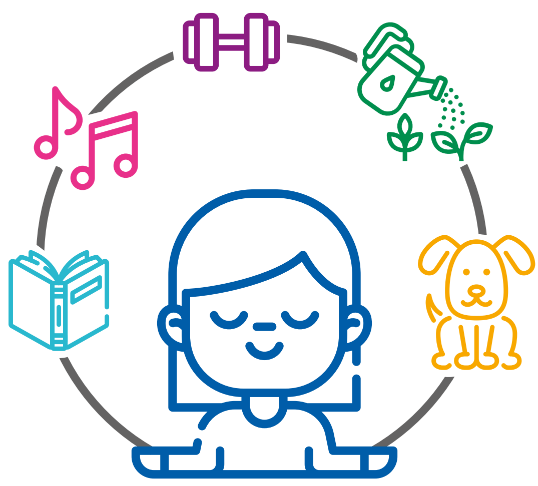
SELF-CARE

FOR PEOPLE WITH PAIN



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FOREWORD

"Woe to that sick person who does not know that he has in his hands that heartbreaking option of having his own pain turned into vinegar or fragrant wine."

José Luis Martín Descalzo

A nurse with a true vocation for the patient thought of me to write this foreword and I could not refuse. I considered myself lucky. I believe in professionals who always try to take into account the voice and experience of the patients. I hope that after reading it, we are able to make you feel at least a little bit better and better understood.

My name is Yolanda Casares Alcalá and I suffer from intercostal neuralgia, a type of pain denoted as neuropathic. It has been eight years since I started my journey; a journey that I know you are also on because you have this book in your hands. A road with steep climbs, sudden descents, arid, rocky, sometimes lonely and that can exhaust body and soul.

Over the years, my attitudes towards pain have been "evolving". I don't know where you are on the road. Are you just at the starting line? Or do you already feel the exhaustion of going from one place to another always carrying your pain??

The bewilderment at the arrival of my pain made me take, in my opinion, an inevitable first attitude: **nervous rebelliousness**. That difficult moment when you ask yourself again and again, why you. When, if you have faith, you ask God to heal you. Here, even the strongest beliefs are shaken. Days of anguish that rob us of our inner tranquility. Do you know what I achieved by maintaining this attitude? I ended up adding a second illness more serious than the first one: **anguish**.

My second attitude was a consequence of the first: **to fall apart** bitterly when my pain was labeled chronic. I saw it as a monster that I would never defeat. At this point I gave myself completely to it. I was not able to appreciate the good parts of my existence (like my small children... yes, that hard) and the responsibilities that I had assumed as mine until that day, and that the limitations of my pain did not allow me to carry out. They fell like a huge weight on my shoulders and generated a lot of anxiety in me. I fell into depression. Remember, just because it happened to me does not mean it will happen to you. However, if it happens to you, I also want you to understand that it is totally normal; because the hardest thing about an illness is that it is prolonged over time. A short pain, no matter how intense, would not be difficult to cope with. What is truly hard is when that

journey lasts for years and years, and even worse, if it is lived with little to no hope of healing. **You, better than anyone else know how strong you are.** Don't ever take that credit away from yourself.

My third attitude was **resignation**. Collapsed, apathetic and bitter, I no longer had the nervous rebelliousness I had at the beginning. This posture is somewhat less harmful to us since, at least, our inner tension is somewhat defused. I was a "passive" patient. I thought that I could do little more than take medication, put myself in the hands of the health professionals and accept whatever they proposed.

And now, comrades... Let's welcome and give a warm round of applause to the fourth attitude! **Acceptance.** It could be said that it is the next step after resignation, but beware, what a step! Acceptance overtakes resignation on the left and leaves passivity behind. As the treatments began to have some effect and my pain subsided, my posture became more hopeful. I became a patient with a definition I really like: **a hopeful woman with "realistic pain"**. I went from not wanting to read, not wanting to meet people with my disease and not wanting to go to more doctors, to standing up to my disease and saying, "You do not define me, I will not allow you to be the center of my life and I am going to do everything in my power so that, since I have to live with you, I can do so in the best way possible, and live my moments of least pain as intensely as I can".

At this point I want to clarify that you should not consider it a failure if, once you reach acceptance, you fall back to one of the other positions. It happens to all of us. It happens to me, we are human. The important thing is not to lose sight of the attitude that helps us.

Read this, it is very important: **whatever happens, you do not have the right to waste your life, to demean it, to stop living, to believe that ,because you are sick, you have an excuse not to fulfill your duties or to make those around you bitter** (I say this with love, I know you did not choose to be in pain). With conviction, I tell you that you should consider your illness as a challenge, and that you ought to look for all the ways and means to get better. I am sure this book will be of great help to you. Its name makes it clear: Self-care for people with pain. Believe it or not, **there are many things in your hands you can do to make your pain go down**.

When faced with a professional indication to perform adequate and responsible analgesic self-care, you may think: "My pain my responsibility? I'm lost!" Or... that something inside you clicks, and you take control of your illness. And the fact is that, only by making yourself physically and emotionally responsible for it, you will be able to make your day to day life more bearable.

I invite you to become a patient who reads about her/his disease to know it well, **an educated and informed patient**. A patient who is up to date with the latest advances in the treatment of his or her condition. All this will help you prepare and make the most of the consultations you have with your pain management team.

There is one last thing we, chronic pain patients, cannot lose. **Hope.** Today, the fight against pain is stronger and better than ever. A thousand times more expert professionals, hospitals and scientists are discovering and applying new drugs and treatments every day to try to restore our health. Medicine is advancing; maybe not at the pace we would like, maybe we will not see the cure for our pain. But I am sure that new treatments and care will provide us with a better quality of life. And we have to live!

If you recognize me on the road, say hello, partner. I look forward to hugging you.

Yolanda Casares Alcalá.

Author of the book: *Mamá tiene una amiga invisible*.

(Mom has an Invisible Friend).

01

LIFESTYLE AND SELF-CARE

- SELF-CARE
- KNOWING, WANTING, AND BEING ABLE
- 6 TIPS TO HELP YOU

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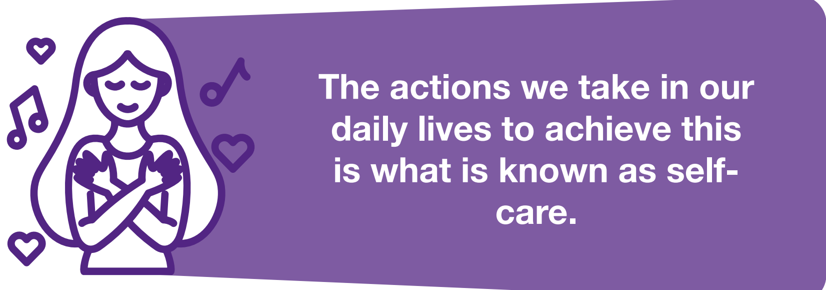
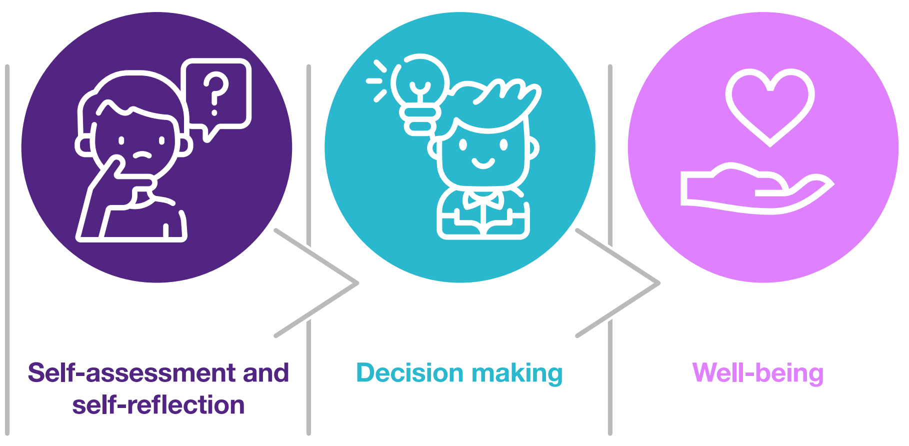
People with any chronic health problem, as is the case of those of us who experience chronic pain, need to adopt measures to **achieve the highest level of autonomy and quality of life** that the situation of the disease allows us.



SELF-CARE

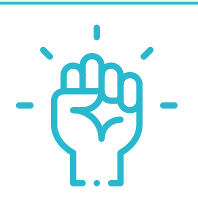
> **"Self-care is defined as the practice of activities that people initiate and perform to maintain their own life, health and well-being."**
>
> *Nurse Orem*

These are intentional actions with a specific purpose, in our case, **to reduce or prevent pain**. This implies that, previously, each one of us has made a self-assessment and self-reflection, which has led us to make a voluntary decision about what is appropriate to do, or not, at each moment to achieve **well-being**.

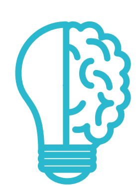


KNOWING, WANTING, AND BEING ABLE

Since self-care is a behavior, the ability to perform these activities will depend on our capabilities and three components:



Motivation or attitude: **wanting** to perform self-care actions.



Knowledge or aptitude: **knowing** how to perform self-care actions.

Skills: that **enable** you to perform self-care actions.

According to Nurse Orem (1993), in order for people to be able to work on their own self-care, we must have or acquire the following faculties and skills:

- **Knowledge:** it is necessary to be equipped with theoretical and practical knowledge, as well as skills for the performance of self-care actions.
- **Attention:** keeping attention on oneself and on the internal and external factors that condition self-care.
- **Energy:** control of physical energy, to perform the necessary body movements for self-care actions.
- **Motivation:** maintaining motivation and orientation of self-care towards objectives in accordance with their significance for life, health and well-being.
- **Daily life:** integration of self-care actions in relevant aspects of personal, family and community life.

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6 TIPS TO HELP YOU

1

Seek and secure the appropriate professional help (doctors, nurses, psychologists, physiotherapists...) to better perform self-care and adjust it to your needs and capabilities.

2

Become aware of and pay attention to the effects that pain has on normal functioning and/ or performance of daily activities.

3

Effectively carry out visits to your healthcare professionals, diagnostic measures, rehabilitation and prescribed pharmacological and non-pharmacological treatment indications (e.g., keep a pain diary).

Be aware of and pay attention to the adverse effects of the prescribed measures, in order to detect them in time and act appropriately (minimizing or eliminating them).

Modify your self-concept and self-image to accept yourself as a person with a specific health condition and in need of specific health care.

6

Learn to live with the consequences of chronic pain at the individual, family and social levels, making a process of adaptation to integrate the new reality to your lifestyle, allowing it to affect you as little as possible at these levels and adopting a lifestyle that promotes continuous personal development.

IF YOU WANT TO FIND OUT MORE...

Agenda for pain monitoring.

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The importance of self-care | Talk with Cristina Mitre.

CLICK HERE TO ACCESS

Neuroscience applied to everyday life. David del Rosario, neuroscience researcher.

CLICK HERE TO ACCESS

02

HOW TO IMPROVE CHRONIC PAIN THROUGH NUTRITION

- FOOD AND NUTRITION ARE NOT THE SAME THING
- WHAT TO AVOID
- WHAT ARE HEALTHY HABITS?

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It is not only what we eat, but how much we eat, and how we eat that has to do with our health and certain pathologies we suffer from. Eating is a habit that is part of our lifestyle.

Sometimes, certain health problems can be affected by lack of nutrition, and some diseases or pain can be aggravated by this.

Therefore, taking care of our diet can improve health and directly influence the experience of pain.

FOOD AND NUTRITION ARE NOT THE SAME THING

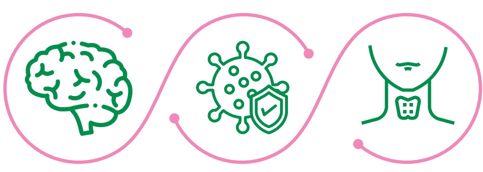
FEEDING

Consuming foods and beverages that contain the nutrients necessary to keep us alive.

NUTRITION

The process by which our body absorbs, transforms and uses nutrients from food to obtain the energy needed to live.

These definitions show that **our food intake can be adapted with the intention of nourishing ourselves better** and thus achieving greater health benefits.



WHAT TO AVOID

"MIRACLE" DIETS

Any diet plan must be individual and adapted to each person. For this reason, when in doubt, it is helpful to seek advice from a professional specialized in nutrition.

OVERWEIGHT AND OBESITY

A heavy weight overloads the joints, promotes bad posture, and favors the onset of pain and other diseases.

We must adjust our diet to our real needs (weight, size, occupation, etc.), making sure that it contains the nutrients we need on a daily basis.

TOXIC HABITS

In general, it is recommended to minimize alcohol consumption and avoid tobacco and other drugs.

Toxic habits increase inflammation, pain in certain diseases, and create dependency.

SATURATED AND TRANS FATS

They can be found in butter, pre-cooked foods, hydrogenated vegetable oils, sunflower oil and safflower oil..

Reducing saturated and trans fats, in addition to helping to control cholesterol and triglyceride levels, reduces the risk of cardiovascular diseases and inflammatory processes.

WHAT ARE HEALTHY HABITS?

STAY HYDRATED

Dehydration
is associated with:

- Increased sensitivity to pain.
- Muscle stiffness.
- Appearance of cramps.
- Muscle fatigue.

KEEP A BALANCED DIET

TAKING CARE OF THE GUT MICROBIOTA

The gut microbiota is unique and varies according to modifiable factors such as: dietary habits, drugs used, environment and lifestyle, overweight/obesity; and other non-modifiable factors such as: genetics, anatomy of the gastrointestinal tract, age of the embryo, type of delivery and age of the individual.

Where can we find probiotics?

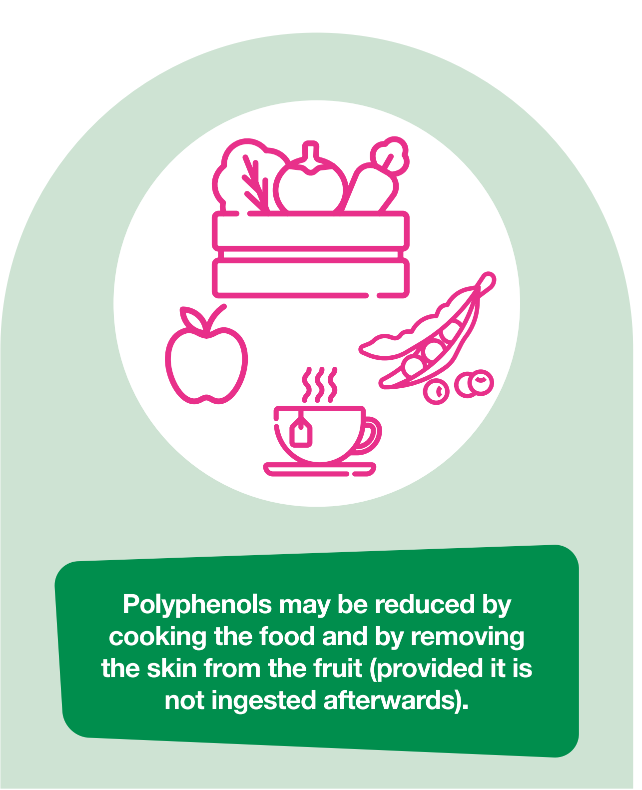
In foods such as natural yogurt, sauerkraut, fermented soybeans, kombucha, kefir, sourdough bread, pickles (gherkins, spring onions...), among others.

Some studies link probiotics to inflammation, and they are thought to help reduce abdominal pain in people living with irritable bowel syndrome.

POLYPHENOLS

Benefits: polyphenols have antioxidant properties, vasodilatory effects and help control cholesterol and triglycerides. A diet rich in these compounds can improve health and decrease pain and reduce the risk of developing other diseases.

Where do we find polyphenols? Mainly in foods of vegetable origin.	
Fruit (mainly in the peel)	Apple, grapes, strawberries, raspberries, blueberries, pomegranates, citrus peel.
Vegetables	Tomato, peppers, celery, parsley, beets, eggplant, onion, garlic.
Legumes	Soybeans and derivatives, lentils, beans, peas.
Whole grains	Buckwheat.
Drinks	Tea, yerba mate, cocoa, chocolate, virgin olive oil.



