that psychological treatment is simply a complement to a complete approach to your condition, but it is much more than that. It is very important you understand clearly why your doctor is recommending psychological treatment for you.

For some years now, our health model in Spain has formed part of what is called a biopsychosocial model. This is a participative model or focus

on health and illness that assumes that biological, psychological (thoughts, emotions and behaviours) and social factors play a significant role in human activity in the context of an illness or disability. Indeed, health is better understood as a combination of biological, psychological and

It is very important you understand clearly why your doctor is recommending psychological treatment for you

social factors and not purely in biological terms. This model can be applied across the board, regardless of whether or not a disease has a clear medical cause.

In this model, any illness should be treated simultaneously in a cross-disciplinary manner by different specialists in medicine, physiotherapy, nursing, occupational therapy and psychology, among other areas. Unfortunately, mainly for functional, organisational and economic reasons, this does not always happen in our healthcare system, especially in the case of psychological assessment and treatment.

Numerous scientific studies show that medical treatment (including medicines prescribed by your doctor), moderate aerobic physical exercise and psychological treatment now constitute the key basic treatment elements for improving quality of life in fibromyalgia. Consequently, psychological treatment shouldn't be seen as an alternative option, but as an essential component, together with medical treatment and physical exercise, for managing your illness.

It is also important for you to know the main goals of your psychological treatment. First of all, let go of the idea that psychologists work only with people with mental problems or disorders. That is just not true. There is another speciality within psychology, called the psychology of health, which offers the best tools for the biopsychosocial model of health mentioned earlier.

Let go of the idea that psychologists work only with people with mental problems or disorders

Health psychology is a recent and relatively unknown discipline. However, it provides many effective solutions to improve numerous health problems such as physical disability, sleep problems and chronic pain. These solutions also promote healthy habits related to physical exercise, diet and reducing stress. In other fields, many health psychologists work to improve the quality of life for patients with skin, respiratory, cancer or cardiovascular problems, among others.

In your specific case, as someone with fibromyalgia, psychology can offer you extremely useful tools, particularly from the perspective of health psychology. When explaining factors affecting pain, it is known that certain psychological processes (such as focussing on the pain site, negative and/or catastrophic thoughts about pain, personal beliefs about controlling your illness, and how you accept and cope with pain) are decisive aspects that influence the intensity and variety of symptoms and quality of life among different people with the same medical diagnosis.

That is why psychological treatment will provide you with highly useful tools to recognise (and modify if applicable) the psychological factors that tend to increase your symptoms. You will learn new patterns of thought and behaviour that help to improve your symptoms.

One of the most widely-recommended psychological perspectives in fibromyalgia is the cognitive-behavioural concept. This is because it is a proven, scientific-based approach. It is not a passive therapy; with this focus, you are an active participant in your health and illness. The therapist provides the appropriate tools and you are responsible for putting them into practice in your daily life, in coping with your condition. A psychologist never prescribes medicines but works instead with cognitive and behavioural techniques, i.e., evaluating, with you, any maladaptive or unhealthy patterns of thoughts, behaviours and emotions



that you have, working on changing them to more adaptive patterns that will help you improve your quality of life.

For example, and to give you an idea of the benefits psychological treatment can offer you, below are some areas in which the cognitive-behavioural approach may be especially helpful.

One very well-studied area is known as the vicious circle of pain-anxiety-pain. When you perceive pain, your thoughts can act to intensify or alleviate the sensation of pain. Consequently, excessive attention to the pain, an exaggerated focus on the pain sensation, excessively negative (catastrophising) or repetitive thoughts (rumination) and believing you have poor control over pain and are unable to defend yourself, all amplify the painful sensation. Anxiety plays a key mediating role in this process. The increase in these non-adaptive thoughts provokes an increase in anxiety; this in turn causes an increase in the perceived pain, contributing to the vicious cycle.

When you perceive pain, your thoughts can act to intensify or to alleviate the sensation of pain

Likewise, learning techniques (such as breath control, relaxation, meditation or visualisation) that help to lower physiological responses can be a great aid in reducing anxiety. These techniques also

help to lessen muscular and skeletal strain, contributing to decreasing the pain. Psychological therapy will help you recognise your “amplifiers”, equipping you with healthier and more adaptive tools to manage your “pharmacy” of pain-lessening thoughts (intelligent optimism, perception of control and positive re-evaluation, among others).

Another valuable approach that helps people with fibromyalgia is to learn techniques to regulate emotions. It is normal that your disorder, its characteristics, unknown cause and all the uncertainty will trigger different emotions in you, including hopelessness, sadness, anxiety and anger. Throughout our lives, we all learn culturally to hide our pleasant and unpleasant emotions. However, we now know how important it is to identify and express these emotions, regulating and channelling them. An unpleasant emotion should be taken as a sign that you need to make an adjustment. You have to listen to the emotion; you have to identify it.

Many studies show that inhibiting emotions causes an increase in symptoms

Many studies also show that inhibiting emotions causes an increase in symptoms, because unexpressed emotions end up being somatised, that is, expressed physically.

Psychology is also useful to improve other important areas of your treatment, such as keeping up with physical exercise. It is a fact that many people with fibromyalgia do not take walks even though their doctors have prescribed them. The reason behind this behaviour involves concepts studied and developed in psychology; positive intentions and facilitating thoughts can help you keep to your doctor’s instructions.



Finally, another important application of psychology in fibromyalgia is what is called acceptance and commitment therapy. Accepting your new situation after a recent diagnosis is essential to establishing areas of improvement and personal change, and making changes to your previous lifestyle. Acceptance is not the same as resignation. Quite the contrary: accepting means establishing new goals willingly. Although this therapy is particularly relevant in the initial stages of the condition (immediately after diagnosis), it is effective throughout the course of the illness, even with chronic or serious conditions. The latest studies have shown that acceptance and commitment therapy is highly recommendable. It is the only type of psychotherapy that works with values, the meaning of life and committed actions. In long-lasting illnesses that change lifestyles, patients find this form of therapy especially effective and acceptable.

Accepting your new situation after a recent diagnosis is essential to establishing areas of improvement and personal change

As you can see, psychology contributes to a comprehensive approach to fibromyalgia for managing all your medical physical symptoms. The reason for this, as we have discussed, is that thoughts, emotions and behaviours explain part of those symptoms. Besides, if fibromyalgia has a significant impact on your mental health (depression or work problems, among other issues), psychology can likewise help you to improve your mental health from a more clinical point of view, which is the better known facet of psychology. But, as you have seen, that is not psychology's main contribution to fibromyalgia. It is important to choose a specialist who is experienced with fibromyalgia and knows what psychology can do to improve it. And, most important of all, learn how YOU can influence the course of your illness.



KEY POINTS



Psychological treatment in people with fibromyalgia is fundamental, along with medical treatment and physical exercise, based on the biopsychosocial approach to the illness.



One of the focuses with the greatest proven effectiveness is the cognitive-behavioural concept. Here, you play an active role; you are understood to be decisive in your illness.



Psychological treatment provides you with tools to learn about and modify the thoughts, behaviours and emotions that make your symptoms worse.



Some of the techniques that can especially help you concern the relationship between anxiety and pain, the negative effect that emotional inhibition has on your symptoms and how you can keep up a healthy physical exercise programme.



Psychological treatment can also be based on acceptance and commitment therapy. Constructive acceptance and the search for meaning are core elements in coping with fibromyalgia.



PHYSICAL ACTIVITY

“Caminante no hay camino,
se hace camino al andar”.

*“Traveller, there is no path; paths
are made by walking.”*

Antonio Machado

As mentioned earlier, physical exercise is one of the most commonly recommended non-drug treatments of all the strategies for managing your illness, both for the benefits it brings and for its lack of harmful side effects.

Physical activity has the same effects in people with fibromyalgia as in non-sufferers: it improves heart and lung function, reduces risk of heart disease, lowers cardiovascular death rates and illness and improves psychosocial function, among other things. It also increases muscle strength and joint mobility, and improves balance and postural control, giving you better functional capacity for performing day-to-day activities.

As regards the effects on the symptoms of fibromyalgia, aerobic physical exercise produces improvements in many symptoms, such as pain, anxiety levels, mental health in general and the overall impact of fibromyalgia on patients' lives. The benefits of specific muscle strengthening or flexibility programmes on symptoms are currently more limited and less well known, but you should work on these aspects to maintain your functional capacity at an optimum level. In fact, multidisciplinary programmes that focus on a

combination of aerobic capacity, strength and flexibility have demonstrated benefits on pain, functional capacity and various psychological aspects.

