



The Journey Booklet

“A guide for people living with pain”

Introduction

The journey booklet has been created to help anyone who is experiencing a pain that has lasted longer than the normal healing time. Any pain lasting longer than three months is called 'chronic pain'. This also includes pain after surgery or other procedures, pain during or after cancer treatment, or dental procedures.

Being diagnosed with chronic pain can be a lengthy and frustrating experience, and finding the right treatment for you is often through trial and error. Learning what works for you is important, as there is no 'one size fits all' for managing chronic pain.

This booklet will help you talk with your healthcare professional about your pain so that you can start your journey to getting an early diagnosis and finding the right treatment for you.

Remember, you can always bring a supportive friend or family member with you to your appointments.



Getting a Diagnosis

“This pain is not going away”

Having the right types of words can help you describe your pain experience to your healthcare professional. Think about these 5 questions:

1. How long have you had pain?

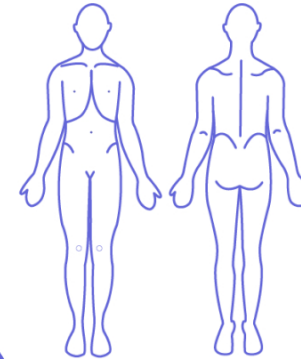
- Has it been weeks, months, or years?
- Does it come and go, or is it there all the time?
- Is there a 24-hour pattern, is it worse at a particular time of the day, or not?
- Can you say what makes it worse or better?

For example:

- ✓ Weather makes it better/worse
- ✓ Exercise makes it better/worse
- ✓ Medication makes it better/worse
- ✓ Rest makes it better/worse
- ✓ Stress makes it better/worse

2. Where is the pain?

It might be easier to mark on a body chart or diagram where the pain is – ask if you can do this.



3. How intense is the pain?

Can you say how bad your pain is on a scale of 0 to 10? ‘0’ means you do not have any pain, and ‘10’ means that the pain is the worst it has ever been.

If the scale doesn't help you describe how bad it is, can these pictures below help you?



4. What does the pain feel like?

People can feel pain differently. For some, it is a throbbing sensation. For others it can be a stinging or electric sensation. Take a look at these words below and see if any of them help you describe your pain.



- | | |
|-----------|----------|
| Throbbing | Numbing |
| Aching | Nagging |
| Itching | Burning |
| Stinging | Shooting |
| Stabbing | Stinging |

5. How does the pain affect your life every day?



Think about the things you avoid doing or have difficulty doing because of the pain, and how it makes you feel. Your healthcare professional should understand how the pain impacts all parts of your life. This includes your home and work life, and relationships with family and friends.

This will help in deciding treatment options for you, that allows you to get back to living your life the way you want to.

For example, how does it affect:

- | | |
|---------------|---------------------------------|
| Your mood | Hobbies |
| Concentration | Relationships/friendships |
| Sleep | Driving |
| Work | Personal hygiene |
| Housework | Ability to travel/go on holiday |

Take the time to think about these five questions, write the answers down and use this information to have a meaningful, and productive conversation with your healthcare professional.

Your expectations

“I have chronic pain, what now?”

For many people chronic pain may be a life-long condition. How pain affects your life over time can change, sometimes you will feel on top of it, and other times it might get on top of you. Here are some suggestions that you can do to help yourself manage the pain.

1. Engage with your healthcare professionals

- Remember it is important to discuss your treatment options with your healthcare professional, and your expectations about how well they will help your pain symptoms.



- There are a variety of treatment options that you may be offered including physiotherapy, rehabilitation, and psychology. You may also be offered medications, injections, or acupuncture
- These treatments may offer some pain relief, but their main goal is to improve your quality of life, focusing on areas such as sleep, mood, ability to work and other activities of daily living.



- Finding out what works best for you should be something that you and your healthcare professional talk about together.





2. Find a support group

- A support group will include people who have had a similar experience to you, but who might be able to help you as they have already been on a journey to get their diagnosis and treatments.
- Sometimes having chronic pain can feel lonely, as others around you like your family and friends might find it difficult to understand what you are going through. Being around others who have chronic pain can validate your experience.

3. Learn about chronic pain

- The more you understand about chronic pain, the more you can do to manage it day to day. Ask your healthcare professional to explain to you in plain language what is causing your pain. Remember it is your right to ask questions if anything they say is not clear.
- Take a look at the Plain Talking website for resources on understanding more about chronic pain:

<https://europeanpainfederation.eu/efic-plain-talking/>

Self-management

“What can I do myself every day to stay in control of my pain?”

1. Use recommended resources

- Learn more about your pain and the treatment options available to you.
- Knowing more will help you feel in control. It will also help you talk with your healthcare professional about your pain, the treatment options available to you, and being involved in making decisions about your health.
- The Plain Taking website has a number of reputable resources, as will your support group.



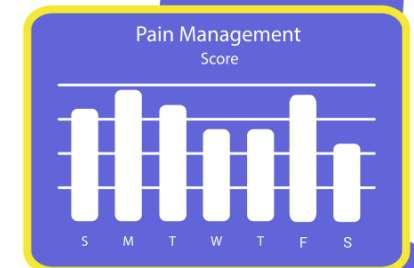
2. Use self-management strategies

- Your healthcare professional can teach you how to include these in your daily life. Pacing your activities and work, being physically active, able to problem solve, to set and achieve goals that are important to you, and be able to manage flare-ups can help.
- Think back on how you managed difficult situations in other aspects of your life and use these experiences to remind you how capable you are in dealing with difficult situations.



3. Monitor your progress

- Using the five questions in the ‘getting a diagnosis’ section will help you monitor changes in how you experience your pain.
- This will help you understand if the treatments you are using are working for you by looking back at what you wrote down and comparing over time.



To learn more, please visit our website (europeanpainfederation.eu/efic-plain-talking/) and follow our #EFICPlainTalking campaign on Facebook, Twitter, LinkedIn and Instagram.

If you would like your feedback on issues addressed in this booklet to be included in the updated version of this booklet, please send an email to: angela.palomares@efic.org.



COLLABORATORS:

Brona Fullen
Dusica Stamenkovic
Harriet Wittink
Laura Mackey (Chair Of The EFIC 'Plain Talking' Campaign)
Magdalena Kocot-Kępska
Nadia Malliou
Nadja Nestler
Raul Marques Pereira
Ruth Zaslansky
Ángela Cano Palomares