OMEGA-3

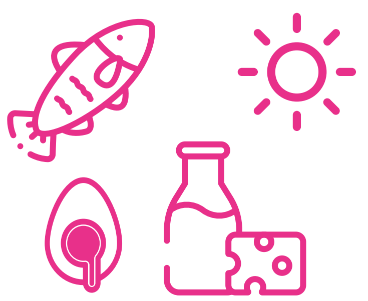
Benefits: helps reduce inflammation and improve the immune system.

Where can we find omega-3?	
Blue fish	Salmon, sardines, anchovies, tuna.
Seafood	Shrimp, spider crab, oysters.
Oils	Extra virgin olive oil, linseed oil.
Seeds	Flax seeds, chia seeds.
Nuts	Walnuts.
Fruit	Avocado.
Vegetables	Lettuce, spinach.
Cereals	Oats.

VITAMINS AND OTHER MICRONUTRIENTS

Vitamin D

Benefits: plays an important role in the nervous, muscular and immune systems, and is essential for bone mineralization at all ages. It is also an antioxidant and its deficiency is associated with muscle fatigue.

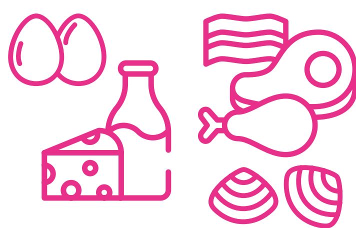


Where do we find Vitamin D? In food and through its synthesis in the skin thanks to sunlight.
Oily fish (salmon, tuna and mackerel).
Beef liver.
Milk and dairy products (cheese, yogurts, etc.).
Egg yolk.

Exposing the arms and legs to direct sunlight for 10-15 minutes (if there is no individual restriction), will have a positive impact on our health.

Vitamin B12

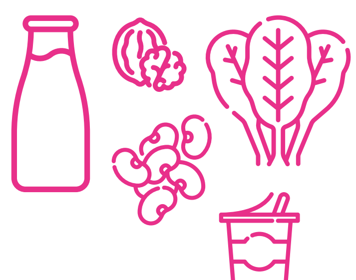
Benefits: it is involved in neurological processes related to pain.



Where can we find Vitamin B12?
Meat, beef liver, poultry, eggs.
Fish and clams.
Milk and dairy products.

Magnesium

Benefits: its deficiency is associated with muscle spasms, inflammation and neuropathic pain.



Where can we find magnesium?
Legumes and whole grains.
Nuts and seeds.
Green leafy vegetables (e.g., spinach).
Milk, yogurt and other dairy products.

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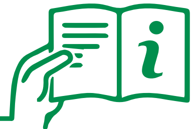
IF YOU WANT TO FIND OUT MORE...



Healthy eating plate. AESAN 2022.

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Healthy and sustainable food campaign.

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Healthy eating. Blog.

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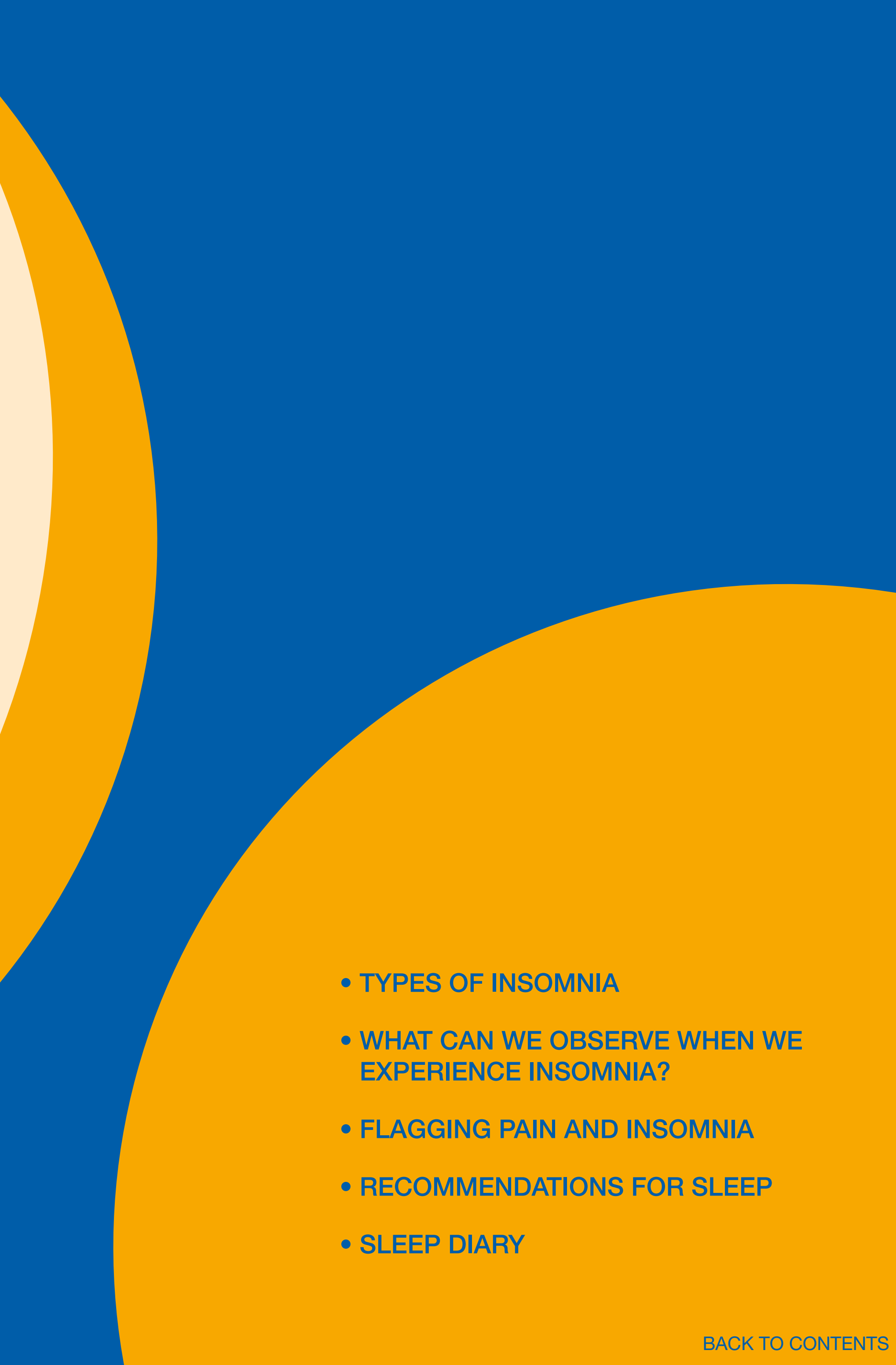
03

THE IMPORTANCE OF SLEEP AND REST



- TYPES OF INSOMNIA
- WHAT CAN WE OBSERVE WHEN WE EXPERIENCE INSOMNIA?
- FLAGGING PAIN AND INSOMNIA
- RECOMMENDATIONS FOR SLEEP
- SLEEP DIARY

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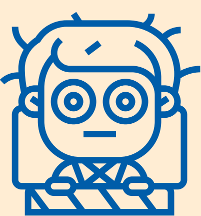
TYPES OF INSOMNIA

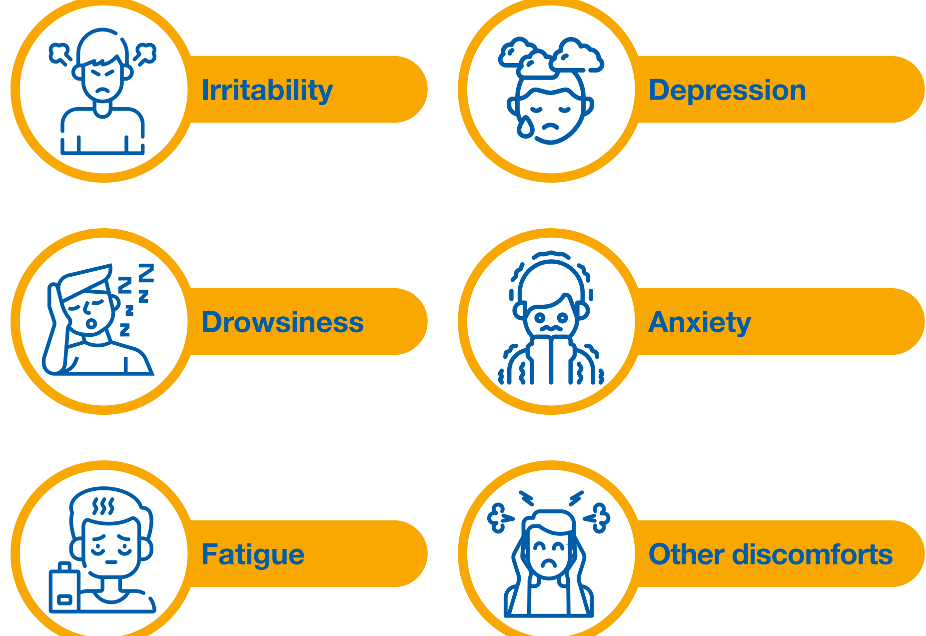


- **Transitory insomnia:** its duration is less than one week.
- **Short-term or acute insomnia:** lasts from one to four weeks.
- **Chronic insomnia:** lasts four or more weeks.

In turn, any of them can be **punctual**, associated to a specific situation we are going through (stress, worries, a medical problem, drugs...); or, if maintained over time, it can be a problem that requires a **specific treatment**.

WHAT CAN WE OBSERVE WHEN WE EXPERIENCE INSOMNIA?

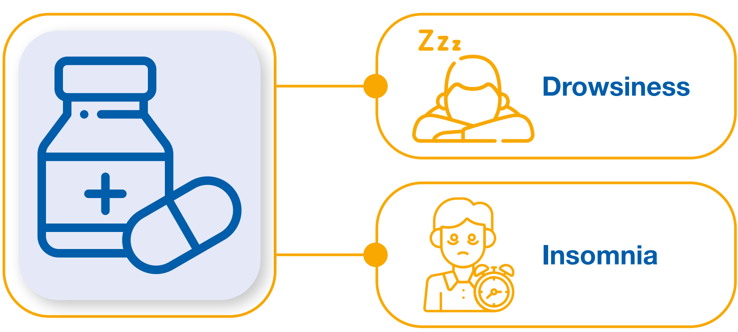
Insomnia has an impact on our quality of life, producing:



FLAGGING PAIN AND INSOMNIA

Rest is important for anyone, and even more so for those of us who experience pain. Pain can be both a cause and a consequence of insomnia.

Drugs prescribed for pain can modify sleep patterns and cause drowsiness or, on the contrary, insomnia. Therefore, the assessment of sleep quality is an important piece of data to know if the analgesic treatment is adequate or not.



On the other hand, painful problems such as **headache** or **back pain** can also cause insomnia.

RECOMMENDATIONS FOR SLEEP

Each of us has a bedtime routine (reading a little, drinking a glass of milk...) and even different needs from our environment to fall asleep (total darkness, some degree of luminosity, etc.).

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However, there are general hygienic measures that help to improve the quality of sleep. Some of them are presented below:

Going to bed only when we are sleepy.

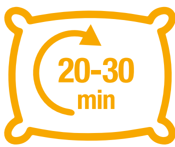
Using screens and/or engaging in stimulating activities before bedtime (watching TV, using the cell phone and/or tablet in bed).

Having a stable sleep schedule (going to bed and waking up at the same time), even on non-working days, and stay in bed for 7 to 8 hours.

Sleep a different number of hours each day, and at different times.

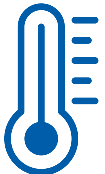
Performing a routine of actions that prepare us mentally and physically to go to bed and practice relaxation exercises before going to sleep.

Using the bedroom as a living room while waiting for sleepiness to come.



Short naps, 20-30 minutes maximum.

Long naps.



Keeping a healthy sleeping environment (temperature, noise, ventilation, etc.).

Unconducive sleep environment: noise, excess or suitability of clothing and bedding.

Exercise daily, for at least one hour and no more than three hours before bedtime.

Physical exercise before going to bed.

Eating at regular times and maintaining a healthy diet, preventing overweight.

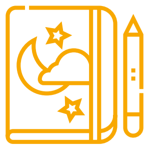
Consuming coffee, alcohol, tea, cola... and other stimulants, especially after 5pm, or having large dinners before going to bed.

If in doubt, ask for help at your primary care centre.

Self-medicating with melatonin, hypnotics or anxiolytics.

In cases of insomnia self-medication is not recommended.

SLEEP DIARY



INSTRUCTIONS:

(1) Fill in the first three rows with the date, day of the week and type of day. **(2)** Write "CAF" inside the box when you drink coffee, cola or tea, "M" when you take any type of medication, "A" when you drink alcohol and "E" when you exercise. **(3)** Put a "C" in the box to record when you go to bed; and a "Z" at the moment

WEEK 1

Date	Day of the week	Type of day (work, school, day off, or holidays)	Noon	1 pm	2 pm	3 pm	4 pm	5 pm	6 pm	7 pm	8 pm	9 pm	10 pm	11 pm	Midnight	1 am	2 am	3 am	4 am	5 am	6 am	7 am	8 am	9 am	10 am	11 am
Ex.	Monday	Work		E					A	Z			C		Z	Z	Z	Z		Z	Z	CAF M				

Adapted by the American Academy of Sleep Medicine. (2021) [2].

when you more or less think you fell asleep. **(4)** Repeat the letter "Z" in all the boxes where you think you were asleep, both in normal sleep and during a nap. **(5)** Leave empty the boxes where you think you were awake at night or during the day.

WEEK 2

Date	Day of the week	Type of day (work, school, day off, or holidays)	Noon	1 pm	2 pm	3 pm	4 pm	5 pm	6 pm	7 pm	8 pm	9 pm	10 pm	11 pm	Midnight	1 am	2 am	3 am	4 am	5 am	6 am	7 am	8 am	9 am	10 am	11 am

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IF YOU WANT TO FIND OUT MORE...

Insomnia and melatonin.

CLICK HERE TO ACCESS

Circadian rhythms.

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What could be the consequences of not sleeping? - Claudia Aguirre (TED-Ed).

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Learning to know and manage insomnia. Information for the patient.

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04

MOBILITY AND FUNCTIONALITY

- PHYSICAL ACTICITY AND EXERCISE: TWO FRIENDS AGAINST PAIN
- RECOMMENDATIONS
- EXERCISE CALENDAR

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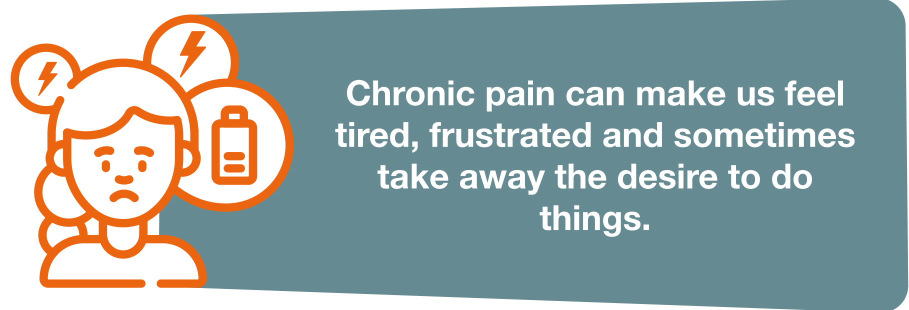


This is one of the worst "traps" of chronic pain: **it makes us move less** and creates a **"vicious circle"**:

VICIOUS CIRCLE

WE FEEL PAIN

WE MOVE LESS

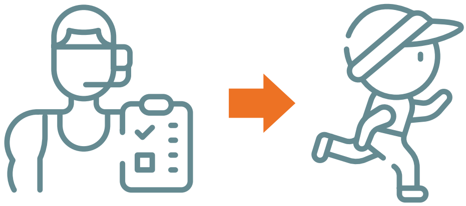
PAIN GETS WORSE

PHYSICAL ACTIVITY AND EXERCISE: TWO FRIENDS AGAINST PAIN

When we talk about ***physical activity***, we mean anything we do that involves movement, from walking to the corner shop, to dancing at a party, to working in the garden.