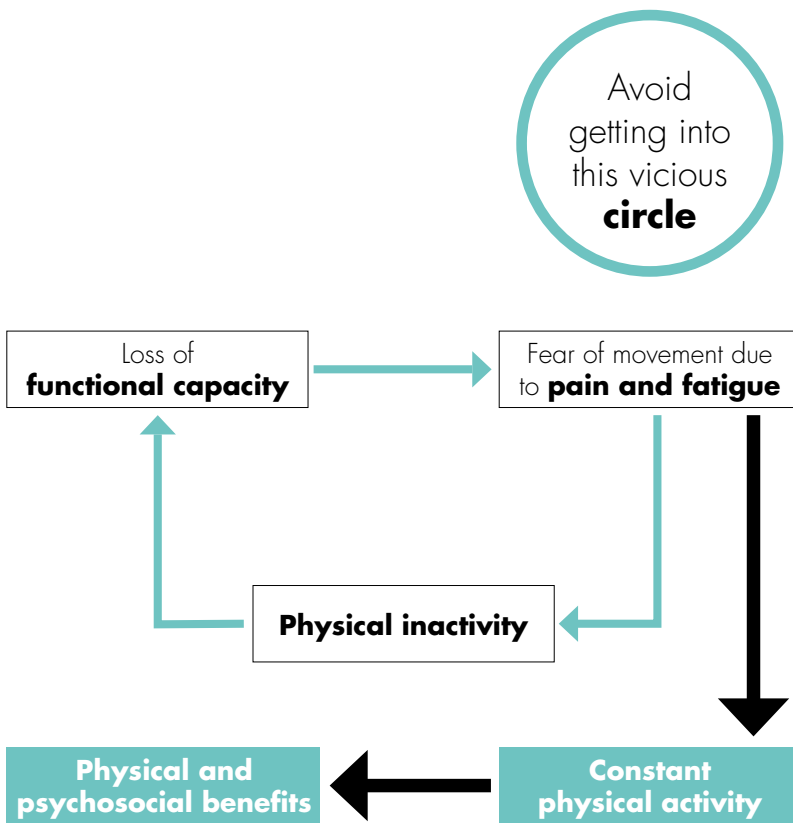
Fibromyalgia affects functional capacity, and physical exercise is vital therapy to help maintain and/or improve it, with resultant benefits for day-to-day life and for

Fibromyalgia affects functional capacity, and physical exercise is vital therapy to help maintain and/or improve it with resultant benefits for day-to-day life and for psychological and social wellbeing

psychological and social wellbeing. It is important that you understand this and are not afraid to exercise. Sometimes, for fear of experiencing more pain, patients tend to reduce their daily activities. This results in weight gain and further loss of functional capacity, making it increasingly hard to perform daily tasks, and leading in turn to more pain. This vicious circle must be avoided at all costs.

Remember it takes time to get used to any physical activity programme. To begin with, in the first few weeks you may experience tiredness, pain or those familiar sore muscles, but you shouldn't think it's having a negative effect on you, because this also happens to people who don't have fibromyalgia.

Most importantly, you should try to find balance in your daily activities, so that you're not entirely sedentary but your pace of life isn't so hectic that it affects or worsens some of your symptoms. This balance is different for everyone, and you will gradually work out what's best for you.



Here are some of the most frequently asked questions about physical activity, together with our answers:

If I've never exercised before, can I start right away?

Yes, it's never too late to start and, in fact, you now have more incentive than ever, because of the benefits physical exercise can bring. Bear in mind that you should begin gradually so that your body gets used to exercising.

If I was already doing some form of exercise, can I continue?

Of course, if you've been doing some form of exercise up to now and you felt well, you should carry on doing it.

What kind of exercise should I do?

Any exercise that essentially involves working on aerobic capacity, muscle strengthening, flexibility and balance. As a general rule, we recommend:

- **Moderate-intensity aerobic exercises** (you should be able to talk while you do them) for at least 30 minutes, 3-5 days a week. Aerobic activity should be done in blocks of at least 10 minutes, preferably spread throughout the week. Choose exercises that are easy on your bones and joints such as walking, low-impact aerobics or dance, stationary bike or exercise in water, all of which involve major muscle groups.
- **Muscle strengthening and balancing exercises** at least 2 days a week. These should be general exercises involving the major muscle groups. We recommend starting with a series of six exercises (alternating arms and legs) and 8-12 repetitions, using your own body weight as the load, with one to three minutes of active recovery between series (walking), and gradually increasing the number of series as you get used to the exercise. Tai chi, yoga and Pilates can be good ways to work on strength and balance, but try to minimise exercises that involve raising your arms above your head, and sustained muscle contractions.
- **Flexibility exercises** with stationary stretches every day or at least on days when you've done another type of exercise. When doing the stretches, avoid getting to the point of acute pain, and do at least one series holding the stretch for 10 seconds to begin with, gradually building up to 30 seconds.

Remember, this is the final, not the initial goal.



How can I fit these exercises into my daily life?

It's important to include physical activity in your daily routine so that it becomes easy or feasible to practise it. In other words, if you decide to join a sports centre or club, try to find one close to home and make sure the activity you want to do is offered at a time that fits in with your other daily tasks. If you've never done physical exercise before, it's advisable to seek the help of a qualified specialist to teach you the correct way to do the exercises. Here are a few suggestions for you to try:

It's important to include physical activity in your daily routine so that it becomes easy or feasible to practise it

- **Head to a sports centre and enrol in a supervised activity 2-3 days a week.** When choosing the activity, avoid high-intensity sport and those that involve physical contact (you shouldn't be exhausted at the end of it). Choose low- or moderate-intensity activities, such as tai chi, yoga, gentle Pilates, therapeutic gymnastics, gentle water gymnastics or swimming. Physical activity in water is highly recommended, provided the water temperature is above 28 °C (82.4 °F). Exercising in warm water helps relax the muscles and reduces the impact of the exercises on the bones and joints. However, if the water is any colder, you'd be better opting for another type of activity.

Tell your coach or trainer about your illness, so that they can make allowances, because how you feel in the class will determine how much rest you will need between exercises. Taking up an activity doesn't mean you have to do every single exercise.

Physical exercise in water is highly recommended, provided the water temperature is above 28 °C (82.4 °F)

- **Go to a sports centre and use the cardio and muscle training gym 2-3 days a week.** If you do this, it's advisable to follow a workout programme. It's a good idea to do a short warm-up on the treadmill or stationary bike for 5-10 minutes, followed by muscle strengthening exercises, aerobic exercise (15-30 minutes on the treadmill, stationary bike or elliptical trainer), and end with stretches. Most gyms have a trainer present who can advise you on which muscle strengthening exercises you can do to work the major muscle groups, bearing in mind the advice given earlier as regards the number of exercises and repetitions. If you have exercised before and you are starting at a reasonable level of physical fitness, workouts with light to moderate free weights (0.5-1.5 kg or 1-3 lbs) or gym machines may be beneficial. Make sure a trained member of staff instructs you how to use the machines before you start.



- **Join in the physical activities offered by a fibromyalgia patients' association.** This option is highly recommended, as in this case everyone has the same illness so the activity will be better suited to you. Also, group activities will give you more social contact with people in the same situation as you.
- **Create your own exercise programme.** In this case, bear in mind the guidelines given above. Walking is ideal for achieving the recommended levels of aerobic activity. Very basic exercises for building strength, as well as stretches, that you can even do at home, are given below. So there really is no excuse for not doing some exercise!
- **Include physical activity in the rest of your daily activities.** This is essential, especially if there are days when you find it really difficult to do the exercises described above. Effective strategies include going on foot to different places or walking up and down a flight of stairs. If you sit for a long time at work or even at home, get up and walk for a few minutes or get up from your chair and sit down again several times in a row.

General recommendations:

- Don't do strenuous or high-intensity exercises.
- Avoid long periods of sitting or lying down.
- Avoid exercising first thing in the morning and last thing at night.
- Don't forget to drink fluids to stay hydrated when you exercise.
- Wear suitable clothing and footwear.

But... what if I'm having a flare-up and have a lot of pain or fatigue? Is it OK to do exercise that day?

Yes! Just one session of warm water physical activity, tai chi or low-impact dance has been shown to have an immediate effect on pain. You will probably feel better at the end of the activity. You just have to be more aware of how your body feels that day in case you need to rest more, reduce the length of the exercise or do a gentler activity, but anything is definitely better than nothing.

Just one session of warm water physical activity, tai chi or low-impact dance has been shown to have an immediate effect on pain

KEY POINTS



Avoid a sedentary lifestyle.



Physical exercise is one of the most commonly recommended non-drug treatments for managing your illness, both for the benefits it brings and for its lack of harmful side effects, if done properly and gradually.



Aerobic exercise is the most commonly recommended type of activity, together with muscle strengthening.



Choose a physical activity that you enjoy and that will fit in well with your daily routine.



Activities such as walking or exercising in water can be effective. Vigorous exercise is not advisable.



MUSCLE STRENGTHENING EXERCISES

UPPER BODY



1

Sitting on a chair or standing, raise one arm in front of you to shoulder height, with a 0.5 kg (1 lb) weight in each hand. Do the same with your other arm.



2

Bend your elbow and then straighten it out.





3

Stretch your arms straight out at shoulder height as shown in the photo, and bring them in until your hands meet in front of your body.



4

Bend sideways at the waist, moving your arm downwards with a 0.5 kg (1 lb) weight in each hand.



- 5 Raise each arm out sideways to shoulder height.



MUSCLE STRENGTHENING EXERCISES

LOWER BODY



- 1 Raise your leg in front of you, keeping it straight. Repeat the exercise with the other leg.



2

Raise your leg out to the side.
Repeat the exercise with the other leg.



3

Raise your leg in front of you while
bending your knee, as shown in the
photo. Lower your leg down again.
Repeat the exercise with the other leg.





4

Bend your knee while lifting the heel to the buttocks. Repeat the exercise with the other leg.



5

Lift your heels off the floor.



STRETCHING EXERCISES

UPPER BODY



1

Sitting on a chair or standing, stretch your neck by tilting your head to one side with the help of your hand.



2

Stretch one arm out in front of you to shoulder height and bend your wrist so that your palm is facing upwards. With your other hand, gently pull the first hand downwards. Repeat the exercise with the palms facing downwards.





Stand sideways to the wall with your right arm outstretched and the inside of your arm touching the wall.