On the other hand, when we talk about ***exercise***, we have to distinguish between two types:

1. ***General exercise:*** what we do to stay fit and healthy. Example: performing certain exercises proposed by a trainer to improve running technique and achieve a good time in a race.



2. ***Therapeutic exercise:*** that with which we treat specific health problems. Normally, in these cases, the type of exercise is important, but above all the **number of repetitions** to be done at each moment will be important. Example: if we experience knee pain, the healthcare professional can prescribe a series of specific exercises, adapted to our problem and with specific recovery objectives.

Therapeutic exercise can be a **great ally** for people with chronic pain, because it can help improve mobility and relieve pain.

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However, we are all different and **what works for one person may not work for another**. So we must avoid prefabricated "exercise tables", the "you have to stretch more" cliché, or that "miracle exercise" to solve a particular type of pain.

The type of exercise will depend on our symptoms, capabilities and, above all, how we feel.

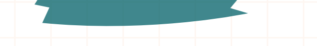
RECOMMENDATIONS

1

START SLOWLY

If you have been a little "out of it" because of your pain, it makes the most sense to start slowly. Choose **gentle physical activities** such as walking or swimming, something that doesn't cause additional stress on your body. Then, as you feel stronger and especially if the pain begins to subside, you can increase the level of activity.

2



CHOOSE AN ACTIVITY THAT YOU LIKE

Staying active will be much easier if you choose an **activity that you really enjoy**. Maybe you like the tranquility of yoga, the energy of dancing, or the coolness of swimming. Remember, it's your journey and you should enjoy it.

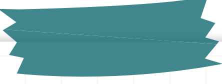
3

MAKE PHYSICAL ACTIVITY A ROUTINE

Try to do some form of physical activity for, **at least, 30 minutes a day, five days a week**. You can break it up into smaller blocks, such as three 10-minute walks a day.

Like any good habit, consistency is key. Therefore, a calendar can be a tool to help us to achieve the goals we set for ourselves (example on the next page).

4



ADAPT THE EXERCISES TO YOUR SITUATION AND NEEDS

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EXERCISE CALENDAR

Here is an example of a calendar that you can use to keep track of the exercise you do during the week. Each day you should fill in the blanks with the type of exercise performed and the time spent. For example: *walking (30 min)*

	MORNING	AFTERNOON	EVENING
MONDAY			
TUESDAY			
WEDNESDAY			
THURSDAY			
FRIDAY			
SATURDAY			
SUNDAY			

IF YOU WANT TO FIND OUT MORE...

Exercises to fight pain.

CLICK HERE TO ACCESS

Plan Be Fisioterapia website.

CLICK HERE TO ACCESS

05

CHRONIC PAIN AND SEX LIFE: IS IT POSIBLE?

• TIPS TO IMPROVE YOUR SEX LIFE

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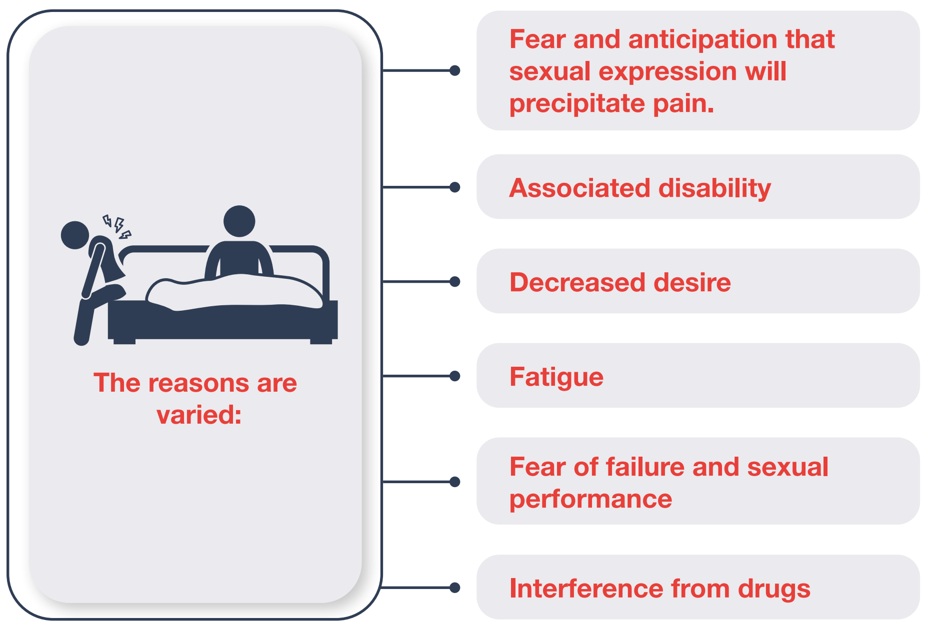
The World Health Organization considers sexuality **as a human right**. We can describe it as the **predisposition to the healthy pursuit and attainment of pleasure**. It has to do with desire, curiosity, fantasies and eroticism, and is part of the human experience and of people's general health.

Some research indicates that pain, and especially **chronic pain**, produces changes in sexuality in at least 70% of the people who experience it, affecting our relationships, and both our own and our partners' sexual satisfaction.

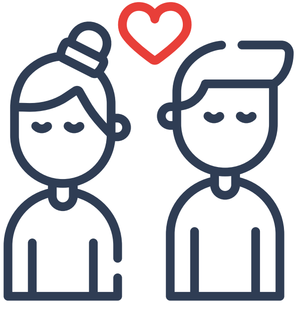


All this can make it **difficult for us to have a pleasurable bodily and sexual experience**, and can sometimes lead to **avoidance of sexual relations**.

In turn, the fact that we do not maintain an active sex life, prevents the release of endorphins and other brain substances, known, among other things, to relieve pain, reduce discomfort and induce pleasurable sensations in a natural way.

It is also necessary to point out that both eroticism and sexuality do not refer exclusively to sexual intercourse; they also refer to fun, pleasure, and mischief. Intimacy, proximity, and confidentiality are part of this same field.

Awakening desire in another person boosts our self-esteem and, in addition, sexual pleasure can act as an analgesic that improves mood and quality of life.



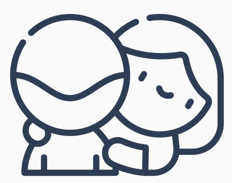
A healthy sexual life is one of the elements to be considered in the active coping with chronic pain. It is about transforming a painful experience into a pleasurable relationship with oneself and one's partner.

TIPS TO IMPROVE YOUR SEX LIFE

Taking care of the body: looking for spaces and moments for self-exploration, alone or with a partner, and relating to our body and our thoughts in a healthy way. **The aim is to avoid associating body and suffering.** To this end, it may be useful to perform simple relaxation routines such as hip opening and closing exercises, shoulder exercises, massages, skin care and grooming.

Stimulate desire and play with insinuation and seduction: sexy clothes, provocative music, insinuating movements... Enriching eroticism reduces painful sensations and gives way to pleasant ones. **Preparing for a sexual encounter increases desire.**

Take into account the moment of greatest effect of the medication to minimize pain and fatigue: consult with the specialist if it is possible to modify the treatment regimen (to adjust it to a specific time of the day), without having to change the drug or dosage.



Identify the specific problems of the sexual relationship: lack of sexual desire and appetite is common among people who experience pain. The fear that the pain will increase when practicing sex decreases its practice and the possibility of exploring new forms of relationship to positively face sexuality. The fear of not being attractive, especially when the condition causing the pain may have altered the body shape, is another of the most frequent concerns. That is why it's important to keep in mind that **sexual behavior includes play, desire, arousal, closeness and intimacy, not just performance and orgasm.**

Use tools to help the sexual relationship: water-based lubricants, sex toys, erotic memories, etc.…

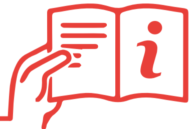
Find the position: to do this, it is essential to determine what changes we can make to adapt to sexual encounters. Use pillows, cushions and positioning wedges to support certain areas of the body and, if necessary, a hot shower before intercourse may be useful. **Posture or the enviromental elements can be adapted to achieve greater comfort.**

Enhance sincere and genuine communication with the partner: both in the sexual relationship and being affectionate with each other. It will be key to share fears, desires, expectations, and experiences; to face difficulties positively, to look for meeting points, and to promote adaptation, communication and solutions.

Ask for professional help from someone you trust: a family doctor, anesthesiologist, psychologist, nurse... will be able to guide and help improve sexual health.

Some professional associations offer workshops on "self-esteem and sexuality" or "therapeutic yoga" for people with pain (for example, on the website of the association included in this section). Consult your health care professional to find out about these possibilities.

IF YOU WANT TO FIND OUT MORE...



Pain and sexuality.

CLICK HERE TO ACCESS

Chronic pain and eroticism.

CLICK HERE TO ACCESS

Chronic pain and sexual relationships.

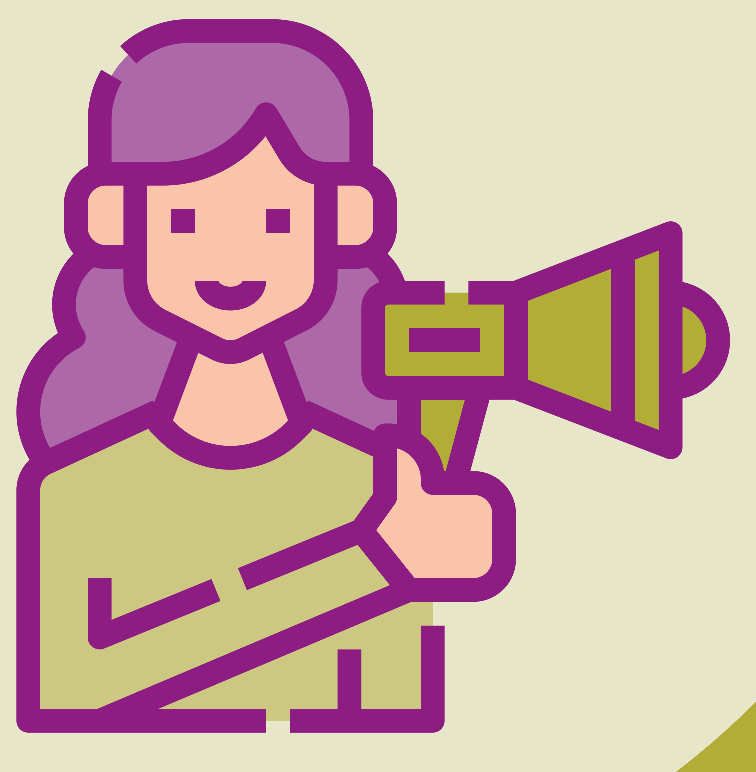
CLICK HERE TO ACCESS

Speaking of sex...

CLICK HERE TO ACCESS

06

COMMUNICATING CHRONIC PAIN



6.1. COMMUNICATION AS A TOOL FOR PAIN SELF-MANAGEMENT AND EMPOWERMENT IN THE FACE OF THE DISEASE

6.2. HOW TO TELL MY CHILDREN THAT I LIVE WITH CHRONIC PAIN

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06.1

COMMUNICATION AS A TOOL FOR PAIN SELF-MANAGEMENT AND EMPOWERMENT IN THE FACE OF THE DISEASE

- IMPORTANCE OF THE THERAPEUTIC RELATIONSHIP
- COMMUNICATION IN THE DOCTOR'S OFFICE: WHAT TO EXPECT?
- ADHERENCE TO THE TREATMENT

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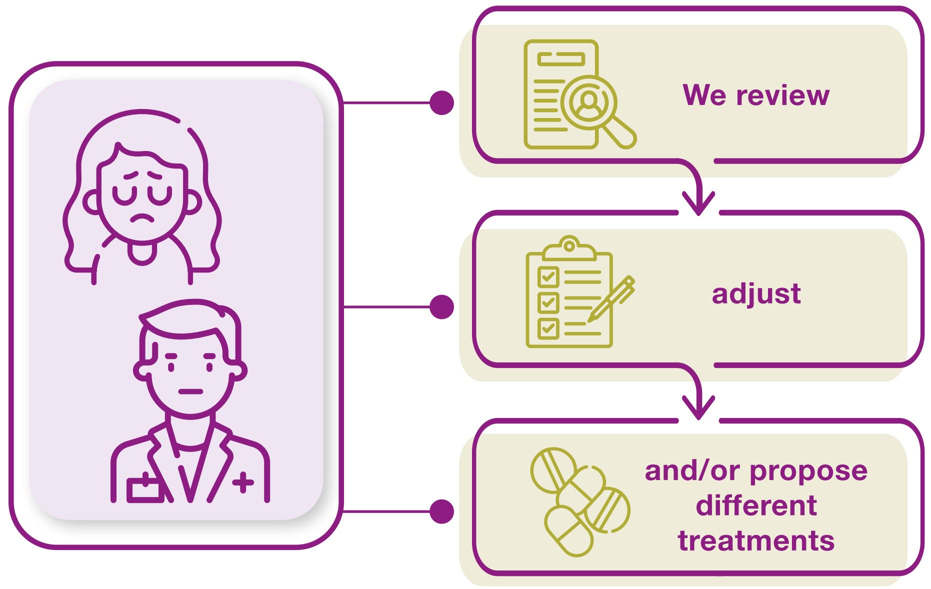
IMPORTANCE OF THE THERAPEUTIC RELATIONSHIP

People with chronic pain present a subjective and **unique experience of physical and emotional discomfort** that often goes unrecognized, requiring a long journey with the healthcare professional where:



with, often, unsatisfactory resutls.

Therefore, the **therapeutic relationship**, defined as the interaction between the person and the health professional with the aim of improving health, is key to the good management of the disease and to promote:

The therapeutic relationship should be centered on acceptance, respect and legitimacy of discomfort.

The therapeutic relationship is a key element in the treatment of pain and, as patients, we must be involved in it.

The **therapeutic alliance and communication between patients and healthcare professionals**, is in itself an irreplaceable therapeutic resource. With professionals, we can share experiences, doubts, and expectations regarding the health-illness process.

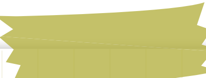
Share your experience with the professional or team that is managing your care. **Open and honest communication will help them better understand your condition.**

If the therapeutic relationship cannot be established, or is not adequate, it is preferable to change teams or professionals.

Without trust, the therapeutic path is difficult

COMMUNICATION AT THE DOCTOR'S OFFICE: WHAT TO EXPECT?

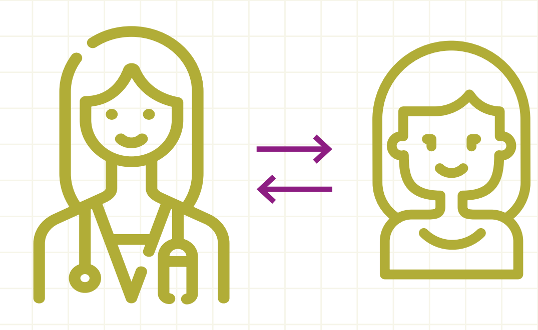
At the health professional's office, it is essential that there is a **suitable environment** where the professional accompanies and guides us in the health care, as if they were a personal trainer.



For this reason we should expect that:

- They introduce themselves at the beginning of the interview and are cordial and humane.
- They offere simple and clear information about our disease and treatments.
- They show empathy and listening skills, look at us and encourage us to express difficulties and doubts.
- They also pay attention to our facial expressions, postures, silence...
- They finish the consultation by summarising the conversation, sharing and coming to an agreement with us on the action plan, and giving clear guidelines as to what we should or should not do from that point onwards.

However, as in all human relationships, establishing this nexus is a two-way thing. You have to work together to achieve a close and trusting relationship.

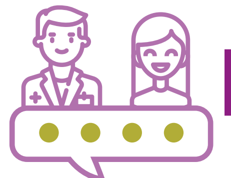


ADHERENCE TO THE TREATMENT

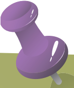
Adherence to treatment **is the motivation to initiate, maintain, and commit to the indicated recommendations, whether pharmacological or non-pharmacological (psychological, physical activity, diet, etc.).**

Complex and long-lasting situations, such as chronic pain, can compromise adherence. For this reason, it is necessary to agree on **specific and feasible therapeutic objectives** with our professional or healthcare team.

It is essential to recognize the small advances made day by day, and to work together with professionals, even when there are adversities or the results of the treatments are not favourable.



Close communication will allow for a more personalized approach to treatment and care.



Trusting our team of professionals is essential: we must talk to them. We are on the same path and have the same desire to achieve our wellbeing.

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EMPOWERED PATIENTS: A PATIENT THAT MAKES DECISIONS IN RELATION TO THEIR ILLNESS

Empowerment is about us, as patients, actively collaborating in our own treatment and encouraging the implementation of healthy actions that can positively influence our quality of life, such as exercise, and dietary or sleep hygiene recommendations.

Meeting or contacting expert patients, patient associations, health schools like in Spain, social networking groups or, in general, other patients with similar diseases to our own to share personal experiences, also **promotes useful, effective self-care and personal autonomy**.

IF YOU WANT TO FIND OUT MORE...

Patient School.

CLICK HERE TO ACCESS

Patient Association.

CLICK HERE TO ACCESS

06.2

HOW TO TELL MY CHILDREN THAT I LIVE WITH CHRONIC PAIN

- PREPARE THE CONVERSATION
- HOW TO ACT?
- KEY MESSAGES TO COMMUNICATE
- RECOMMENDED SHORT STORIES

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The purpose of this section is to provide you with some key messages to be able to pass on to your children the experience of pain - of your pain - without magnifying the information or faking well-being.

Don't exaggerate your well-being or act as if nothing is wrong.

Children are not "dumb", and they detect simulation, which is actually more incomprehensible than pain itself. We usually have a desire to protect them from pain and suffering. However, depriving them of the understanding of this problem prevents them from developing the necessary skills to cope with situations that they will inevitably have to face during their lives; and furthermore, we teach them to externalise emotions, favouring greater emotional self-regulation.

PREPARE THE CONVERSATION

Before informing your children about your illness:

Be well informed about the disease; be clear about what to say and how much information to pass on.

2

Make a list of basic information and anticipate possible questions and answers.

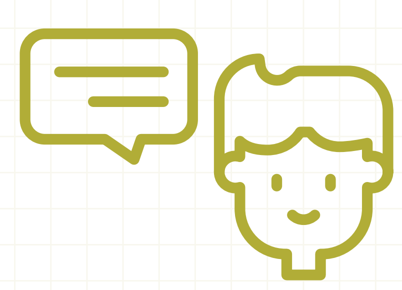
Simplify information and provide only that which they can understand.

For example:

- What you are experiencing: *One side of my head hurts very often.*
- What you need: *I need darkness and silence for a few hours.*
- Your children's cooperation: *I would like you to be quiet for a while.*
- What happens as a result of this: *it goes away and I feel better.*

Possible questions:

- *Is it going to hurt me too?*
- *Does it happen to everyone?*
- *Why does it happen to you?*
- *Can it be cured?*
- *Are you going to die?*



Encourage them to express themselves and resolve their doubts. **It is important that they learn to communicate with you without fear, without trauma, and that they understand the importance of family support.**

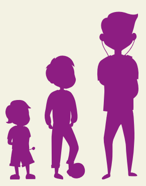
HOW TO ACT?

Children may attribute their parent's illness to misbehaviour and **blame themselves for it**. Try to prevent this from happening and insist that it has nothing to do with him or her.

It is important that **the lives of children and teenagers in the family environment are not excessively modified by your illness**. Their routine will inevitably change and you will need their cooperation. Tell them how they can help you and what they can do to help you feel better.

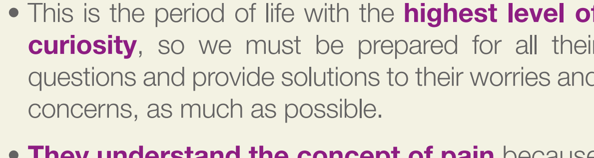
Insist that, despite your pain, **you love them very much**, and you will not stop caring for them. It is in these situations that you should strengthen the maternal/father-child or family bond and develop emotional attachment strategies, and encouraging physical contact such as hugs.

Offer them **alternative care if you are not feeling well**: who they can call, how long they should wait, what they should do...

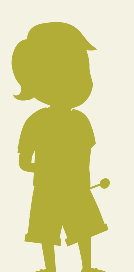


Understanding experiencing pain is very much determined by **age and maturity.** It is important that we adjust to these.

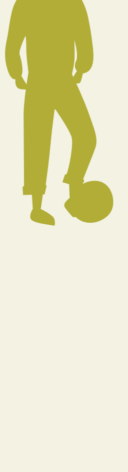
Up to the age of 6:



- This is the period of life with the **highest level of curiosity**, so we must be prepared for all their questions and provide solutions to their worries and concerns, as much as possible.
- **They understand the concept of pain** because they have already felt it accidentally. However, during this stage, **“magical thinking”** predominates and they may believe that something in their behaviour is the trigger for someone else’s pain. This thinking may lead to feelings of guilt that should be anticipated and avoided.
- Also, they often **associate pain with old age, illness and, as a natural consequence, death**. These beliefs may generate fears and separation anxiety. It is important to minimize this.



From the age of 6 until adolescence:



- At this time, **“magical thinking” disappears and more rational and concrete thinking begins**. They are very curious and need to reason everything out and ask for explanations.
- **They interpret experiencing pain as a part of life**, although they do not understand that illness can be permanent or disabling. It is difficult to understand chronic pain that is sustained over time, without being associated with a cause or injury.
- Between the ages of 7 and 12, children may already **have a greater knowledge or awareness of what death entails and may suffer from fear** of abandonment or fear of the unknown.

Adolescence:

- This is a stage of change and transition towards independence, where conflicts are sometimes a result of disengagement and detachment. This can be the origin of **feelings of guilt** if their parent’s pain worsens, attributing the cause to their behaviour. They often do not want to share with adults the emotions derived from observing the pain of others so as not to appear vulnerable.
- We can ask for their help, but they may feel pressured to behave like adults and take on roles that the person in pain cannot perform. However, **involvement and collaboration in domestic and emotional life can also lead to an increase in their self-esteem**, as they begin to feel useful and change the role from cared-for person to caregiver.

KEY MESSAGES TO COMMUNICATE

Authenticity.

Always tell the truth, even if you don't give all the information.

Clarity.

Avoid euphemisms. You can use metaphors, stories or adapted examples to get the message across. At the end of this chapter you will find some resources that might help you.

Tailor information to the capacity of children.

Fragment the information if necessary, completing it according to their maturity. Remember that children's attention span and comprehension depend on their age and cognitive abilities. Avoid graphic and gruesome details.

Share your emotions with your children, avoid intense emotionality.

Convey your pain in a discreet way. Also show interested in their feelings and thoughts about the information you have conveyed.

Choose the right moment to give this information.

When they are focused and more communicative. No distractions.

Encourage questions and address their doubts.

Request their help.

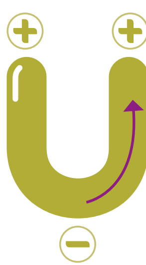
Explain clearly and concretely how they can help you when you feel worse.

Use appropriate physical contact.

Tell them you love them, even if you are in pain. Pain does not disqualify you from expressing affection, and it even benefits the intensity of the pain.

Warm tone of voice.

Convey calmness in your words and speech.



Use the U-shaped strategy.

This is an approach to discourse that is able to "surround" or "wrap" bad news with positive information. The concept is to start with good news, and then gradually move on to communicating bad news, "offsetting" it immediately with a positive impulse.

A practical example of this approach could be:

"Darling, let me hug you because I have something important to tell you. When you see me sad it's because I'm in a lot of pain; but don't worry if I look bad, I'll surely be with you again in a while and I love you just the same, even if I can't take care of you now."

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RECOMMENDED SHORT STORIES

Casares Alcalá Y. Mamá tiene una amiga invisible. Sevilla: Editorial Infantil y Juvenil Mr. Momo; 2020.

Alonso Santamaría M. Los dos pinos. Cuento infantil sobre la empatía hacia el dolor de otros. [Internet]. Guía Infantil; 2021. [Citado 01 oct 2023].

Alamar Barrachina P. Cuentos de magia potagia. Valencia: Legua Editorial S.L.; 2019.

Rivera de la Cruz M. Los cuentos de Mingabe. Vitoria-Gasteiz: Asociación Vasca de Divulgación de Fibromialgia; 2010.

- *Manu y Gus* (de 0 a 6 años), de Beatriz Berrocal, ilustrado por Alicia Cañas y narrado por Magda Labarga.
- *Las cosas que importan* (de 6 a 8 años), de Marta Rivera de la Cruz, ilustrado por Violeta Lópiz y narrado por Manuela Vellés.
- *Danieloto y la caja de madera* (de 8 a 10 años), de Mar Santos, ilustrado por Lucía Serrano y narrado por Conchita.
- *La aurora boreal* (de 10 a 12 años), de Toti Martínez de Lezea, ilustrado por Silvia Bautista y narrado por Cristina Verbena
- *La dama de las grutas* (de 12 a 16 años), de Silvia Pazos, ilustrado por Cecilia Varela y narrado por Anne Igartiburu.
- *Aquella casa blanca número 42* (de 16 a 101 años), de Cecilia Peñacoba, ilustrado por Noemí Villamuza y narrado por Patricia Urrutia.
- *La verdadera y asombrosa historia de la Bella Durmiente* (cómic, de 0 a 101 años), de Silvia Pazos, ilustrado por Patricia Castelao y narrado por Marta Escudero.

IF YOU WANT TO FIND OUT MORE...

How to talk to children about tragedies and other bad news.

CLICK HERE TO ACCESS

Mum has a migraine.

CLICK HERE TO ACCESS

Children's stories.

CLICK HERE TO ACCESS

07

RELAXING MY BODY, CONTROLLING MY MIND

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Pain, when it is chronic, ends up becoming a **stress factor for our body**; not only due to the painful sensation itself, but also due to everything that comes with living with pain and that aggravates the situation (catastrophic thoughts, feeling of lack of control, sleep problems...) (Figure 1).

Psycho-emotional treatments have demonstrated efficacy in pain management and self-management and, within these, relaxation techniques are considered key to improving the quality of life of people living with pain[1,5].

These techniques, among other multiple benefits, contribute to **improving the sleep pattern and prevent the associated catastrophism**, diverting attention, and indirectly achieving a reduction of the painful sensation.

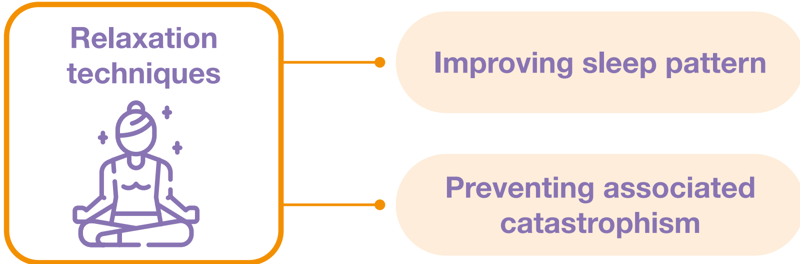
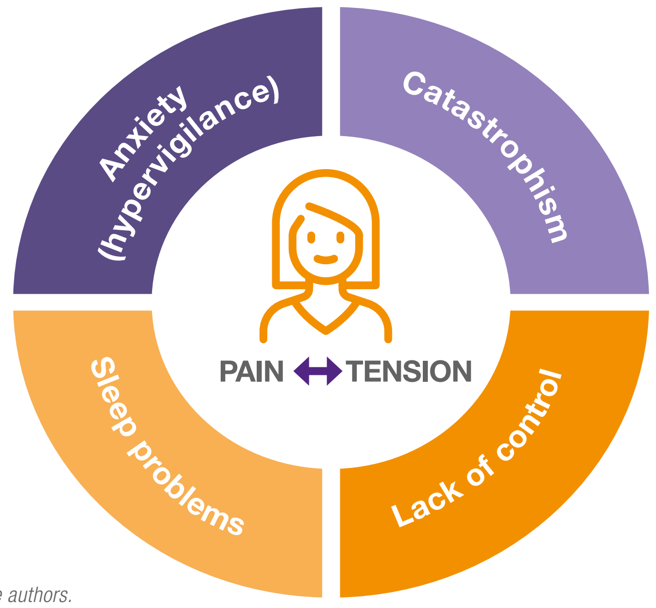


Figure 1. Pain-tension "vicious" circle.



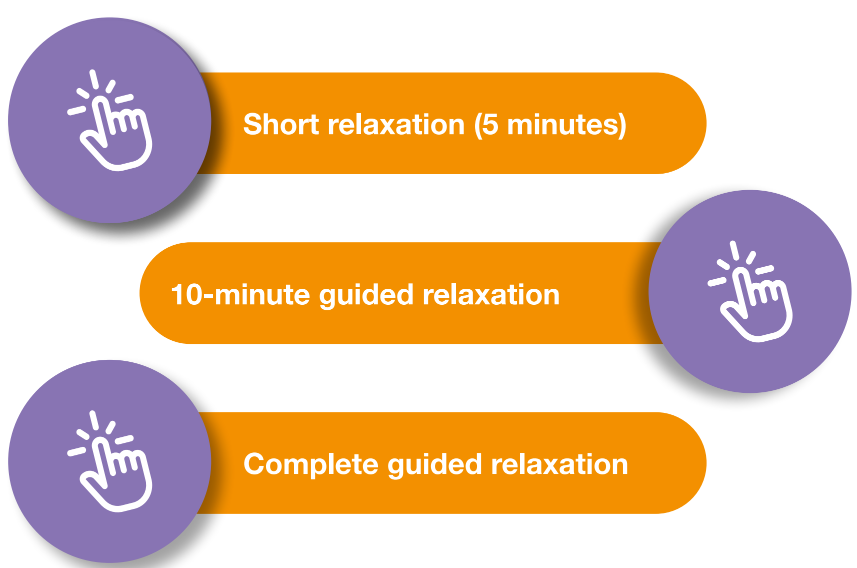
Prepared by the authors.

PROGESSIVE MUSCLE RELAXATION

Progressive muscle relaxation **is a technique to help reduce tension or stress, which is beneficial for people in pain, as both situations amplify the painful sensation.**

Its aim is to **enable us to recognise and differentiate between tense and relaxed areas of the body**, and then to **learn how to relax** those muscles that are tense.

This technique should be practised on a daily basis and training **will require a trained professional** to provide advice. However, to get started, we can follow the indications suggested in the following sections:



AUTOGENIC TRAINING

This is a very useful technique when there is a high muscular tension that causes pain, since, in this practice, **we achieve the relaxation of the musculature by directing the attention to different physical sensations typical of a state of calm and relaxation**.

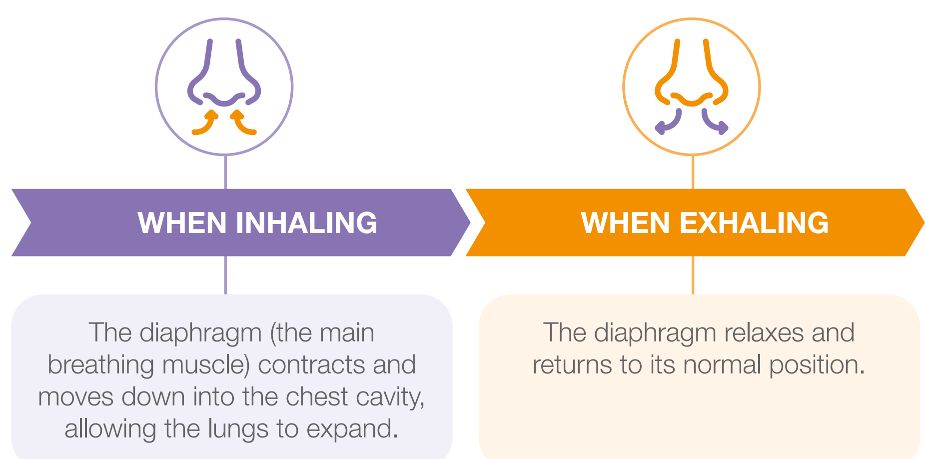
It also requires a trained professional to guide us through the exercise at the beginning, until we learn it and integrate it into our daily functioning.