Turn your body slowly to the left, keeping your arm against the wall.

3



4

Sit or stand with legs slightly apart and arms outstretched. Bend to one side, then to the other. One arm should be above shoulder height and the other touching the body. Keep the pelvis well positioned to avoid overextending the lower back.



STRETCHING EXERCISES

LOWER BODY



1

Hold the back of one foot with your hand and draw the foot slowly towards the buttocks. Avoid overflexing the knees. If you can't get hold of your foot, use rubber bands or a cord looped around your foot. You could also rest your foot on a chair.



2

With feet hip-width apart, extend your left leg forwards and place your heel on the floor with the toes pointing upwards. Bend your right knee, place your hands on the thigh of the outstretched leg and bend your trunk slightly forwards. Keep your back straight throughout the exercise. Then change legs.





Stand with legs apart, bend one leg and transfer all your weight onto it by bending your trunk slightly.



3



Stand at arm's length from the wall, feet parallel and hip-width apart. Place both hands on the wall. Bring one leg forwards with the knee bent, so that it is in line with the ankle joint. The heel should be touching the floor. Extend the other leg backwards as far as you can, with the heel touching the floor.

4



Photography: Oier Aso www.artefotobodas.com

Model: Eli Pinedo www.elipinedo.com
International Handball Player.







PHYSIOTHERAPY

“Un buen profesional no trata la enfermedad, sino a la persona que la padece”.

“The physician should not treat the disease but the patient who is suffering from it.”

Moses Maimonides

Physiotherapy offers a wide range of different tools and techniques that may help minimise your pain and improve your quality of life.

You can access physiotherapy services at your health centre or at a local physiotherapy clinic. Some patient support groups also provide this type of treatment.

Physiotherapy relieves pain and improves your quality of life

The physiotherapy team will assess your symptoms and your state of health and discuss your treatment goals, choosing techniques and tools that are best suited to you.

Your physiotherapy course will be personalised according to your specific symptoms. Not all patients with fibromyalgia receive the same treatment. It's important to have realistic expectations, because a particular technique may see great results in one person with fibromyalgia, but not in others. The wide variability in symptoms means that not all techniques work the same for all patients.

Your physiotherapist will determine how frequently you receive therapy: this can vary between one and several weekly sessions, depending on the intensity and severity of your symptoms. Physiotherapy should continue as long as you are experiencing pain. Physiotherapy is known to give immediate pain relief, and sometimes the effects persist for a short period of time, but it is not a cure for your illness.

Physiotherapy will be used alongside other treatments such as medicines or psychological support prescribed to you by your doctor.

Your physiotherapist will discuss the benefits of individual or group sessions. A combination of the two is often very successful.

Some people with fibromyalgia are affected by problems with their temporomandibular joint (where the jaw joins the skull), in which case physiotherapy may be offered in conjunction with a dental specialist.

Physiotherapists have many different options to help your symptoms, and will normally work with a combination of techniques.

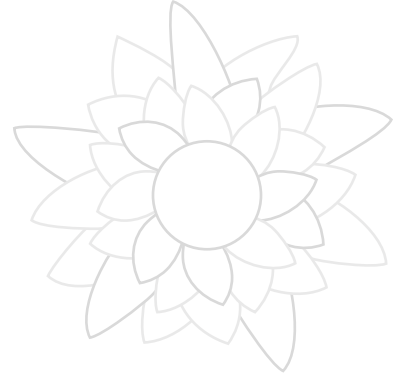
These may include massage, heat therapy, TENS (electrical nerve stimulation), joint

mobilisation, and stretching exercises. All these techniques are designed to get your circulation moving, relax your muscles, prevent spasms, increase muscle function and joint mobility, alleviate tender points and above all provide pain relief. Physical exercise (discussed in the previous chapter) and relaxation techniques are also great therapeutic tools for fibromyalgia, and your physiotherapist will be able to help you find the best exercise or relaxation method for you. A physiotherapist can also give you guidance on good postural habits, how to look after your joints and use of physical aids.

Not all physiotherapy techniques are suitable for all patients

Physiotherapy may also be available at a spa centre, where physiotherapists use the special properties of mineral and thermal water to treat a range of illnesses. Hydrotherapy for treating fibromyalgia can take a number of different forms including jets, baths, showers and hot thermals. The goal is the same as in physiotherapy: to reduce your pain and find relief for symptoms, especially muscular pain.

Physiotherapy or hydrotherapy may also be offered at some swimming pools. In the pool your physiotherapist will focus on teaching you exercises, movements and stretches that you can do in the water to help improve your symptoms.



KEY POINTS



Your physiotherapy course will be personalised according to your specific symptoms.



Your physiotherapist will choose the techniques that are best for your particular case.



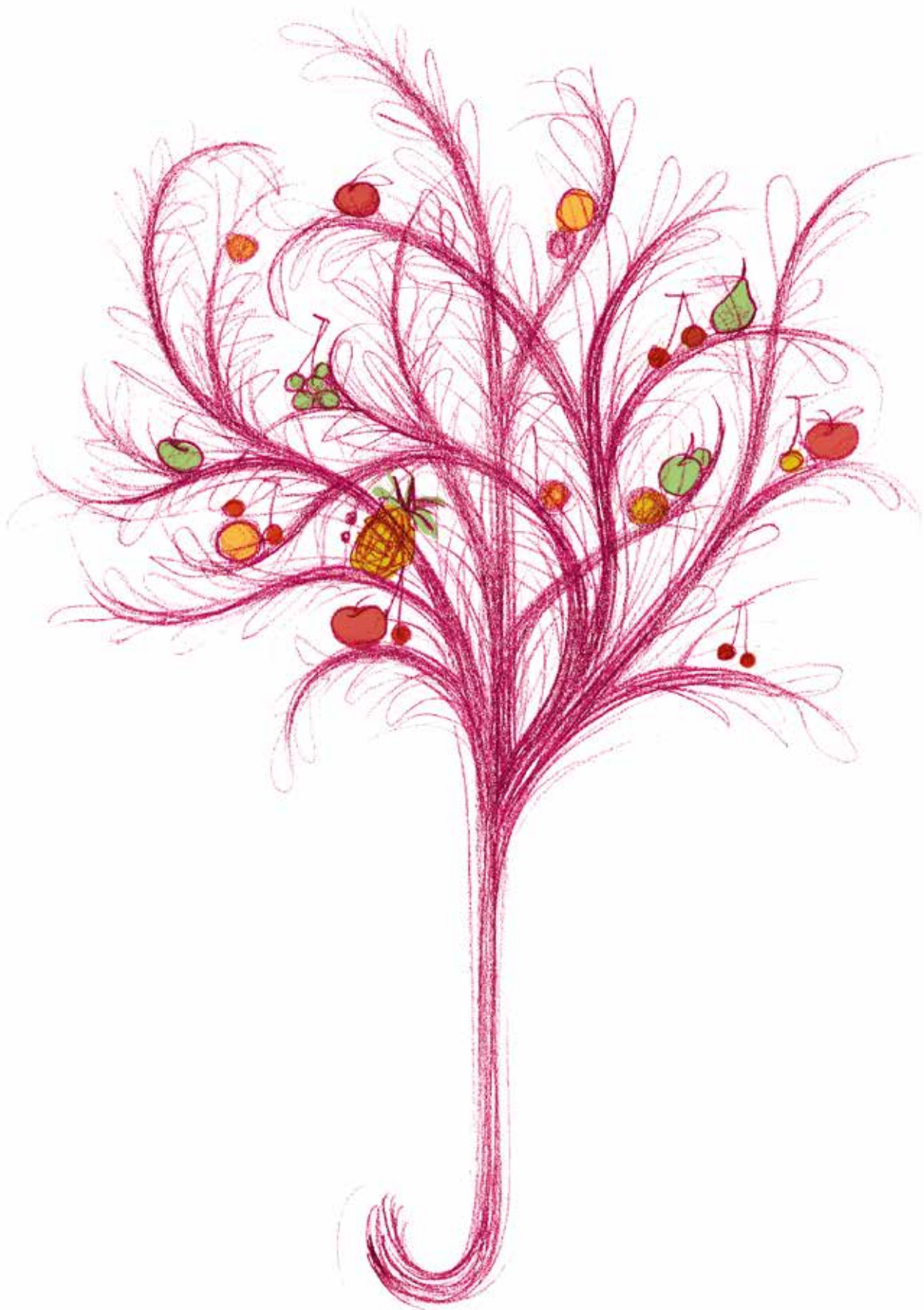
Physiotherapy is effective while you're receiving it.

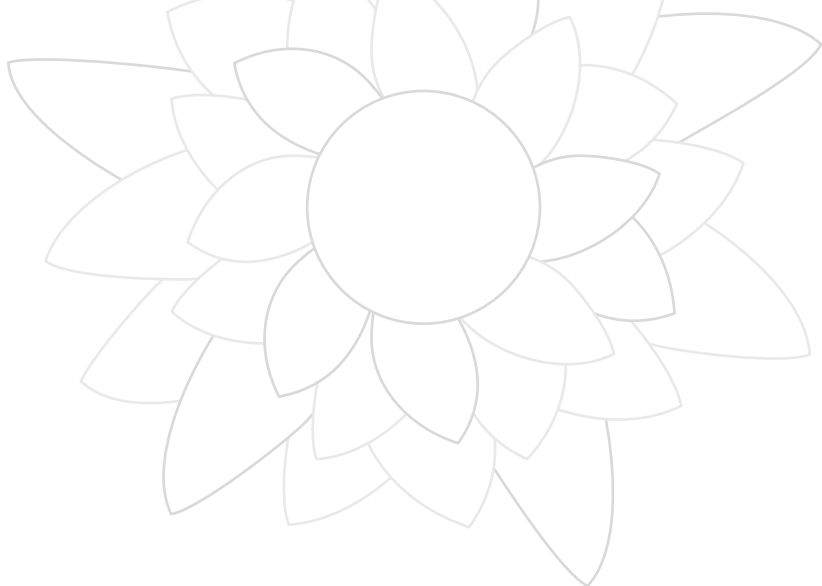


Specialist physiotherapy is available for temporomandibular joint problems.