We can see an example in the next video:

Guided autogenic training

DIAPHRAGMATIC BREATHING

Diaphragmatic breathing consists of deep breathing in which:



The steps to follow in diaphragmatic breathing training are as follows:

1. Lie or sit comfortably and place one hand on your stomach and the other hand on your chest.

2. Inhale slowly through the nose, pushing the air into the lower part of the lungs for 3 seconds. The hand on the stomach should be raised while the hand on the chest should remain still.

3. Hold the air for 3-4 seconds.

4. Exhale with pursed lips for 6 seconds (sometimes it helps to do this audibly, like a little whistle). The hand on the stomach should return to its original position.

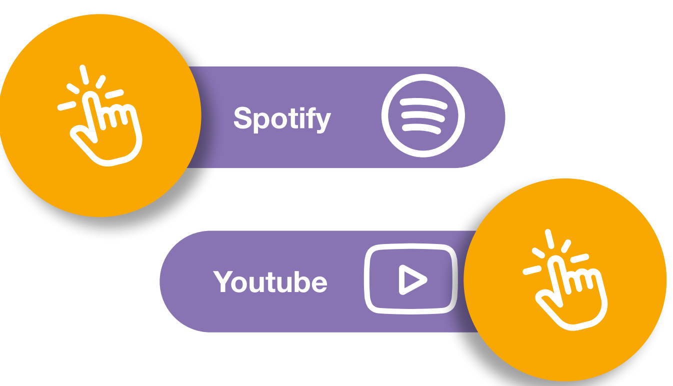
5. Repeat the whole cycle for at least 5-10 minutes and do it several times a day.

3-4 seconds

When this type of breathing is practised, it is common **to see how the stomach rises and falls** (instead of the chest). It is very easy to apply this technique and, once it is controlled, we can put it into practice in any situation and position, achieving results in just a few minutes.

Furthermore, with practice it is possible to establish this type of breathing as our habitual breathing, instead of shallow breathing, which would provide multiple benefits on all levels.

Below, you can see an example of guided diaphragmatic breathing, and a music playlist to help you relax:



Learning and using relaxation techniques requires our active participation. It is important to remember that, for the technique to be effective, we must practise it for at least 5 to 10 minutes a day and persist, even if the benefits are not seen or the pain is initially reduced. This is because it will contribute to better management and produce benefits in other areas of life.

IF YOU WANT TO FIND OUT MORE...

5 relaxation techniques to manage stress and anxiety.

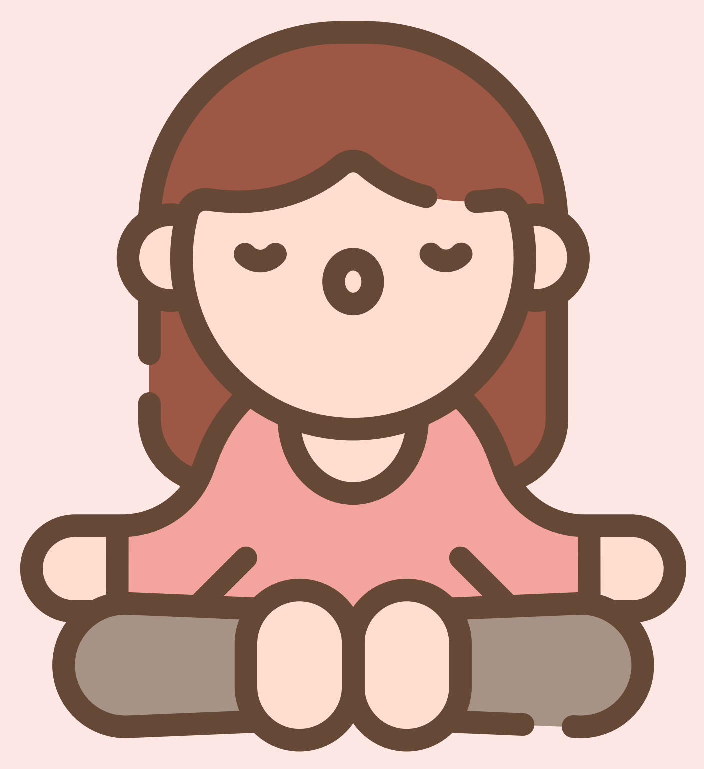
CLICK HERE TO ACCESS

What can I do to relax? Relaxation techniques.

CLICK HERE TO ACCESS

08

EMOTIONAL CONTROL THROUGH MEDITATION



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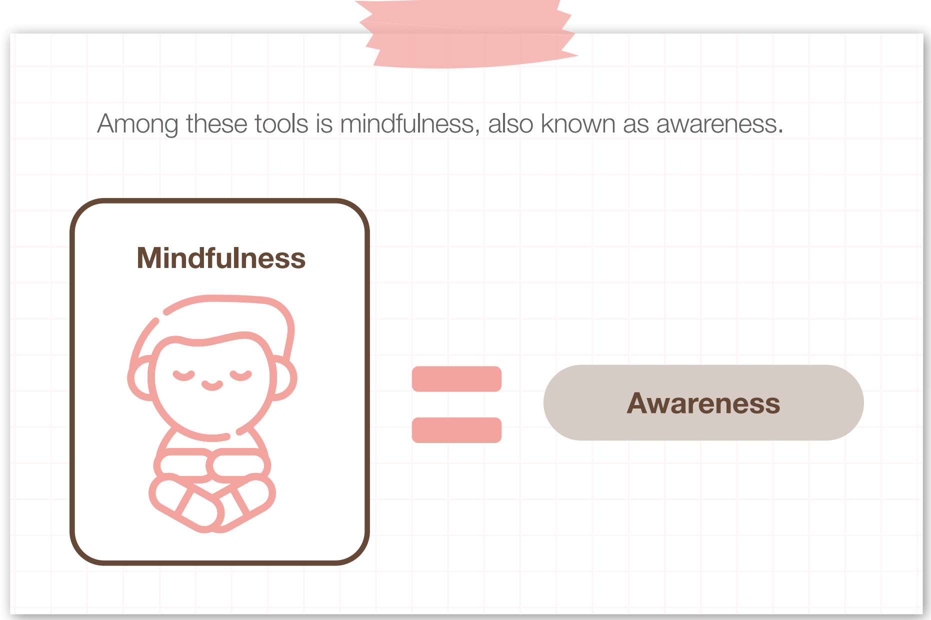
New **body-mind therapies** have positive effects on a variety of chronic diseases, including pain.



MINDFULNESS

Mindfulness promotes the **acceptance of unpleasant physical sensations**, being aware of reality as it is, and seeking to find the wisest way to relate to it, in the "present moment", without evaluation or judgement, with kindness and acceptance of what is happening; observing reality with a **"beginner's mind"**.

Practicing **midfulness** has been shown to be effective in reducing pain and the resulting emotional response, as well as improving mood and quality of life in people affected by chronic painful conditions[4,5].

MINDFULNESS PRACTICE: "FOCUSED ATTENTION MEDITATION"

Meditation basically focuses on the way in **which attention is held**. There are various forms of practice, but the most common is **focused attention meditation**.

This technique **consists of directing the attention towards a previously established focus**. And normally, the most commonly used support is **breathing**:

We focus our attention on the sensations generated when air enters and leaves our nose.

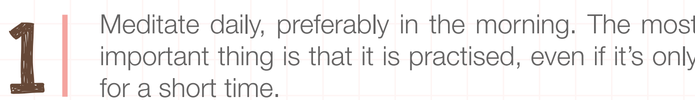
We focus our attention on how our abdomen and thorax rise with our breathing.

Each time attention leaves this chosen focus, we must make an effort to refocus on it, as often as necessary, with a **kind, compassionate, and non-judgmental attitude**.

The posture to adopt when meditating is not important. You can meditate in any of these positions: sitting in a chair, kneeling on the floor, sitting cross-legged, lying down, or even walking.

In case of physically limiting health problems, use the one that is most comfortable (usually sitting or lying down) is recommended.

RECOMMENDATIONS



1. Meditate daily, preferably in the morning. The most important thing is that it is practised, even if it's only for a short time.

2. Carry out routine activities (brushing our teeth, taking a shower, doing the dishes, taking a walk, drinking coffee...) in a conscious way, involving all the senses.

3. Learn how to find the optimal level of practice, so that you find mental comfort through meditation.

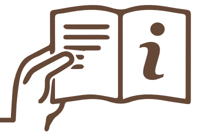
4. Observe pleasant and unpleasant situations that occur in the day. Think about how they make us feel, what sensations we feel at a physical level, and discern if we are responding or reacting (anger, fear, avoidance, etc.) to them.

5. Practise active and attentive listening.

6. Encourage conscious dialogue with yourself.

7. Spend time every day in contact with nature (park, forest, garden, etc.) and paying full attention to everything that is present: smells, sounds, images, sensations, thoughts... This is the pleasure of conscious observation.

IF YOU WANT TO FIND OUT MORE...



Recommended books.

- Kabat-Zinn J. Vivir con plenitud las crisis: Cómo utilizar la sabiduría del cuerpo y de la mente para enfrentarnos al estrés, el dolor y la enfermedad. 1ª Ed. Barcelona: Editorial Kairós S.A.; 2016.
- Vidyamala B, Penman D. Tú no eres tu dolor: Mindfulness para aliviar el dolor, reducir el estrés y recuperar el bienestar. 1ª Ed. Barcelona: Editorial Kairós S.A.; 2016.

Meditation focused on conscious movements.

Breath-focused meditation.

CLICK HERE TO ACCESS

Meditation on love and compassion.

MEDITATION #4
IN THE NEXT LINK

Other guided meditations.

CLICK HERE TO ACCESS

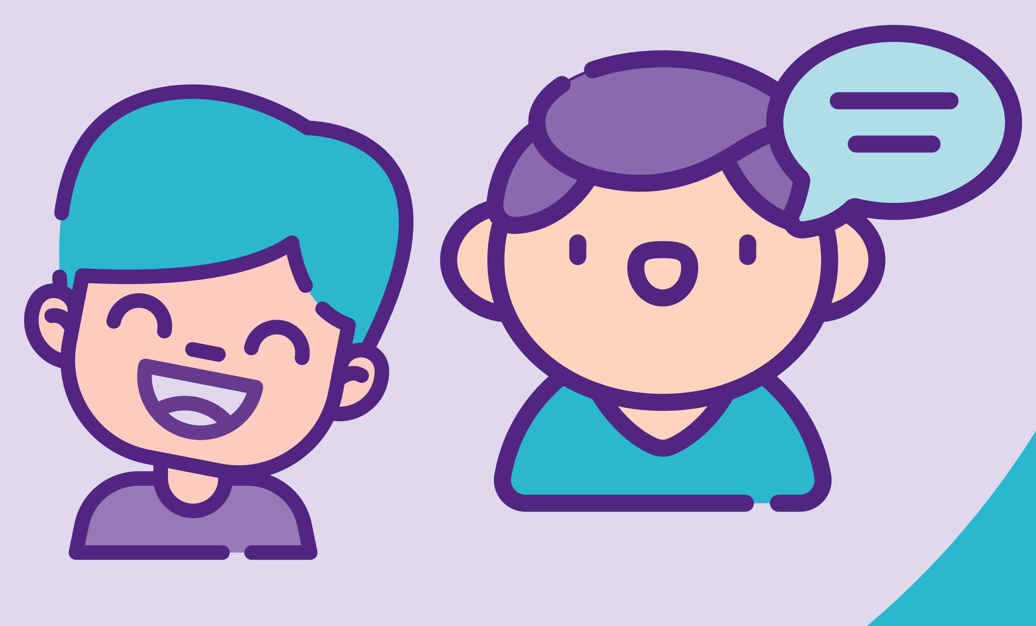
Other tools to train you in meditation techniques:

Patient Associations
CLICK HERE TO ACCESS

Health Schools
CLICK HERE TO ACCESS

09

HUMOR: A GREAT ALLY AGAINST PAIN



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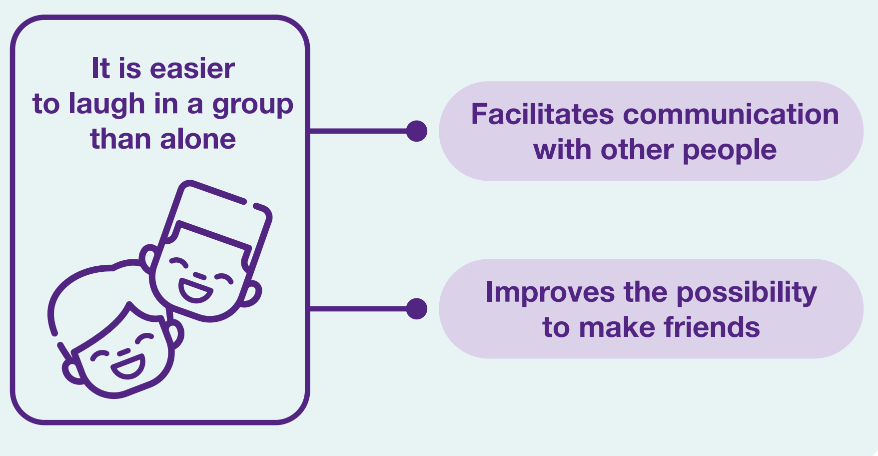
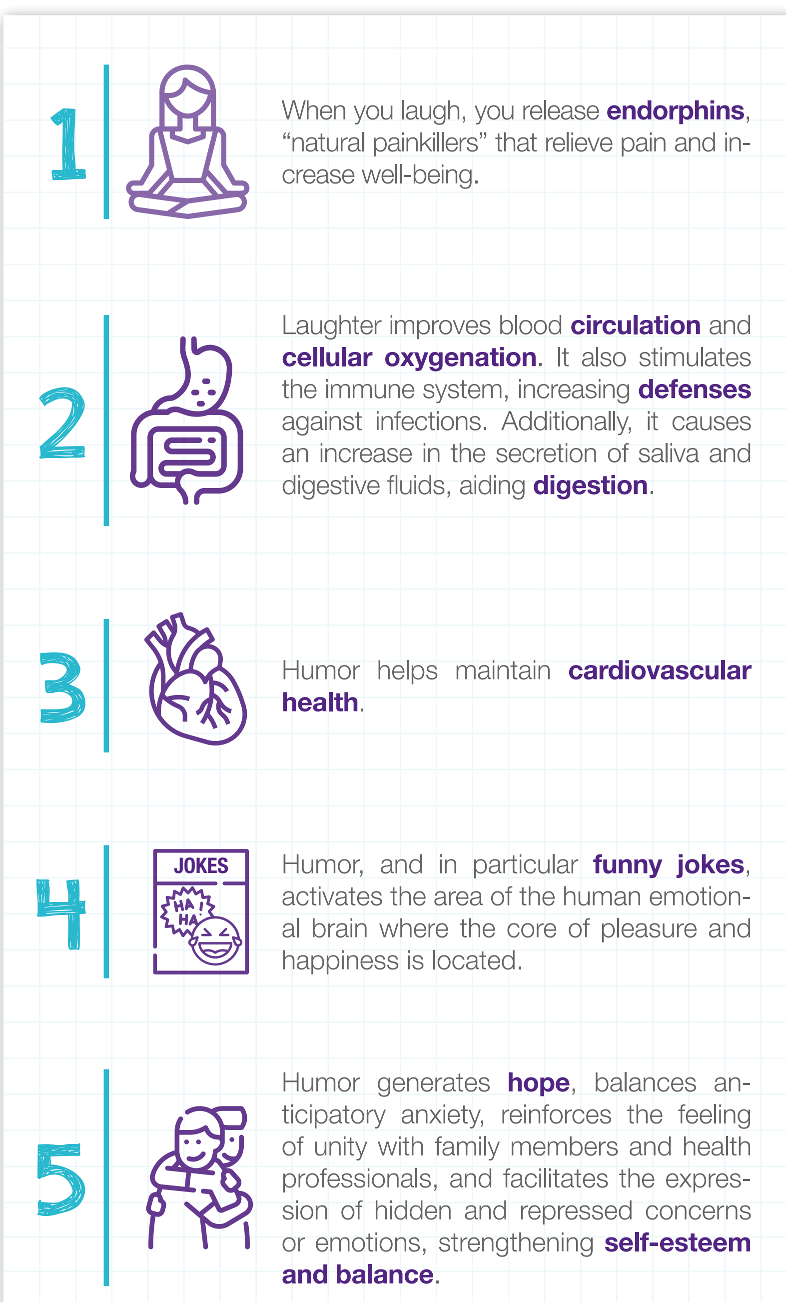
We could say that humor is the way human beings express their reality in a comical, happy or ridiculous way, involving in this **process intellectual, emotional, psychic, physical and social** aspects.



Humor is usually related to **joyful, positive, and happy situations**. It also **improves our emotional and physical health** by decreasing our natural response to stress and eliminating bodily tension.

Humor has proven to be an effective tool in **managing pain and improving well-being**. It is associated with numerous benefits and is effective at all stages of life.

BENEFITS OF GOOD HUMOR



When you laugh, you release **endorphins**, "natural painkillers" that relieve pain and increase well-being.

Laughter improves blood **circulation** and **cellular oxygenation**. It also stimulates the immune system, increasing **defenses** against infections. Additionally, it causes an increase in the secretion of saliva and digestive fluids, aiding **digestion**.

Humor helps maintain **cardiovascular health**.

Humor, and in particular **funny jokes**, activates the area of the human emotional brain where the core of pleasure and happiness is located.

Humor generates **hope**, balances anticipatory anxiety, reinforces the feeling of unity with family members and health professionals, and facilitates the expression of hidden and repressed concerns or emotions, strengthening **self-esteem and balance**.

LAUGHTER THERAPY

Laughter is innate to human beings. It occurs at all stages of life, and helps to create and strengthen bonds between people in the same group.

Laughter therapy is a therapeutic and psychological technique that seeks to generate **mental and emotional benefits through laughter**. It is usually performed through group activities, and the objective of each session is to make people feel more positive, optimistic, and satisfied with their lives.

In studies conducted in hospitalized patients, it has been shown that the use of **laughter as therapy** contributes by:

- Decreasing fear and anxiety during hospitalization.
- Reducing days of admission.
- Reducing the need for painkillers.
- Improving sleep and quality of life.

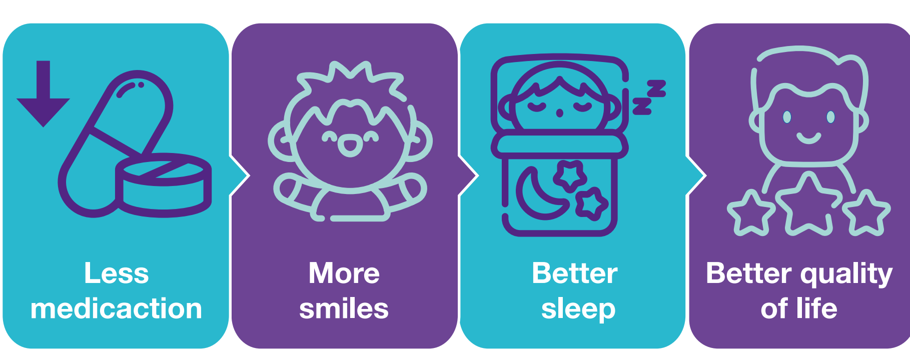
HUMOR AND CHRONIC PAIN

Norman Cousins comments in his book, ***'Anatomy of an Illness'*** (1979), that when he laughed out loud for ten minutes before going to bed, he ensured at least two hours of pain-free sleep, since laughter had an anesthetic effect[2].

Cousins lived with ankylosing spondylitis, and found comic motion pictures (specifically those of the Marx Brothers) to be a nightly relief from his pain.

This example illustrates in a simple way the fact **that humor and laughter** have been associated with a decrease in pain thresholds in patients with chronic pain, possibly due to an increase in endorphins, which make the patient feel better[4-6].

In addition, specific studies have also been carried out on patients with chronic pain in palliative care, and the results showed that, after exposing patients to different humorous situations, they demanded less pain medication, smiled more often, slept better, and, in general, reported a better quality of life[3,4,8].



Humor is a simple, inexpensive, non-invasive, and very effective therapy; useful both for those of us who live with chronic pain and for our families.

RESOURCES TO LAUGH

There are different materials and resources when it comes to introducing more humor in our life. These materials are usually inexpensive and available to anyone. Among the most commonly used resources are:

Comedy movies.

For example: The 50 best comedy movies of all time - Cultura Genial.

Click here to access

Comedy monologues.

For example: Monologues on the web.

Click here to access

Jokes.

For example: The 100 best (or worst) jokes you'll find on the Internet.

Click here to access

IF YOU WANT TO FIND OUT MORE...

American Association for Therapeutic Humor.

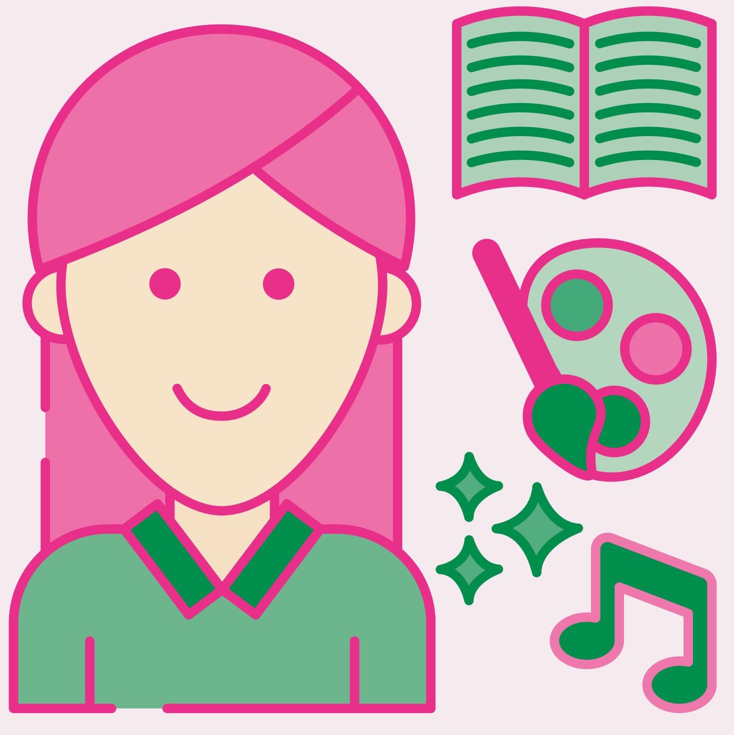
CLIK HERE TO ACCESS

Humor Theory.

CLICK HERE TO ACCESS

10

RELATIONSHIPS, LEISURE AND FREE TIME



• LEISURE AND FREE TIME ACTIVITIES

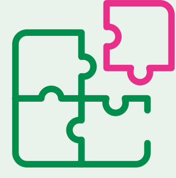
Chronic pain can case feelings of loneliness, uselessness and/or sadness, which sometimes add to certain physical difficulties. Many times, all this causes us to choose to stay home.

Spending our free time actively contributes, not only to fostering social relationships and increasing our self-esteem, but also to relieving pain.

Therefore, it is essential to stay active, enjoy leisure time and if it is shared, so much the better!

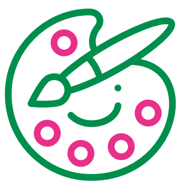
There are several social programs in public institutions that can help us in this task, including **neighborhood and/or cultural associations**, where you can participate in multiple activities free of charge (or at reduced cost).

LEISURE AND FREE TIME ACTIVITIES



TRADITIONAL AND POPULAR GAMES

We can enjoy **board games** (cards, dominoes, puzzles, chess) or **traditional games** such as pool. These types of activities, in addition to entertaining, stimulate mental agility and promote communication and social participation.



ART THERAPY

This allows the use of **artistic expression to recover health and emotional well-being**. It facilitates communication through **drawings, painting or writing**. We can also enjoy art by **visiting museums and art galleries**.

HANDICRAFTS

Manual work increases our creativity, stimulates our imagination, and improves the mobility of our hands and fingers through the use of materials with different textures, thus preventing the “stiffness” of our joints.

To carry them out, you can find **specific courses**: handicraft and painting workshops, plasticine, plaster, wood, cardboard, ceramics, sewing courses, embroidery, knitting, crochet, bobbin lace...

MUSIC THERAPY

Music therapy is the **use of music and/or its elements** (sound, rhythm, melody and harmony) **by a qualified specialist** (music therapist), in order to promote or restore people’s health, satisfying physical, emotional, mental, and social needs.

Therapy may include musical improvisation, music composition, song writing, singing and/or relaxing to music. The music therapist bases treatment on our particular needs, such as managing pain, decreasing anxiety, or learning new coping skills.

In addition to music therapy, **listening to music as a routine in our self-care can help well-being**.

Benefits of music:

- It stimulates communication with others, allows us to express our emotions, and helps relaxation and socialization.
- Listening to it stimulates parts of the brain that allow the secretion of serotonin, the hormone of good mood and happiness.
- It attracts and retains attention, especially if it is our favorite style of music, which seems to have greater positive effects on chronic pain and anxiety reduction.

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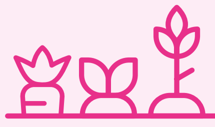
DANCING

Dance develops the ear, rhythm, coordination, and is a form of expression. It is possible to attend **classes adapted to age and condition** in dance schools, gyms or attend local festivals. It is a way to exercise and share time with other people.

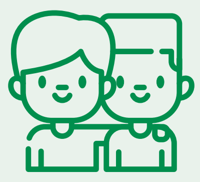
GARDENING

Gardening creates motivation and provides a new responsibility. It is an activity that can be shared. It allows you to enjoy the environment, escape from routine, and obtain healthy food. In addition to being a hobby, it allows interaction with other "farmers", as well as being able to gift others with fruits and vegetables grown by oneself.



In some cities there are **urban gardens** regulated by the municipalities.

Another option is the **raised vegetable beds for terraces or balconies** that can be found in DIY chains.



GOOD CONVERSATIONS AND CHATS WITH FRIENDS

Through interaction with others, we meet basic needs for **affection, belonging, identity, security and approval**. Social support, more specifically that of friends and family, is a coping-protective resource for the disease that can help people to improve our physical, psychological, and social situation.

READING

Reading stimulates learning, memory, and concentration. It allows us to share ideas, thoughts, and experiences. **Reading and writing** stimulates the brain and helps us escape.

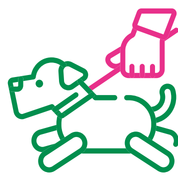
Some **associations or public libraries** organize **reading clubs**, in which you can participate free of charge.

TRAVEL

Travel is an option to stay active, stimulate the mind, and cultivate social relationships. In addition, there are different **programs adapted** to different needs.

We can find **travel clubs or programs** in different agencies.

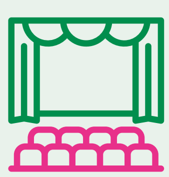
PET CARE



A **companion animal** implies a series of responsibilities related to its care and hygiene.

Having a pet activates people and reduces the feeling of loneliness.

CINEMA-THEATRE-MUSEUMS



Attending cultural activities such as **cinema, theater, opera**... entertains, relaxes and helps reduce stress. It is an option that can be done with family or friends, and helps us to socialize.

SOCIAL MEDIA

It can help us to stay informed, relate to each other and combat loneliness. **Social Media** allows us to share knowledge and experiences among people with the same problem. It is necessary to know and choose those that best suit our needs.

In social media you can find profiles of other people talking about their experience with chronic pain, virtual communities, and other interesting content.

Remember to include the time you spend on leisure and socializing in your pain diary or journal (available below and in more detail in Chapter 15 of this guide).

IF YOU WANT TO FIND OUT MORE...

Games for family fun.

Older people journal. Blog.

Leisure activities for the older people.

CLICK HERE TO ACCESS

Some resources on music therapy.

CLICK HERE TO ACCESS

Travel.

CLICK HERE TO ACCESS

Music therapy in the treatment of pain.

CLICK HERE TO ACCESS

11

CREATE A COMFORTABLE ENVIRONMENT

- SENSITIVITY OF PAIN TO CLIMATE
- OTHER FACTORS THAT AFFECT THE ENVIRONMENT

BACK TO CONTENTS

The environment around us can influence our perception of pain, both physically (the painful sensation itself), psychologically (sadness, melancholy, stress, etc.), socially (loneliness, unhealthy homes, etc.) and in the most transcendental aspect, the meaning of life.

We are all immersed in an environment from which it is difficult to isolate ourselves; however, we will see how to influence it and make it more comfortable.

SENSITIVITY OF PAIN TO CLIMATE

We have probably heard or spoken these expressions on numerous occasions, and they are not really far-fetched. There are studies that show a **relationship between cold, air humidity and atmospheric pressure, and the increase of painful symptoms of certain diseases** such as, for example, osteoarthritis or rheumatoid arthritis.

HOW DOES COLD AFFECT US?

People with neuropathic pain (pain that manifests as stinging or burning, cramping, tingling, prickling...) often experience pain associated with cold. This is known as ***allodynia***, and consists of **perceiving pain in response to stimuli that are not painful in themselves (in this case cold)**.

Neuropathic pain often occurs in people who are receiving (or have received) chemotherapy, who have had a nerve injury, who have had herpes viruses; or it may be associated with other types of illness or injury.

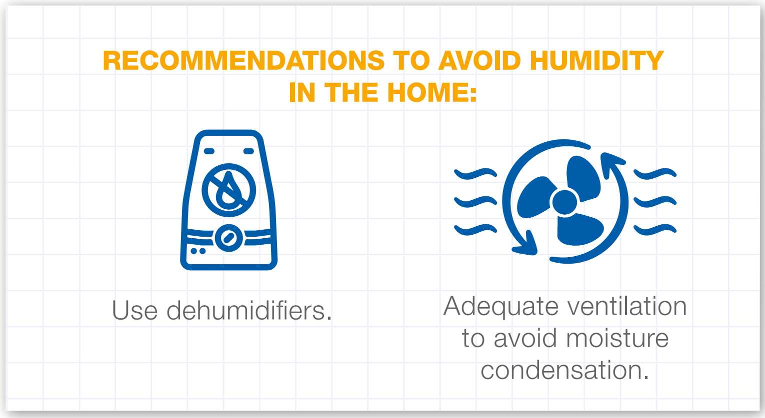
In addition, extreme cold itself is experienced as pain, and this is because it produces an alert or survival response for the possible deep and irreversible damage it can cause.

HOW HUMIDITY AND ATMOSPHERIC PRESSURE AFFECT US

A **high level of humidity, or a sudden change in temperature**, can influence the perception of pain in certain people, such as those living with fibromyalgia.

Several studies suggest that low atmospheric pressure is related to increased pain, stress and certain emotional states[4,5].

This climate sensitivity differs from person to person. It is more common in women (especially during menstruation and menopause) and older people.



OTHER FACTORS INFLUENCING THE ENVIRONMENT

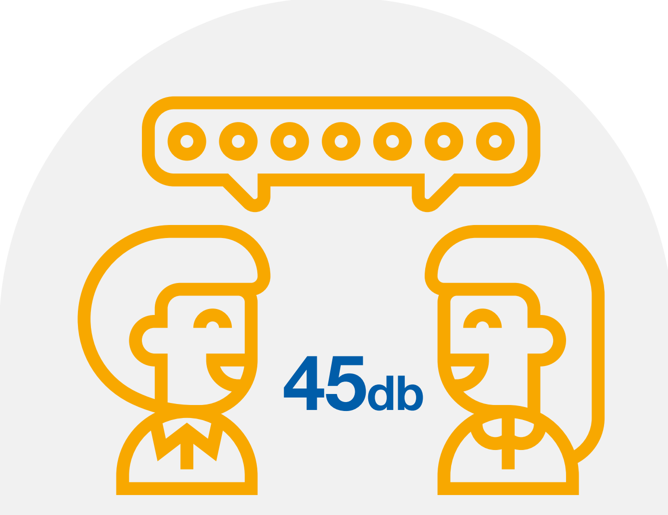
There are other factors that can influence people, altering daily activities such as sleep and rest, which in turn influence the perception of pain. This is the case with light or noise.

For example, in people with migraine, excessive light has a negative effect, as do extreme heat or cold, high humidity, dry air, windy or stormy weather, and changes in atmospheric pressure.

HOW DOES NOISE AFFECT US?