You can find physiotherapy services at your health centre, a specialist clinic, a spa centre, a swimming pool or through patient associations.





HEALTHY HABITS

“Lo que importa verdaderamente en la vida no son los objetivos que nos marcamos, sino los caminos que seguimos para lograrlos”.

“What really matters in life are not the goals we set, but the paths we take to achieve them.”

Mahatma Gandhi

In your everyday life, especially doing housework or at work, good posture is important to avoid overloading your locomotor system and the negative impact of doing so.

Good posture is important to avoid overloading your locomotor system

Here are some helpful suggestions:



Standing

Standing for a long period of time can cause problems such as fatigue, swollen ankles or feet and back pain.

You should change position often. For example, stand with one foot ahead of you and later transfer your weight by switching to the other foot.

When you have to do the ironing, washing-up or put on make-up, it is a good idea to rest one foot on a box or stool, again switching feet at intervals.

Another recommendation is to wear comfortable shoes with a medium-height heel, between 2 and 5 cm (1 and 2 inches).



Sitting

Keep your back straight, supported by the back of the chair, with both feet touching the floor.

If necessary, use a cushion for your lower back.

Avoid soft seats and seats without back support.

It is best to use chairs with armrests, to make it easier to get up.



Lying in bed

The mattress and base should be medium-firm, to support the natural curve of the spine.

A slim pillow is best, to prevent neck strain.

Don't always sleep in the same position. The "foetal position" is a good choice: lying on your side, hips and knees slightly bent, with your neck and head aligned with your spine.

Sleeping on your stomach is not recommended, as it usually strains the lower part of your spine and makes you twist your neck to breathe.



Getting out of bed

To get out of bed, it's best to bend your knees first, turn to lie on one side, push up sideways until you're sitting on the edge of the bed, wait a moment, and then get up gently.

Getting dressed

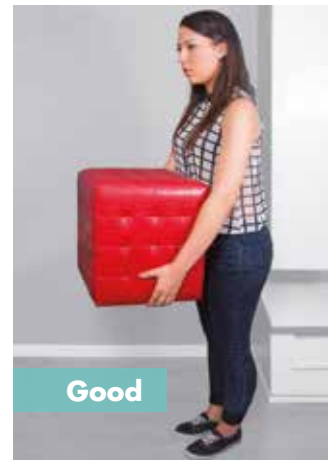
Sit down and cross your legs to put on your tights or socks and shoes. If necessary, put your foot on a stool to do up your laces.



Picking something up

To pick something up from the floor, avoid leaning over and bending your back; it's better to squat, bending your knees and keeping your back straight.

To pick up a heavy object from the floor, hold it close to your body rather than lifting it with your arms outstretched.



Here are some tips to make your household chores easier:

Cooking

Heavy saucepans and equipment you use most often should be placed where it's easy to pick them up, at waist-to-chest height. Use a sturdy stool or step ladder to reach the top shelves in your cupboards.

Cleaning

Instead of stretching up to clean windows, walls and doors, use a sturdy stool or step ladder to avoid overloading your spine.

For cleaning at a low height, squat or kneel to avoid bending over. Keep your back straight at all times.



Doing the laundry

Squat in front of the washing machine to put in or take out the washing without bending over, always keeping your back straight.



Shopping

Split up your shopping over several days, to avoid very heavy bags.

Use large shopping trolleys with wheels that move smoothly. The push bar should be chest height.

If you use bags, distribute the weight evenly between both hands and avoid carrying a total of more than 4 kg (9 lbs). Alternatively, carry the weight close to your body.



Photography: Xabier Quintana.

Model: Cristina Trillo.

NUTRITION IN FIBROMYALGIA

A healthy diet ensures you keep your weight in check, which is essential for improving the symptoms of this chronic illness and avoiding muscle and tendon overload. Healthy eating is one of the most important ways you can improve your quality of life.

Balanced diet


You should familiarise yourself with the food groups shown in the Food Pyramid and learn how to combine the appropriate daily servings of each type of food from the different groups, to make sure you're eating nutritionally balanced meals.

Here is the Healthy Food Pyramid, which is adapted to local produce and eating habits.

A healthy diet ensures you keep your weight in check, which is essential for improving your symptoms. It is one of the most important ways you can improve your quality of life.



Healthy Food Pyramid



Key to the pyramid:

- Moderate daily physical activity (walking, swimming, etc.)
- Daily intake of water as the main drink. Avoid drinking alcohol (even moderate amounts of wine or beer).
- The largest daily serving should be based on cereals, starchy foods and their derivatives (rice, potatoes, bread, pasta).
- A large daily serving of vegetables and fresh fruits (part should be eaten raw, the rest cooked).
- A small daily serving of raw olive oil, preferably virgin.
- A moderate daily serving of dairy products (milk - lactose-free if you have lactose intolerance - yogurt, cheese).
- A smallish daily serving of meat, fish, eggs, nuts or pulses (a generous portion in the case of pulses).
- Only an occasional, moderate serving of processed meats, fats, sweetened products and sweets.

Food and your symptoms

A proper diet can help alleviate some of the most common symptoms of fibromyalgia.

1) Constipation

Recommended foods: fresh fruit, vegetables, pulses, whole grains.

Foods to avoid: sugar and highly refined foods such as white flour, white pasta and white bread.

Tips: Drink water on an empty stomach, orange juice with pulp and eat prunes.

2) Diarrhoea

Recommended food: Lactose-free milk, vegetable-origin milks (oats, rice, quinoa, spelt), fat-free plain yogurt, white fish, chicken, turkey, boiled ham, carrots, apple juice, baked apples, very ripe bananas, quince, potatoes, rice, semolina, pasta without sauce, toast, and oil in small quantities.

Cooking methods: boiling, steaming, grilling and baking.

3) Dry mouth

Recommended foods and textures: All food groups. Puree, soup, jelly, sorbet, mousse, ice cream, ice lollies. Above all, drink plenty of water.

Foods to avoid: dry and hard-to-swallow foods (toasted, in batter, fried).

Tips: Increase salivation with mint. Tongue exercises (move your tongue from side to side) and good oral hygiene. Sugar-free sweets and chewing gum.

4) Headache and migraine

Foods to avoid (if they have a bad effect on you): onions, oranges, dried fruit and nuts, chocolate, cheese, processed meats, wine, beer, coffee and tea.

Tips: Reduce consumption of foods with additives (ready-prepared foods) and nitrites (fresh and processed meats).

5) Menstrual pain

Foods to avoid: red meat, butter, margarine and pastries.

Recommended foods: fish and relaxing herbal teas (linden flower, mint).

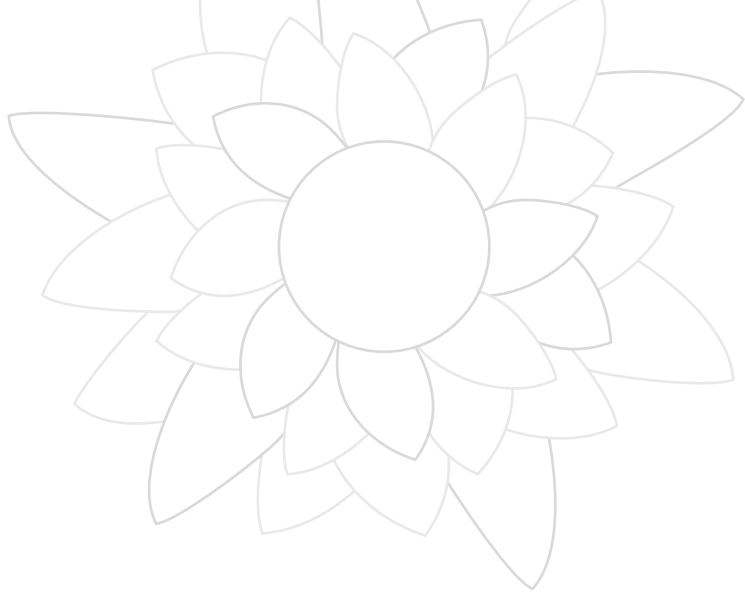
6) Disturbed sleep

Foods to avoid: coffee, tea, energy drinks, mate, guarana, chocolate, alcohol and spicy foods.

Recommended foods: whole grains and leafy green vegetables.

General recommendations for healthy sleep:

- Eat a moderate-sized dinner a couple of hours before bedtime.
- Follow a bedtime routine and go to bed at the same time every night.
- Take moderate exercise and finish at least 3 hours before bedtime.
- Don't take naps.
- Use your bed only for sleeping, not for working or watching TV.
- Make sure your room is cool, quiet and dark.
- Relax before you go to bed (e.g. listen to soothing music, have a hot bath, meditate).



KEY POINTS



Keep a good posture to prevent overloading your locomotor system.



Avoid unnatural spine positions.



Eat a healthy diet to keep your weight in check and improve your symptoms.