***Noise* can be defined as "sound with no value".**

The World Health Organization defines it as sound **above 65 decibels**.



To get an idea, a quiet conversation between two people is about 45 decibels.

Noise is highly harmful and is one of the environmental factors that can cause the most health alterations, after air pollution.

Prolonged exposure to low frequency noise levels could cause health problems such as: stress, anxiety, sleep disturbances, reduced academic performance, cardiovascular, respiratory, and metabolic effects... And some of these problems coexist with chronic pain, increasing our discomfort.

IF YOU WANT TO FIND OUT MORE...

Oxfam Intermón Blog. Section on noise pollution.

CLICK HERE TO ACCESS

Strategic health and environment plan.

CLICK HERE TO ACCESS

12

PLAY IT SAFE

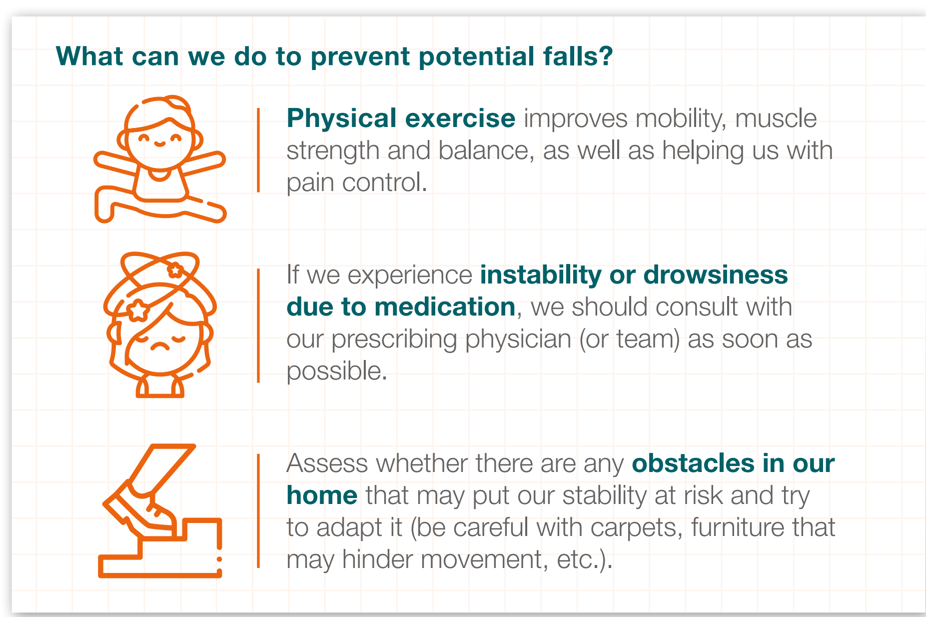
- FALL PREVENTION
- KNOW YOUR MEDICATION

BACK TO CONTENTS

Our **right to personal autonomy** implies the freedom to make decisions about our own health. To this end, it is essential to improve our knowledge, skills, and attitudes in order to be able to manage our self-care, **incorporating safe actions that reduce the risk of harm to ourselves as much as possible**.

FALL PREVENTION

Pain and its repercussions limit physical capacities and, therefore, increase the risk of falls, as can the possible adverse effects of the drugs indicated for our treatment.



KNOW YOUR MEDICATION

Medication errors are one of the leading causes of avoidable injury and harm. They are the most frequent source of patient safety problems.

There are 5 key moments for the safe use of medicines, and within them, aspects that we should be aware of:

1. Before you start taking the medicine:

- **a.** What is it called?
- **b.** What is it for? What can I expect from it?
- **c.** What are its potential side effects?
  - **i.** What should I do if I notice them?
  - **ii.** Which of these effects require medical attention?

2. When I take the medicine:

- **a.** How many times a day do I have to take the treatment?
- **b.** When and how?
  - **i.** Before or after meals?
  - **ii.** Orally ingested, skin patches, injected...?
- **c.** What dosage should I take each time?
- **d.** What if I miss a dose?

3. When I have to add another drug:

- **a.** Did I understand the reason why I need to take yet another medication?
- **b.** Does this new medication affect or interfere with the medications I am already taking?

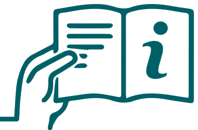
4. When my medication is reviewed:

- **a.** Should I keep an updated list of all the medications and products I take?
- **b.** Am I taking any medication that I no longer need?

5. Before stopping the intake of a medication:

- **a.** When should I stop taking a medication?
- **b.** If I have to stop my medication because of a side effect, who should I inform and where should I go?
- **c.** We will have to periodically evaluate if the medication we are taking for the pain is helping us. If this is not the case, consult your doctor to evaluate its withdrawal.

IF YOU WANT TO FIND OUT MORE...



Institute for the Safe Use of Medicines (ISMP): Information for patients.

CLICK HERE TO ACCESS

Where to get official drug information.

Guide to medications that can be cut or crushed.

CLICK HERE TO ACCESS

Information about medications that affect nutritional status.

CLICK HERE TO ACCESS

Breastfeeding compatible drugs.

Review of the first aid kit at home.

Safety infographics for patients and caregivers.

13

THE MEANING OF LIFE WITH PAIN: VALUES AND BELIEFS

- PAIN AND ITS NEGATIVE IMPACT
- COPING

BACK TO CONTENTS

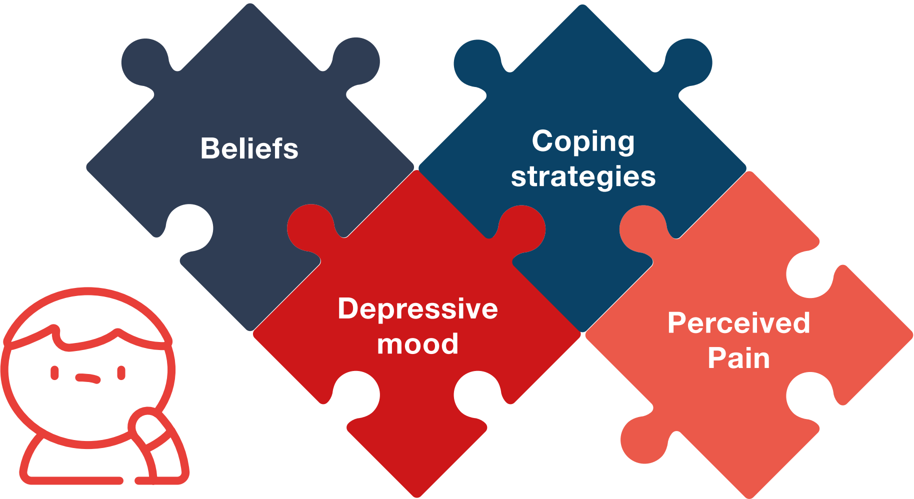
Each one of us is unique in our essence and in the experience of illness and pain. Moreover, the moment of life in which they appear, conditions to a great extent the experience of the symptoms, the consequences and the limitations they produce in us.

Professor Diego Gracia, in defining the concept of health, differentiates between two terms, biological health and biographical health:

- ***Biological health:*** absence of disease or dysfunction in the physical body.
- ***Biographical health:*** a state of perfect physical, mental and social well-being.

Both views of health, biological and biographical, will be influenced by our values and beliefs.

- ***Values:*** set of community-acquired norms that regulate human behaviour in society.
- ***Beliefs:*** multiple aspects such as the world in general, health, self-perception, etc.

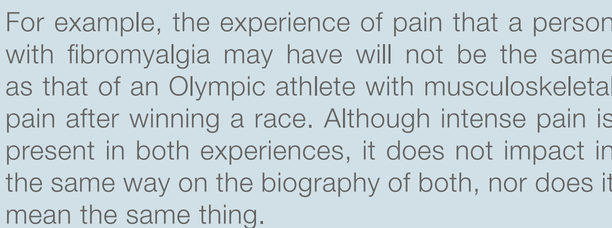


It is known that there is a relationship between our beliefs and our coping strategies, perceived pain, and depressive mood.

PAIN AND ITS NEGATIVE IMPACT

Whenever pain occurs, it has an impact on you, but this is related to your own experience of pain.

Two people may at any given time have the same intensity of pain, measured on a scale; but depending on personal experience it may have a different impact.



For example, the experience of pain that a person with fibromyalgia may have will not be the same as that of an Olympic athlete with musculoskeletal pain after winning a race. Although intense pain is present in both experiences, it does not impact in the same way on the biography of both, nor does it mean the same thing.

Therefore, pain experience is very personal and depends on various factors.

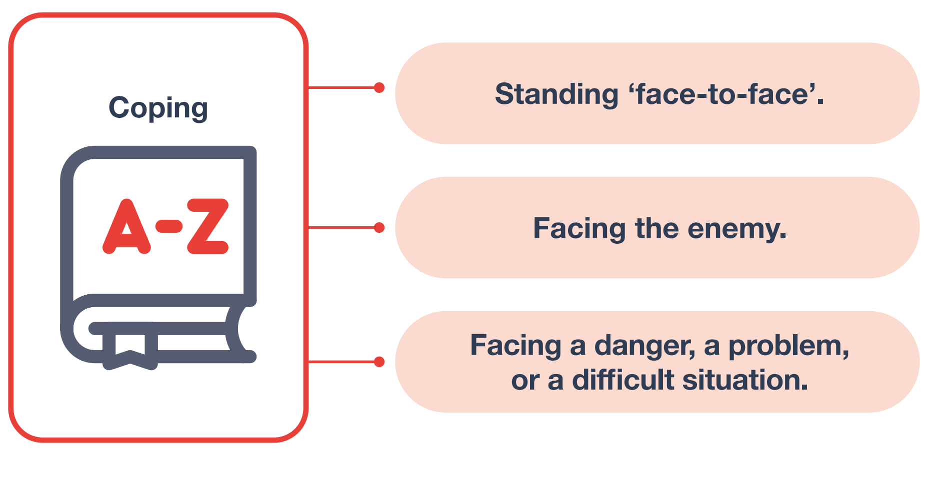
Viktor Frankl, after his experience as a prisoner in the Auschwitz concentration camp, wrote:

> **“The meaning of life differs from one man to another, from one day to the next, from one hour to the next. So what matters is not the meaning of life in general terms, but the concrete meaning of the life of each individual at a given moment”.**
>
> *Viktor Frankl*

And we can influence this meaning of life by finding those moments or people that make us find “the meaning”, because **we are not pain, we are people who have pain.**

COPING

If we look up in the dictionary what coping means, it gives us multiple definitions:



Definitions that can be summarized as “I face a problem, pain”.

The Spanish Association for the Study of Anxiety and Stress defines *coping* as "any activity, both cognitive and behavioral, that the individual can put in place, in order to cope with a given situation".

The holistic view and treatment of pain therefore requires **attention beyond the purely physical aspect**, where the psycho-emotional and social spheres, as well as the meaning in life, are equally important in coping with pain.

Coping with pain requires strategies that can be **learned**, including knowing how to take care of oneself to reduce pain, and this is where we play a key role.

To assess the level of our coping, there are different questionnaires. One of them is the one we present here (Soriano J, 2002): the Chronic Pain Coping Questionnaire (CAD).

CHRONIC PAIN COPING QUESTIONNAIRE	Totally disagree	Mostly in disagreement some in agreement	Neither agree, nor desagree.	Mostly in agreement some desagreement	Totally agree
Religion					
1. I pray for my pain to go away.					
2. I pray for strength and guidance on the problem.					
3. I pray to heal.					
4. I use faith to relieve my pain.					
5. I ask God to relieve my pain.					
Catharsis (seeking emotional social support)					
6. When I am in pain, I try to talk to someone and tell them what is happening to me. This helps me to cope with it.					
7. When I am in pain, I tell others how much I am hurting, because sharing my feelings makes me feel better.					
8. I tell people about my situation because it helps me to find solutions.					
9. I talk to people about my pain, because talking helps me feel better.					
10. I look for a friend or someone close to me who understands and can help me feel better about my pain.					
Distraction					
11. When I am in pain I imagine pleasurable situations					
12. I look for something to think about to distract myself.					
13. I ignore pain by thinking about something else					
14. I try to mentally recreate a landscape					
15. When I'm in pain, I think about something else					
16. When I am in pain I try to distract myself with a hobby.					

CHRONIC PAIN COPING QUESTIONNAIRE	Totally disagree	Mostly in disagreement some in agreement	Neither agree, nor desagree.	Mostly in agreement some desagreement	Totally agree
Mental self-control					
17. I focus on the point where it hurts the most, trying to reduce the pain.					
18. I forget everything and focus on my pain trying to make it go away.					
19. When I am in pain, I focus on its location and intensity to try to control it.					
20. When I am in pain I focus on it and try to reduce it mentally.					
21. I try to let my mind go blank.					
Self-affirmation					
22. I think that I must have strength and not lose heart.					
23. I give myself courage to endure pain					
24. I tell myself that I have to be strong.					
25. When I am in pain, I don't give up, I fight.					
26. Even though it hurts, I hold back and try not to let it show.					
Information search (search for instrumental social support)					
27. I look to a friend, family member, or professional for advice on how to overcome the situation.					
28. I try to get them to explain to me what I can do to reduce pain.					
29. I talk to a professional (doctor, psychologist, etc.) about the problem to help me cope with it.					
30. I try to learn more about my pain so that I can cope with it.					
31. I talk to someone who can do something specific about my pain.					

Adapted by Consejería de Salud del Servicio Andaluz de Salud. (2008)[1].

The scores corresponding to each response option are as follows:

0 | Totally disagree

1 | Mostly in disagreement some in agreement

2 | Neither agree, nor desagree.

3 | Mostly in agreement some desagreement

4 | Totally agree

The scores give us an idea of how we are coping in the present, according to how we score each item; and then in follow-up measurements to see how we are doing. **The test result is not a summary**, but each statement gives us a better or worse rating according to the score at the time, which can help us to identify those interventions which work well for us, and those which work less well.

IF YOU WANT TO FIND OUT MORE...

Life is on the other side of fear | Miguel Ángel Tobías & Gennet Corcuera | TEDxSevilla.

#OAFICONGRESS2021 | How to fill yourself with positive energy.

Tools for better living - Stress, pain experience and happiness.

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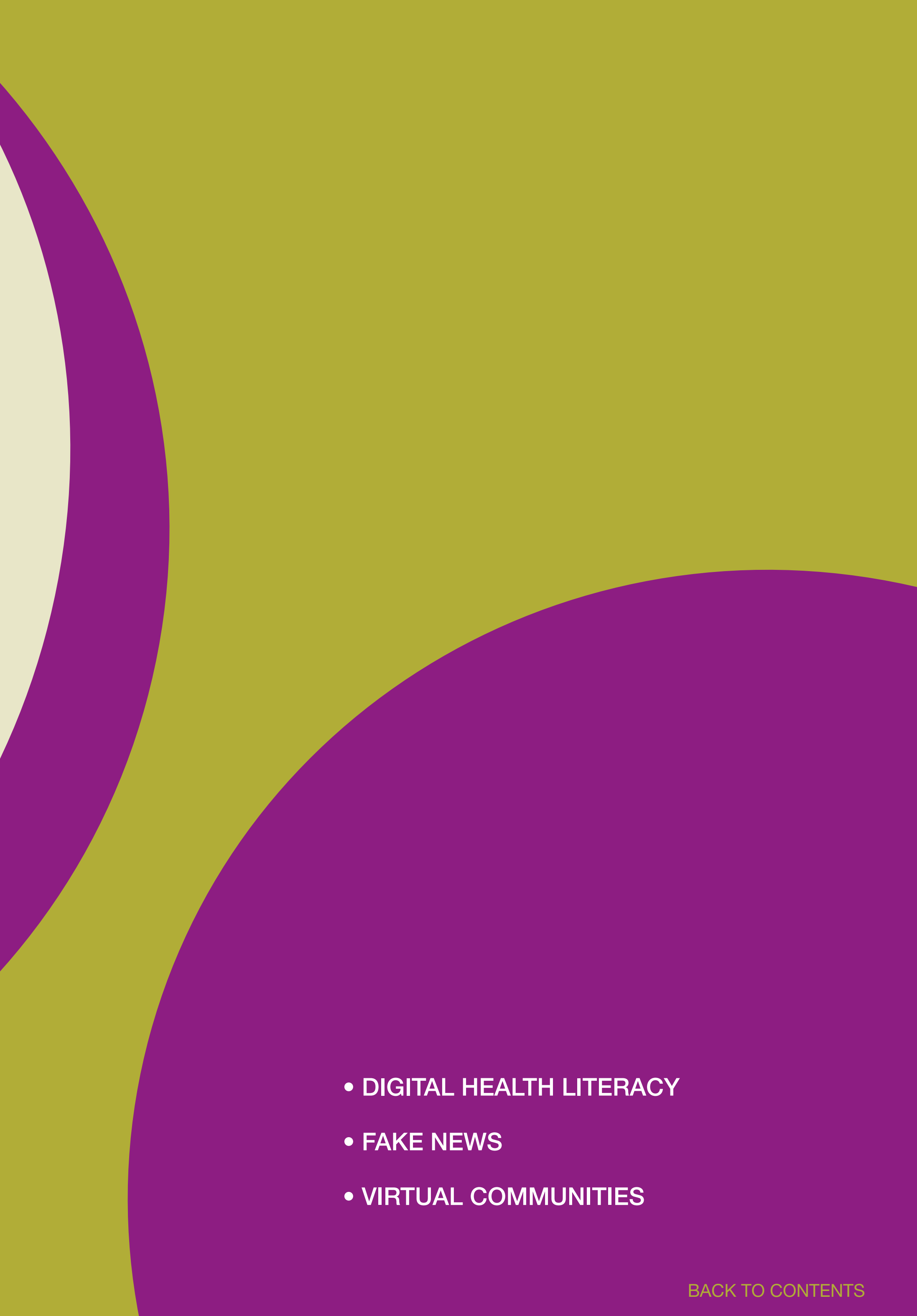
14

DIGITAL HEALTH USE



- DIGITAL HEALTH LITERACY
- FAKE NEWS
- VIRTUAL COMMUNITIES

The **digital revolution** has transformed the way we access information, including in the field of healthcare, where it has enormous potential to improve our care.