Eat a moderate-sized dinner a couple of hours before bedtime.





RELATIONSHIPS WITH FAMILY AND FRIENDS

“No hay problema que no podamos resolver juntos, y muy pocos que podamos resolver por nosotros mismos”.

“There are no problems we cannot solve together, and very few that we can solve by ourselves.”

Lyndon Johnson

Previous chapters have highlighted the importance of social factors in understanding health, which, together with biological and psychological factors, contribute to the so-called biopsychosocial model. We don't live in isolation. What we do or say influences those around us, and conversely, the things people around us do or say influence us. This is inevitable and is part of how we live and behave in the world.

**We don't live in isolation.
What we do or say influences those
around us, and vice versa.**

If we accept this, we will also see how it applies to events such as being diagnosed with a health problem. In your case, as you will have learnt from this Guide, you are facing a chronic problem, with a range of symptoms that have a definite impact on

social and family life. Given the influence we have on one another (and the more we love each other, the greater this influence is), you must bear in mind that this new situation is going to be difficult for everyone: for you, with your new diagnosis, and also for your partner, your family and even your friends. So, one of the most important things to help you cope will be learning how to handle your relationships in this new context, making it easier for others to share the learning process with you.

This kind of problem will need team work. In a team, everyone has their tasks and responsibilities, but it is important for you to realise that it is the team leader who sets the “tone”: whether the atmosphere is positive

or negative, cooperative or uncooperative, and even whether people want to remain part of the team. In this case you are the leader, so this message is for you. We'd like to make just two suggestions that have proved effective: 1) good communication and 2) social reinforcement. By social reinforcement we mean the relationship between our behaviour and its social consequences. A positive, pleasant outcome will tend to lead us to repeat this behaviour.

You need to be aware that these two things are important areas to work on at a psychological level when tackling problems with chronic pain. Now that you have been diagnosed, your family, your partner and your friends need to know how they can help you lead a life that is as functional and active as possible. The people closest to you will want to work with you on this new task. However, bear in mind that you can only control your own behaviour, and therefore any change has to stem from you, on the understanding, as mentioned above, that your actions will change the way others behave.

This kind of problem involves team work, with you as the leader

Any change has to stem from you

1. Regarding the first area to work on, we recommend you keep up good communication with the people who are important to you. Naturally, this involves talking about your symptoms, their effects and any treatments, but don't make the mistake of talking about nothing else but your problem. There's much more to you than your health problem; don't forget you're still the same person you were before your diagnosis. Admittedly, it's difficult to talk about your illness, especially at first, when you can't explain what is causing your problem or why a treatment isn't curing you but just relieving your symptoms. This causes uncertainty, not just in you but also in your family and friends. And from uncertainty to anxiety and fear there is but a short step. You may be afraid of "having something worse", "feeling misunderstood by others" or of others "getting fed up with you"; equally, the people around you may be afraid that you may have "something worse", "you'll think they don't believe you" or that they are "bothering you". Uncertainty and fear undermine us all. To stop these niggling thoughts dominating your day-to-day life, you need to be well informed about your illness. This information will be provided by health-care professionals, and specifically by the doctor who is in charge of your care. Your family and friends also need this information. Ideally, they should have the same information as you so that you will all "speak the same language". After all, a common language is essential when it comes to communication. Knowledge puts you in control; it gives you a clear view of your opportunities and limitations. If you, your family and

There's much more to you than your health problem; you're still the same person you were before your diagnosis

friends know what you've got, how to manage it, what you can expect and what is good or bad for you, you can all come to terms with it and adjust your approach and your goals to meet this new challenge.

Ideally, the people you care about should have the same information as you so that you will all "speak the same language"

Learn to communicate assertively. We'll explain how in a moment. When people communicate and interact with others they can be assertive, inhibited or aggressive. The first of these styles - assertiveness - is the one you need to focus on, because it brings the best results for everyone. The

essence of an assertive style is to recognise your own rights, wishes and feelings and those of the people around you. In any type of relationship, knowing and exercising your own rights and acknowledging them in others will be socially positive for you and make you feel good. For example, we all have the right to say no, to ask for help, to refuse it, to not know something, to change our minds, to make mistakes or to not care about something. An assertive style involves not sacrificing what you want, while taking into consideration what others want. So to develop an assertive attitude you need empathy, putting yourself in the other person's shoes, accepting when they refuse something or change their mind, and not always interpreting their behaviour in terms of your problem.

An inhibited style means you only take account of other people's rights and feelings and neglect your own, which can cause you a lot of suffering. An aggressive style means you only take into account your own rights and feelings while ignoring everyone else's, and this inevitably leads to conflict. Always sacrificing what you want and feel (inhibited style) or always imposing yourself (aggressive style) tends to create negative feelings all round.

Note that assertiveness is not in a person's nature, but in their behaviour. So, you can learn to behave assertively at home and when you're out and about. Sometimes people need professional help to learn to be assertive; if you need help, don't hesitate to ask for it.

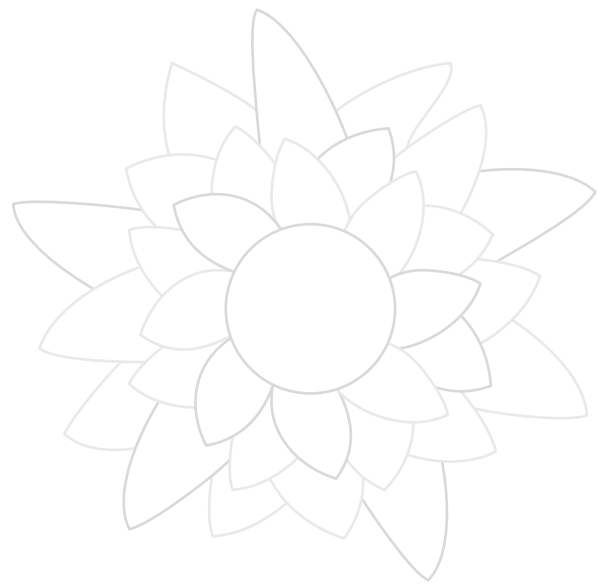
2. Our second suggestion was about social reinforcement. Now that you are informed about your health problem, you, your family and friends will know that it is important for you to keep functionally active, following your doctor's instructions, while keeping your established opportunities and limitations in sight. This is where techniques based on social reinforcement come into their own. You won't achieve your goals if you're over-protected or inactive. Equipped with your new knowledge, you probably don't want to be inactive in any case, because you know this will be harmful in the medium to long term. Your goals will focus on fostering activities that are functional and enjoyable, not only for you but also for the people you care about. Like you, your family and friends will know how far you can go and will give you all the support you need.



You, your family and friends will have to learn not to lay blame, be too tough or simply ignore the effort you put into staying active or the effort others put into supporting you in your plan. A word of acknowledgement for achieving what you set out to do that day will help you stay on track with your goals and keep a positive attitude. Everyone in your team should focus on what is being achieved, rather than on the more overwhelming part of what may not have been achieved. You must all learn to appreciate your own and each other's achievements: completing a task, making an effort, getting involved in a social activity. If you pay attention to these things and acknowledge your achievements, you'll be able to verbalise how enjoyable these tasks and activities are, and - believe it or not - they will become more and more present in your life. That doesn't mean denying the pain and its consequences; the pain will be there, but it will be in the background rather than in the foreground or between you and the people you care about. Keeping this perspective is harder than you might think. It may sound obvious - just common sense - but if you don't get it right, not only do you fail to achieve your goals, there may be negative consequences. It takes a certain amount of training to make this team project work, but your doctor and other healthcare professionals will be there to help you and guide your progress.

**It is important to keep active.
Like you, your family and friends
will know how far you can go and will
give you all the support you need.**

**You must all learn to appreciate your
own and each other's achievements:
completing a task, making an effort,
getting involved in a social activity**



KEY POINTS



The way you and your team behave has a big impact on managing your illness.



Thinking carefully about how you communicate and being familiar with the concept of social reinforcement will help you to come to terms with your new situation.