DIGITAL HEALTH LITERACY

Literacy in this field means knowing the following:

- Devices
- Software
- Formats
- Types of documents
- Digital tools
- Web plataforms

They are necessary to develop our activity in the online field.

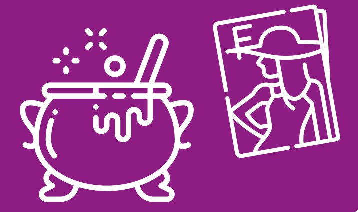
In order to do so, it is necessary **to develop digital skills** that allow us to surf the web, manage e-mail, store information, etc.

Knowing how to identify, analyze, and critically evaluate health websites in order to differentiate between those that are reliable and of high quality, and those that are not, will help us to reduce "infoxication" and/or health hoaxes or fake news.

FAKE NEWS

Fake news is a growing problem in the digital age, especially in the field of health, where we can be particularly vulnerable to this type of information because of our own desire to find quick answers and easy solutions to complex problems.

Thus, fake news about "miracle" treatments or quick cures can cause us to make the wrong decisions leading to serious consequences.



Fake news can damage our health and polarize our opinions.

RECOMMENDATIONS

1. Always seek **information from reliable or reputable sources**: scientific societies, health organizations (like in Spain), patients' associations, etc.

2. Consult **health professionals**, because they are prepared to address our questions and concerns, and provide us with guidance and advice based on sound scientific evidence.

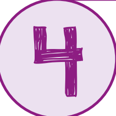
3. Make use of **Health Schools** (if available, like in Spain), which can help us in the process of our illness and in the field of digital tools.

How do you know that a digital information source is reliable?

Truth: "the ultimate cure" and "miracle recipes" do not exist.

Transparency: check companies with commercial interests.

Updated: scientific knowledge is advancing. Information on the Internet is sometimes outdated.



Legitimate provider: ensure you know the identity of the information provider.

Accessible documents: possibility of contacting the authors and promoters to check the information.

Endorsed website: by prestigious institutions or professionals.

Verified: by your healthcare professionals.

Adapted from #FFPatient Partnership (2019)1,4.

RELIABLE SOURCES OF INFORMATION

- Patient Associations
- Health Schools (if available, like in Spain)
- Scientific societies

- Official websites of government departments and city councils
- Patient sections on pharmaceutical company websites
- Virtual communities

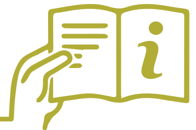
VIRTUAL COMMUNITIES

Virtual patient communities are social structures made up of people learning together, interacting, and building relationships with each other.

Among the objectives of these communities are:

- ✔ Facilitate **interaction between patients and health professionals**, simplifying access to authoritative health information on the Internet.
- ✔ Position the **patient actively and proactively** in social networks.
- ✔ **Group patient-generated projects or initiatives.**
- ✔ Expand the **network of contacts** between users.
- ✔ Share **evidence based information** to help patients' self-care, among many other activities.

IF YOU WANT TO FIND OUT MORE...



Video-infographic #FFPatient - How to know if a health website is trustworthy.

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Health without hoaxes.

CLICK HERE TO ACCESS

Your life without pain.

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Dolor.com website

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15

PAIN DIARY: MONITORING

- GENERAL DATA
- DESCRIPTION OF PAIN AND WHERE IT HURTS
- PHARMACOLOGICAL TREATMENT SCHEDULE
- HOW MUCH DOES IT HURT?
- WHAT I DO TO CONTROL PAIN?
- PLANNED CONSULTATIONS AND OTHER NOTES

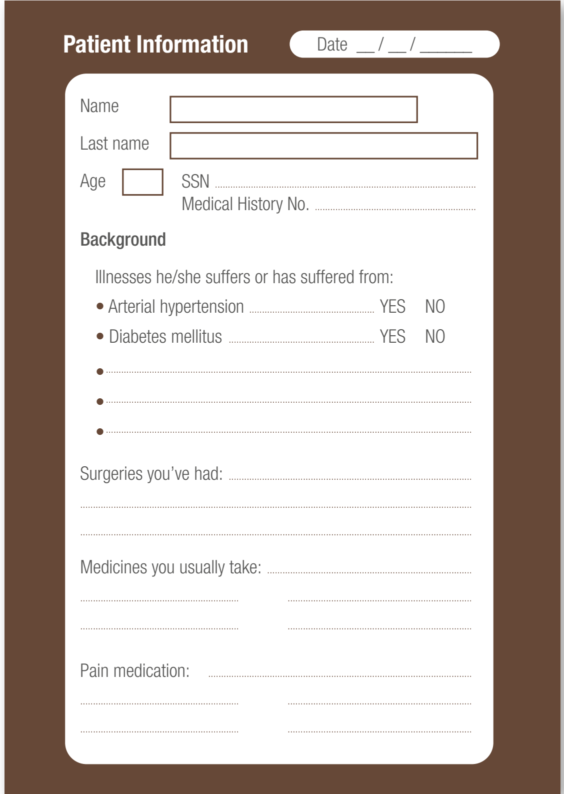
BACK TO CONTENTS

Self-management of pain includes organising everything that has to do with the pain we feel: medication we take, pain intensity, doctor's appointments, physiotherapist's appointments, health centre nurse's appointments, psychologist's appointments, relaxation classes, etc.

To this end, it is advisable **to keep a diary or journal in which to record these aspects**, as it may help us to better understand what is happening to us and to make our response to treatment more understandable.

On the <<dolor.com>> website there is a resource available for this purpose, which you can find in the 'If you want to find out more' section of this chapter if you wish to downlaod it.

GENERAL INFORMATION SHEET



Patient Information

Date __ / __ / ______

Name

Last name

Age

SSN ....

Medical History No. ....

Background

Illnesses he/she suffers or has suffered from:

- Arterial hypertension .... YES NO
- Diabetes mellitus .... YES NO
- ....
- ....
- ....

Surgeries you've had: ....

Medicines you usually take: ....

Pain medication: ....

Start with a first sheet where we will collect **general data**: chronic illnesses, medication (dosage and schedule), allergies, etc.

DESCRIPTION OF PAIN AND WHERE IT HURTS

DESCRIPTION OF PAIN

Date ....

Indicate the place or area where you feel pain:

Description of pain:
(indicate what you feel: intense, dull, continuous, throbbing, burning, cramping...)

....
....
....
....

Does this pain relate to anything in particular? ....
....
....

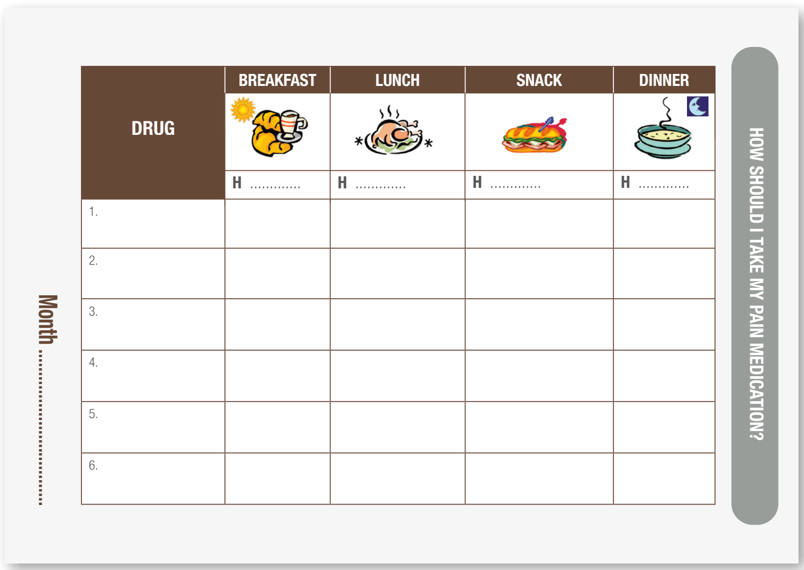
As we can see, in this section we can:

- Locate the place where we feel pain and mark it.
- Define or describe what we feel, what the pain is like (prickling, burning, tingling...). Describing it helps professionals to identify the type of pain.
- Define when it appears, for example, if it is related to an activity or action.

In addition, it is important to note the day, date and time. Our experience of pain may differ at various times of the day.

BACK TO CONTENTS

PHARMACOLOGICAL TREATMENT SCHEDULE



HOW SHOULD I TAKE MY PAIN MEDICATION?

Month ....

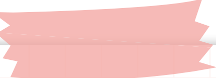
DRUG	BREAKFAST	LUNCH	SNACK	DINNER
	H	H	H	H ....
1.				
2.				
3.				
4.				
5.				
6.				

In this section you can make a note of the **medication schedule** indicated by the professional: how to take, when to take, etc.

HOW MUCH DOES IT HURT?

There are various questionnaires to find out 'how much it hurts', what is the **intensity of the pain** we feel.

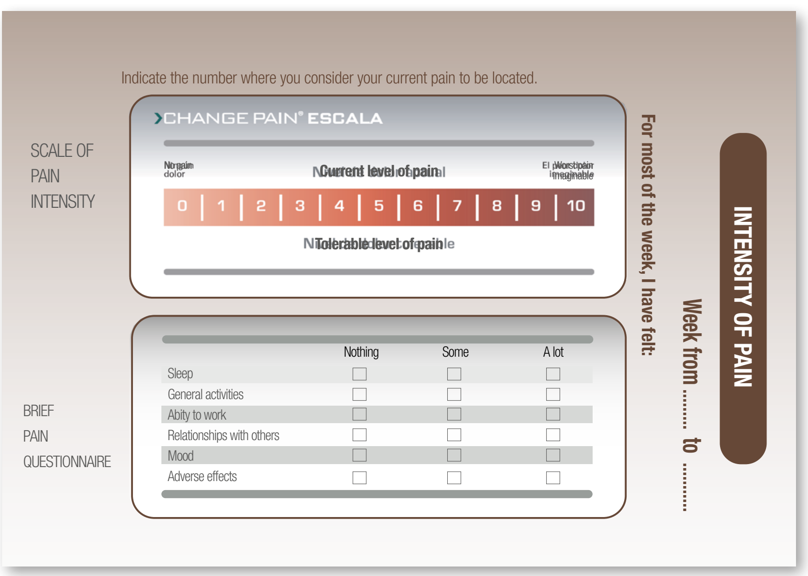
In this document we show you a simple way to measure it, through a scale that goes from the value 0 (no pain) to the value 10 (maximum pain that we can imagine).



It is like a scale where the value 0 corresponds to the absence of pain, value 1 is some pain, value 2 is a little more... up to 10 which would be the maximum pain imaginable.

In other words, the higher the number, the worse we feel.

In addition, this way of measuring can help us to assess other problems such as stress, anxiety, insomnia, etc.



INTENSITY OF PAIN

Week from .... to ....

For most of the week, I have felt:

SCALE OF PAIN INTENSITY

Indicate the number where you consider your current pain to be located.

CHANGE PAIN® ESCALA

No pain

Current level of pain

Worst pain imaginable

0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10

Tolerable level of pain

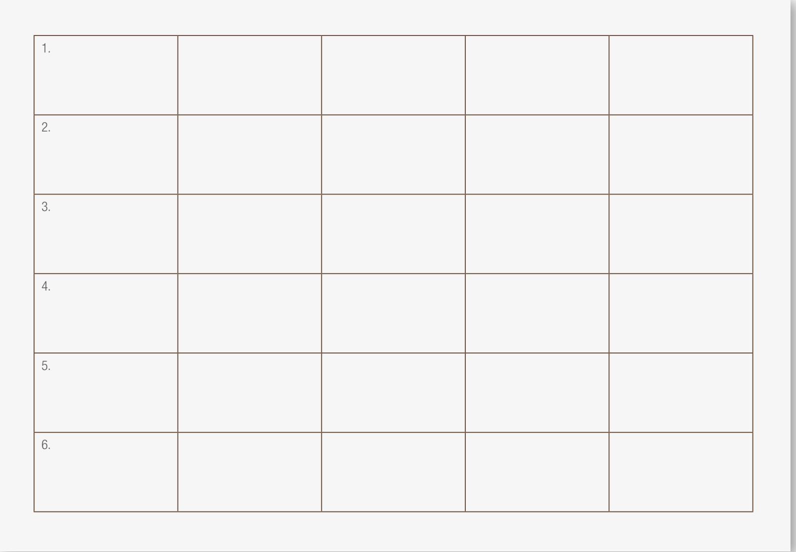
BRIEF PAIN QUESTIONNAIRE

	Nothing	Some	A lot
Sleep	☐	☐	☐
General activities	☐	☐	☐
Abity to work	☐	☐	☐
Relationships with others	☐	☐	☐
Mood	☐	☐	☐
Adverse effects	☐	☐	☐

At the bottom of the picture, we see another questionnaire that talks about the influence of pain on different daily activities such as: sleep, activity, ability to work, etc. The aim here is to find out what influence the pain has on these day-to-day activities, for example: 'Has the pain interfered with my ability to work? The answer should be between 'none', 'some' or 'a lot', depending on whether or how much it has influenced.

WHAT I DO TO CONTROL PAIN?

In addition to the prescribed pharmacological treatment, we know the importance of **self-care activities,** as we have seen throughout this guide. These should be recorded together with the intensity of the pain.



1.				
2.				
3.				
4.				
5.				
6.				

For example: 'Today, March12 , I woke up at 7am with more pain than on other days. My intensity rating is 8, and it has also affected my ability to work A LOT... but I did some mid-morning stretching and the pain improved and went down to 3 on the intensity scale'.

It is interesting to express **how we felt before and after the intervention**.

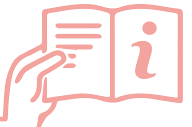
PLANNED CONSULTATIONS AND OTHER NOTES

In this pain diary, we will also include everything related to **tests and visits** with the professional who deals with this problem, any side effects of the drugs, doubts... as well as the date of the next visit.

Finally, this document should include **the address and telephone number of the professionals** who manage our care, as well as the **emergency number.**

These would be the points to record in a pain diary and journal, material that we can certainly improve with our own input. Get a notebook that you like, and start managing your pain.

IF YOU WANT TO FIND OUT MORE...



Infographics about pain

CLICK HERE TO ACCESS

Diary for the follow-up of the pain patient.

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