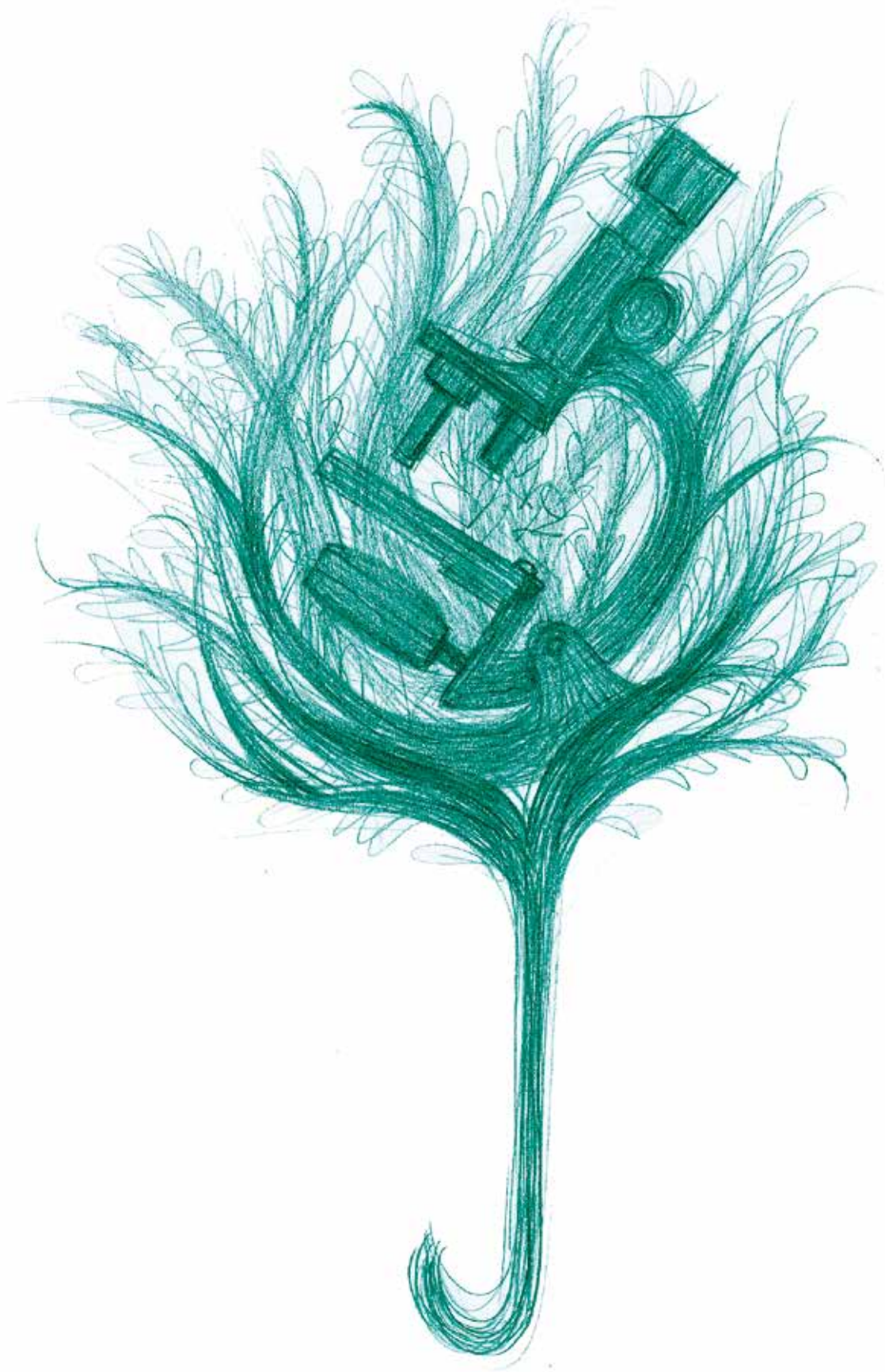
The people who are close to you should learn how to help you keep as fully functional and active as possible. But don't forget that any change has to stem from you.



Communicate assertively. Tell others what you want and what you think; remember you also have the right to change your mind. Accept other people's opinions as well and try not to interpret their behaviour in terms of your problem.



You'll need to learn not to blame others or ignore other people's efforts. Recognising achievements, however small, is an effective way of coping with your illness.



THE FUTURE AND THE CURRENT STATE OF RESEARCH

“El dolor es inevitable, pero el sufrimiento es opcional”.

“Pain is inevitable, but suffering is optional.”

Buddha

The number of studies focused on investigating different aspects of fibromyalgia has grown exponentially over the last 20 years

We couldn't end this guide without addressing one last subject that we think you will find interesting: the current state of research on fibromyalgia.

Are researchers studying fibromyalgia? Are professionals investigating the

causes of what's happening to you? Are they researching effective treatments for your illness? You will undoubtedly have had questions like these going around in your head, and we'd like to reassure you that the answer to all of them is a resounding “Yes!”

The number of studies focused on investigating various aspects of fibromyalgia has grown exponentially over the last 20 years. Why? Firstly, because the syndrome is quite prevalent in the general population. Secondly, because fibromyalgia affects approximately 2% to 6% of patients seen by general practitioners and 10% to 20% of patients seen by rheumatologists. Thirdly, according to a European report from 2012, out of all the diseases characterised by chronic pain, fibromyalgia is associated with the highest rate of unemployment, the highest disability benefits claims, and the most days lost through sick leave per year. So, fibromyalgia has high costs for the healthcare system and society as a whole.

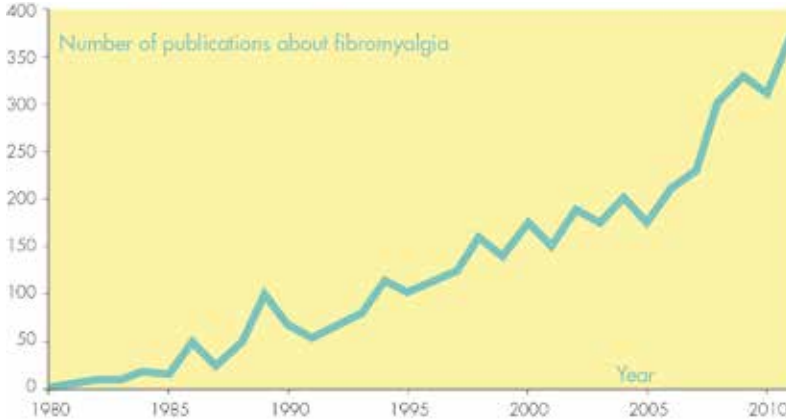
Given the scale of the problem, there are numerous research groups focused on improving, day by day, our understanding of the causes of this syndrome, the possible clinical subtypes or subgroups of patients, the effectiveness of the different pharmacological and non-pharmacological treatments currently available, and the subsequent search for new, more effective treatments with fewer unwanted side effects. Currently, there is a considerable amount of scientific literature available on many aspects of this condition, but research doesn't stop; we want to keep finding out more, so that we can help you, and others with the same problem, more effectively.

Fibromyalgia affects approximately 2% to 6% of patients seen by general practitioners and 10% to 20% of patients seen by rheumatologists

In **Figure 1** you can see a clear increase in the number of scientific publications on fibromyalgia over the last thirty years (1980-2010).

Scientific publications on fibrositis or fibromyalgia identified in the database PubMed between 1980 and 2010.

Figure 1

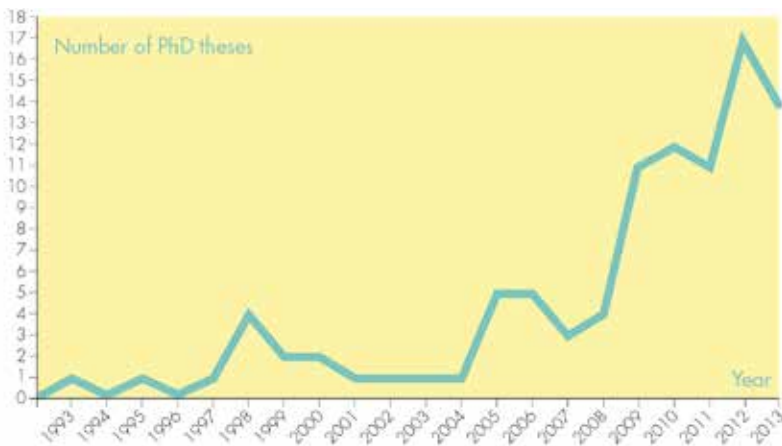


Source: Graph published in 2013 in the scientific journal *Nature Reviews Rheumatology*.

In **Figure 2** you can see that the number of PhD theses written in Spain about fibromyalgia has increased significantly over the last 20 years (1993-2013).

PhD theses on fibromyalgia written each year in Spain between 1993 and 2013.

Figure 2



Source: Data supplied by adfm, the *Fibromyalgia Awareness Association*.

After several decades of research on fibromyalgia, what scientific findings are considered the most solid?

Below, you can find a summary of the best scientific evidence available. As you will see, some of these aspects have already been discussed in earlier chapters of this Guide.

1. The diagnosis of fibromyalgia is made based on its characteristic signs and symptoms (see the chapter on “What is Fibromyalgia” in this Guide). Currently, there are no medical tests that can confirm the diagnosis. Doctors generally take a detailed medical history and use a chart of the human body to locate the areas where you feel pain.
2. After osteoarthritis, fibromyalgia is the most common rheumatological disease.
3. Worldwide, prevalence in the general population ranges from 2% to 8%.
4. With the diagnostic criteria established in 1990, fibromyalgia was found to affect many more women than men. Using the 2010 criteria, the ratio is 2 women for each man.
5. Fibromyalgia can develop at any age, including in childhood.
6. There is no scientific evidence to support an increased prevalence of fibromyalgia in western or industrialised countries.
7. It is common for patients with fibromyalgia to also have other medical problems, such as headaches, dysmenorrhoea (painful menstruation), temporomandibular disorder (problems with your lower jaw joint), chronic fatigue, irritable bowel syndrome, gastrointestinal disorders, cystitis and endometriosis (a condition causing pelvic pain in women).
8. There is more and more evidence that certain environmental stress factors, such as some infections and traumatic events (for example, car accidents), could trigger the onset of fibromyalgia.
9. Many people with fibromyalgia also have psychological problems (mainly depression and anxiety), which can make treatment more complicated.
10. Poor sleep quality, obesity, physical inactivity and job dissatisfaction are risk factors.
11. The presence of catastrophic thoughts about pain (the tendency to think that the pain you experience will have terrible consequences) is associated with a worse prognosis (outcome).



Current recommendations are for “multi-component” treatments (a combination of at least two non-pharmacological treatments) and a multidisciplinary approach to the disease. Non-pharmacological treatments, such as aerobic physical exercise and cognitive behavioural therapy, have been shown to be effective and reduce the need for excessive medication.

Current recommendations are for “multicomponent” treatments (a combination of at least two non-pharmacological treatments) and a multidisciplinary approach to the disease

No matter what, it is essential that, as the patient, you take an active part in managing your condition and that you are motivated to follow the treatment recommendations from your general practitioner or specialist.

As mentioned earlier, research efforts are unceasing. As professionals, we want to increase our understanding of this condition and improve many aspects of it. Here are some areas that are currently being investigated:

1. Can fibromyalgia be considered a central sensitisation syndrome? Many experts agree that fibromyalgia is the result of an abnormality in the central nervous system that increases sensitivity to pain. Findings to date seem to indicate that this is the case, but more research must be done.
2. Genetic factors, as yet unconfirmed, could explain the increased propensity some people have over others to developing fibromyalgia. One of the most important initiatives in this respect, carried out in Spain, is the recent creation of a “DNA bank” of affected patients and their first-degree relatives, to try to identify the genes that could be key in the development of fibromyalgia.
3. Studies performed using functional magnetic resonance imaging of different regions of the brain (known as the neural pain matrix) have confirmed that a significant proportion of patients with fibromyalgia have abnormal activation of the neural pain matrix when low-intensity stimuli (heat, pressure, etc.) are applied. We expect to see more studies on brain structure and function in patients with fibromyalgia in the coming years, thanks to the recent development of more sophisticated neuroimaging techniques.
4. Not all treatments are equally effective for all patients. In fact, one of the main aims for healthcare professionals who are currently doing research in this field is to find the pharmacological or non-pharmacological treatment that is the most effective for you, taking into account your individual characteristics and circumstances. As a result, researchers continue their quest to find the most effective pharmacological and non-pharmacological treatments and identify specific types of patients for whom each of these treatments are most effective. This is undoubtedly one of the areas of research that is attracting most interest.



KEY POINTS



Fibromyalgia is attracting scientific and academic interest: the number of scientific articles and PhD theses on fibromyalgia has increased substantially in recent decades.



Fibromyalgia has a high prevalence worldwide. It is a major burden in terms of healthcare and social costs.



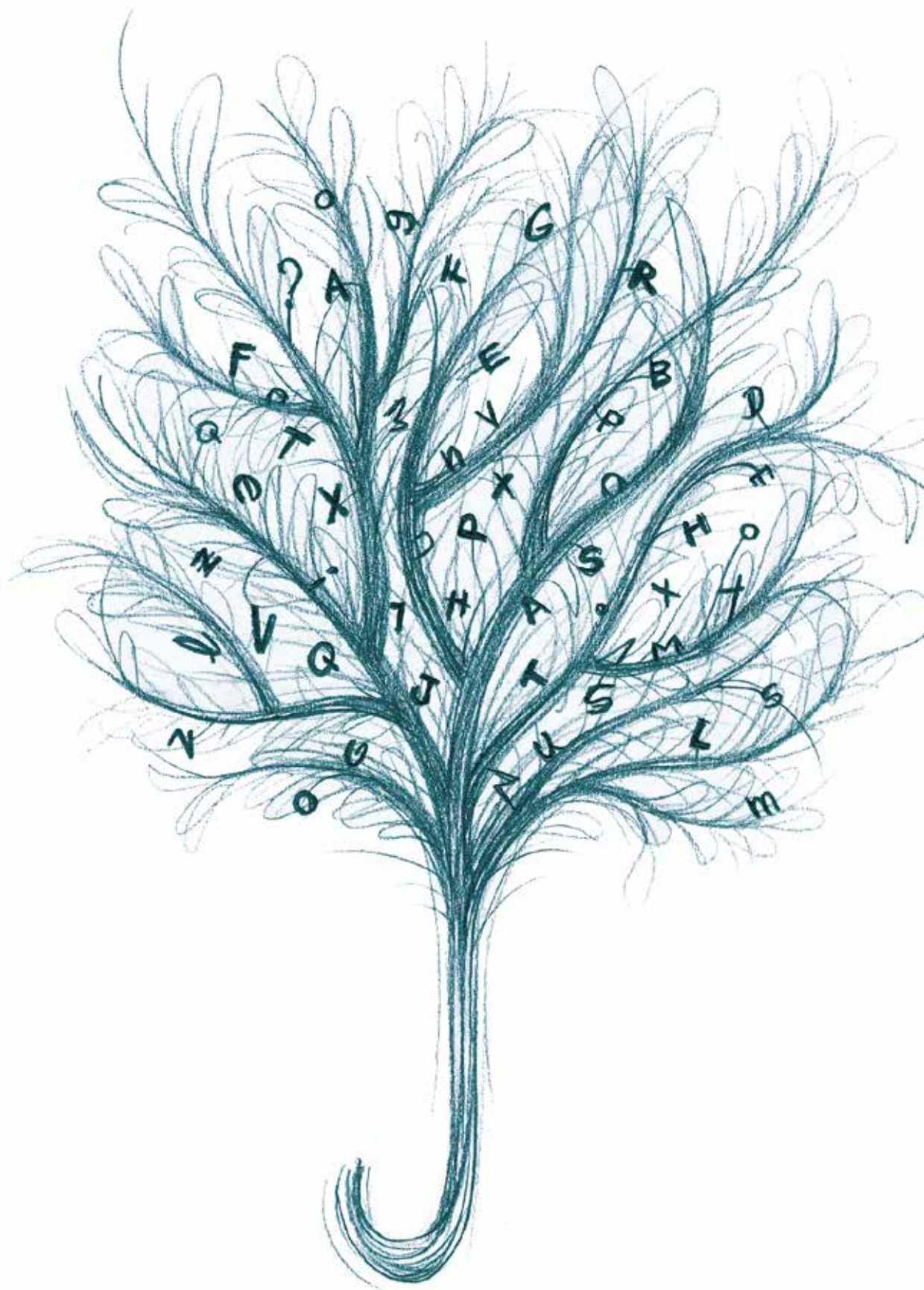
Although the cause of fibromyalgia is unknown, the evidence available suggests that there is some type of abnormality in the central nervous system that is responsible for the increased sensitivity to pain. Some experts suggest that fibromyalgia is a failed attempt of the autonomic nervous system to adapt to a hostile environment.



To date, there is no curative treatment. No single treatment works for all symptoms in all patients. A multidisciplinary approach adapted to the characteristics of each patient works best, especially when patients take the lead in their own rehabilitation.



Research on fibromyalgia is aimed at identifying what genetic polymorphisms (changes) are associated with an increased susceptibility to developing fibromyalgia, understanding which of the structural and functional abnormalities in the brain result from this disease, and developing treatment programmes that are more effective.



FAQs

“Por muy larga que sea la tormenta,
el sol siempre vuelve a brillar
entre las nubes”.

*“No matter how long the storm lasts, the
sun always shines again
through the clouds”.*

Khalil Gibran

What type of doctor should I be seen by?

The type of specialist isn't that important. It's more important that your doctor should be familiar with fibromyalgia. General practitioners and rheumatologists are the most experienced when it comes to treating patients with this condition.

Why am I being given antidepressants if I've got a problem with pain?

Antidepressants have a proven analgesic effect in patients with fibromyalgia. They can also improve your mood if you have symptoms of depression.

Is fibromyalgia degenerative?

No. Although we don't know what causes fibromyalgia, it doesn't share the characteristics of degenerative illnesses, so it doesn't belong to that family of diseases.

Will I end up in a wheelchair?

No. The goal of your treatment is to maintain and improve your functional capacity, enabling you to lead a normal life. A good therapeutic approach will avoid this type of complication.

Can I still become pregnant?

Yes. There are no physical changes that will prevent you from having a normal pregnancy.

Will my children inherit my condition?

No. They may inherit a predisposition to the illness, but other triggers are needed to develop fibromyalgia.

Is fibromyalgia the only condition that causes these symptoms?

No. Widespread pain and fatigue are common to several conditions, including some neuromuscular and autoimmune diseases, and endocrine disorders. As a general rule, these illnesses are accompanied by other symptoms that point to the diagnosis.

Are natural herbal products beneficial?

Natural herbal products have not been shown to be effective for the treatment of fibromyalgia. When a product is shown to be effective, it is made available immediately in pharmacies.

In Spain, are any treatments withheld from our health service because they're too expensive?

No. The healthcare system in Spain is keen to make all effective products available, regardless of their cost.

Can I go on working?

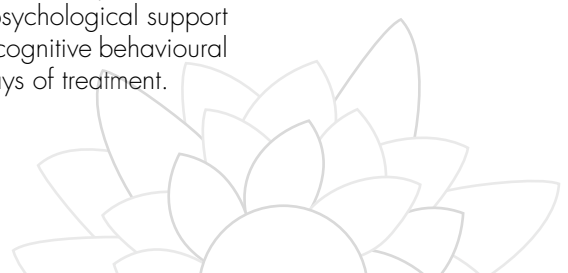
It's advisable to maintain a good balance in all aspects of your life, including work. After all, it's one of the most important aspects of our lives for several different reasons.

If I'm referred to a psychologist, does it mean I have a mental illness?

No. This is just another form of specialist treatment that can help improve your quality of life. Nowadays it is known that pain is processed in the central nervous system. Therefore, certain thoughts and emotional states, such as anxiety and depression, can aggravate your pain. A psychologist will help you tackle your symptoms so that they have the least possible impact on your quality of life.

Is psychotherapy beneficial?

Yes. Emotions play a big part in fibromyalgia. Chronic pain has a knock-on effect on your daily life and appropriate psychological support will reduce the overall impact of your illness. In fact, cognitive behavioural therapy is now considered to be one of the mainstays of treatment.



What is the best kind of physical exercise?

Without doubt, the best form of exercise is whatever you enjoy most or whatever you did before your diagnosis, provided it doesn't cause more pain. Although there are differences between the various types of physical exercise, bear in mind the practical considerations such as time, place, cost and how much you enjoy it. For this reason, the most important thing is to choose the exercise you can do regularly, every day.

Will I have to be on medication for the rest of my life?

Not necessarily. As with other illnesses, it depends how your symptoms progress. The goal is to take as few medicines as possible, because none of them will cure your condition and they all have side effects, which can sometimes be worse than the symptoms of fibromyalgia itself.

Am I inventing my pain?

No, you're not inventing your symptoms. It's true there's no objective clinical test to evaluate the intensity of someone's pain, but this applies to all types of pain, not just in fibromyalgia. To gauge pain intensity, a doctor listens carefully to what a patient reports. The perception of any type of pain (with or without the presence of physical injury) depends on attention processes or focus, emotions (e.g. anxiety and depression) and your own thoughts. It's part of the pain itself, so you can be sure it's real.

What can I do to avoid my flare-ups?

The best way of making flare-ups milder, shorter and less frequent is to do all you can to stay in the best possible health.

However, you need to understand that your illness has a fluctuating course – and don't forget that means that flare-ups will subside in the end.

How can a patient support group help me with my illness?

Patient groups are non-profit organisations with years of experience. They usually provide services that include information, support through workshops, and group and individual therapies. We recommend you check some out and ask about the services they offer.

Is it normal to experience a lack of libido?

Yes. A lack of interest in sex is common. Libido is suppressed by the well-known side effects of some medicines as well as the illness itself.



Is it normal to have a poor memory?

This symptom is classified as a cognitive disorder characterised by traits such as poor memory, lapses, forgetfulness and difficulty concentrating. A poor memory is common in fibromyalgia and is also increasingly associated with the use of certain medicines such as benzodiazepines.

Will continued use of medicines bring problems in the future?

Under normal conditions, medicines used in fibromyalgia are safe and so there is no need to be concerned about their effects on your body. However, you should always make sure you use medicines as prescribed.

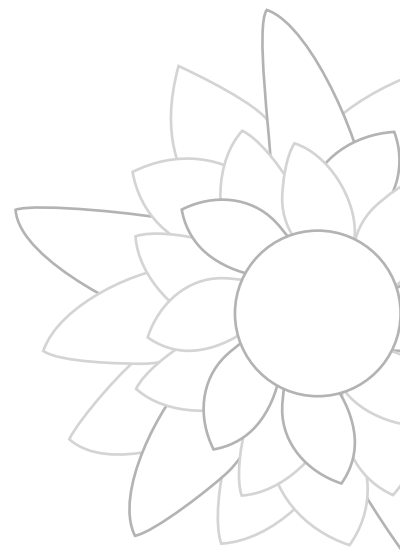
EPILOGUE

Fibromyalgia is a very common disorder, sometimes being accompanied by other “central sensitisation syndromes”, and yet it very often goes unrecognised. It is not just misunderstood by the general public: the same is true of many doctors, particularly - and unfortunately - those deciding whether sufferers of chronic illness are entitled to support in Spain.

With this condition, the doctor/patient relationship is frequently difficult and frustrating on both sides: for fibromyalgia sufferers, because the hopes they place in the treatment prescribed by their doctor are dashed, and for doctors, because they realise that their work is not achieving the results they usually see with other rheumatic disorders.

This is why guides like the one produced by the Fibromyalgia Awareness Association are so helpful.

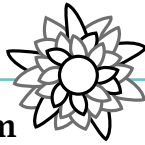
This Guide is written in clear, precise language, and yet is extremely sensitive. It informs the patient about the disorder, calms fears about its seriousness and focuses expectations on achievable goals. It also shows the sufferer how to become an “expert patient”, a genuine partner to the doctor in controlling the illness, and the focal point of short-term plans for patient care.



Congratulations to Andoni Penacho for coordinating this excellent work, and to all the contributors. And if you're reading this invaluable "Beginner's Guide to Fibromyalgia", congratulations to you too; everyone, on both sides of the rheumatology consultant's desk, should have one.

José Vicente Moreno Muelas

Chair
Spanish Society for Rheumatology



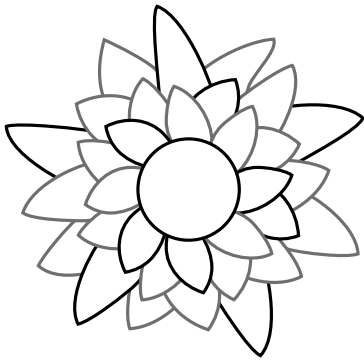
adfm
fibromyalgia
awareness
association

We are the Fibromyalgia Awareness Association, based in Vitoria-Gasteiz in northern Spain. We differ from other patient organisations in many ways. We are very, very small. The smallest of all, in fact. So small that the members of our scientific committee outnumber us, and the people we collaborate with outnumber us and our scientific committee put together. All three of these groups, and our honorary patron, Basque television presenter Anne Igartiburu, receive the same financial compensation for our work: *nada*.

Our mission remains the same as when we were founded: to focus solely on raising awareness of this illness. Our modus operandi is almost always the same: we start with an idea, assess it with relevant experts, and build and develop the idea until it is ready to be given away freely to anyone browsing our websites.

Our achievements so far include:

- Publishing "**Fibromialgia, punto de encuentro**", ISBN 84-611-0002-6 (2006).
- Creating the "**Celeste International Prize for Psychology in Fibromyalgia**" in 2007.
- Organising the **Conference for Professionals working in Chronic Fatigue Syndrome** (Bilbao, October 2007).
- Organising the **Inaugural National Congress for Psychology in Fibromyalgia** (Vitoria-Gasteiz, January 2008).
- Being finalists for **Best Patient Service Initiatives** in 2008 and 2009.
- Publishing the "**Guía de ejercicios para personas con fibromialgia**", ISBN 978-84-692-2868-5 (2009), which was endorsed by the Portuguese Institute for Rheumatology (IPR), and recommended for rheumatology patients by the Spanish Society for Rheumatology (SER).
- Publishing "**Los cuentos de Mingabe**", ISBN 978-84-614-1423-9 (2010).
- Publishing "**Guía didáctica de los cuentos de Mingabe**", which was recommended by the General Psychology Council of Spain (COP) in 2010.
- Publishing "**Guía de debut en Fibromialgia**", ISBN 978-84-606-5840-5 (2015), recognised with an award and endorsed by the Spanish Society for Rheumatology (SER) and endorsed by the General Psychology Council of Spain (COP) and by the Spanish Society for Internal Medicine (SEMI).
- Publishing "**A Beginner's Guide to Fibromyalgia**", ISBN 978-84-608-7833-9 (2016), funded and endorsed by the Spanish Society for Rheumatology (SER) and endorsed by the General Psychology Council of Spain (COP) and by the Spanish Society for Internal Medicine (SEMI).
- Launching the website www.fibro.info, aimed at a non-professional audience.
- Launching the website www.fibro.pro, aimed at a professional audience. This medical website is accredited by and recommended for rheumatology patients by the Spanish Society for Rheumatology (SER).



Our logo, the “Eguzkilorre”

Travelling through remote parts of the Basque Country, even today you may still see old *Eguzkilorres* pinned to the doors of houses and country lodges.

Eguzkilorre is Basque for “flower of the sun”, the silver thistle or *Carlina Acaulis*, which grows in the mountains, meadows and fields of the Basque Country, Cantabria and the Pyrenees, as well as in various parts of central Europe, and in countries as far as Iceland, Sweden and Norway.

This plant has been attributed with many medical and healing properties but is best known in Spain for its deeply-rooted links to Basque folklore.

The legend goes that Amalur (Mother Earth) created the *Eguzkilorre* to protect houses from evil spirits: from witches, genies, the witch-like Basque supernatural beings *lamiak* and *sorginak*, illness, thunder and lightning, and other forms of evil.

A few years ago, the practice of pinning *Eguzkilorres* to front doors came back in, leading to the flower’s near extinction. Because of this, picking them from the wild is now strictly prohibited.

Here at the Fibromyalgia Awareness Association, we wanted to call upon the “magic powers” of the silver thistle, but were also mindful of conservation. We decided to adopt the *Eguzkilorre* in its symbolic form as the logo of our organisation, so that it can also protect our homes, and those who live in them, from the suffering of fibromyalgia.



facebook.com/fibroinfoweb



@fibroinfoweb



fibroinfoweb



fibroinfoweb



info@fibro.info



First edition June, 2016

Illustrator Noemí Villamuza www.noemivillamuza.com

Editor and translation team coordinator Emma Goldsmith www.goldsmithtranslations.com

Layout and design Patanegra Publicidad www.patanegrapublicidad.com

ISBN 978-84-608-7833-9

Published under a Creative Commons license

Attribution-NonCommercial-NoDerivatives (CC BY-NC-ND).

This guide should not be hosted in part or in whole on any website without the written permission of the Fibromyalgia Awareness Association. info@fibro.info



What is fibromyalgia?

Primary care

Psychological treatment

Physical activity

Physiotherapy

Healthy habits

Relationships with family and friends

*The future and the current state
of research*

FAQs

www.fibro.info

www.fibro.pro



info@fibro.info

Commended and funded by:



Endorsed by:

