

# Making decisions to help you **live well with chronic primary pain**

## What is this document?

**This document is called a decision aid.** It is for people aged 16 years and over with chronic primary pain.

It can help you think about what options you might like to consider to help you live well with pain.



There may be one person, or several different people working together, to help you live well with your chronic primary pain. For example, your GP, pharmacist, other healthcare professionals, social care practitioners, social prescribers and wellbeing coaches. We'll call them your health and care team.

## **1** What is chronic primary pain?

Pain that lasts for more than 3 months is known as **chronic pain** or **persistent pain**. 'Chronic' means it has lasted for a long time, it does not refer to how bad the pain is. Chronic pain can sometimes be caused by an underlying condition causing inflammation or damage in the body. Examples include arthritis or endometriosis. This is known as chronic secondary pain.



But sometimes, the pain is **not** due to underlying inflammation or damage. The pain is real, but the cause may not show up on blood tests or scans. Or the pain is much worse than would be expected from the test and scan results. This is called **chronic primary pain**, for example, chronic widespread pain (such as fibromyalgia).

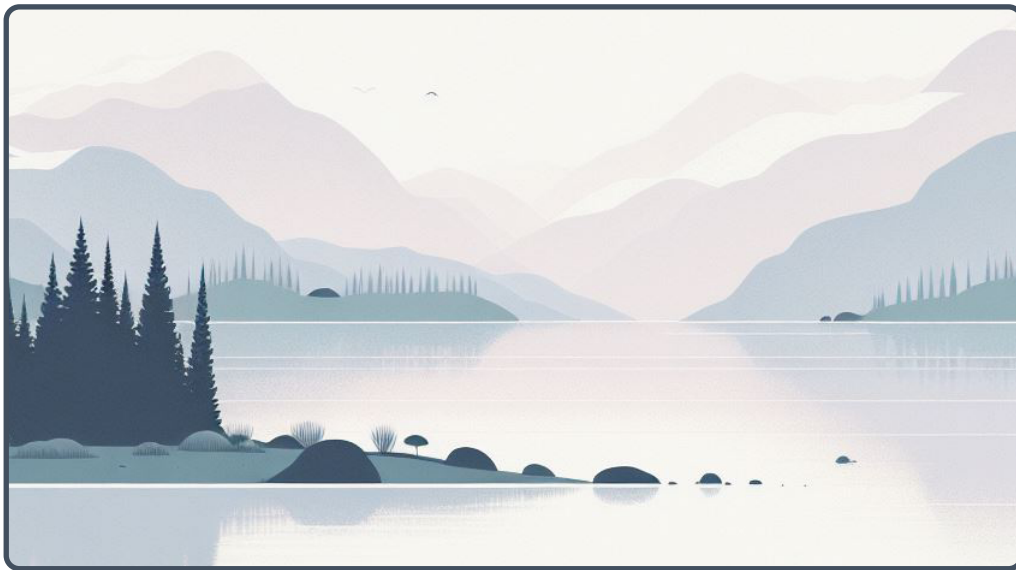
Chronic primary pain can be difficult to live with and everyone feels pain differently. It is a complex condition with many possible related symptoms as well as pain. These can include brain fog, low mood, fatigue (feeling 'washed out') and anxiety.

## 2 More on chronic primary pain

Chronic primary pain is **common**, affecting between **1 and 6 in every 100 people** in the UK. As with all types of pain, social circumstances, levels of stress, worry or concern can play a part. Some past and present life experiences (for example difficult childhood experiences, emotional trauma or domestic violence) can also affect how you feel pain.

These factors may also increase your risk of having chronic primary pain. Understanding how these factors can influence pain can help you work out what kinds of support might help you manage your symptoms better. For some people, chronic primary pain may have been triggered by an illness or an injury.

Some people can have a combination of **short-term pain** (pain that lasts less than 3 months, such as from an injury), **chronic secondary pain** and **chronic primary pain** all at the same time. Some things that can help short-term pain and chronic secondary pain, such as some medicines, often do not help chronic primary pain very much. So you might need to try different things.



Pain is **difficult to live with** and **everyone feels pain differently**.

It may not be possible to get rid of your pain or your symptoms altogether. But there are things that can help you manage the impact that your pain and symptoms have on your daily life.

It is important to explore the things that can help you live well with pain and the other symptoms that come with it.

## How to use this decision aid

You do not have to use all of this document – you can just use the sections which you think might be helpful to you.

You can complete this decision aid in your own time, and you do not need to complete it all in one go.

You might like to bring this document to your appointments and go through it with your health and care team. Having a good relationship with them, where you feel able to talk openly, is important in supporting you to manage your symptoms and will help you make the right decisions for you.

### This decision aid has 3 sections:

You can use the **link buttons to the right of this box** to help you navigate through this document.

#### **Pages 4 to 8 are about how your symptoms affect you and your life**

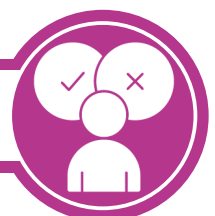
It has some statements for you to reflect on and space for you to write down your thoughts if you wish. It may help your health and care team understand what is important to you. It can also help you prepare for your appointments.

#### **Pages 9 to 17 give details of the different options to help you manage your symptoms**

This section lists what options may be available that you may like to try and what they involve. It includes things that you can do yourself as well as things that your health and care team can help you to access.

#### **Pages 18 to 22 help you think through your options**

If you want to try something different, this section may help you decide what you want to try. You do not have to choose any of the options, if you do not want to. Also, you can always change your mind and try different things.





On the next few pages, there are some statements which might help you to think about your current feelings and experience. Mark a dot on the scale next to each statement to show how much you agree or disagree with it. For example, see below:

Strongly disagree

Strongly agree



I understand my diagnosis



If a statement does not apply to you, or you prefer not to answer it, you can just leave it blank.

## My understanding of my pain diagnosis

Strongly disagree

Strongly agree



I do not think enough has been done to find out what is wrong

I understand my diagnosis

I would like to understand more about why I have pain

I would like to understand more about the different physical and mental health symptoms I have

I have had enough time to explain how I am feeling and how my symptoms affect my daily life

I do not feel my health and care team understand my situation

Other thoughts I have about my pain diagnosis:

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# How my symptoms are affecting me now

Strongly disagree

Strongly agree



I have good and bad days

I feel in low mood

I feel stressed or anxious

I feel embarrassed about the things I cannot do

I feel lonely and unsupported

I am not sleeping well

I am struggling with daily activities such as housework, chores, gardening, managing stairs

I am struggling to do the activities I used to enjoy or are important to me

My ability to work, study or train is being affected

I have worries about money, benefits or housing

I am unable to spend as much time as I want to with friends and family

My personal or sexual relationships are being affected

People I care about are being affected

Other people do not understand how I am feeling

Other symptoms I have which are affecting me now:

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# My concerns for now and the future

Strongly disagree

Strongly agree



I worry about the future and how my symptoms will affect this

I would like to find a way of doing something that does not make things worse

I would like more knowledge, skills or confidence to manage my own health and wellbeing

My pain is getting worse

I find my symptoms unmanageable

I am not sure if the medicines I am taking help

Other concerns I have:

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You can use this space to write down anything else you wish:

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## 4 What would you like to focus on today?

You may find that there is not enough time at your appointment to talk about everything. You could pick 3 things to focus on today by putting a mark in the boxes below. You can always focus on other things at a later appointment. Your health and care team may not have all the answers and they may need to explore other sources of support for you. If you need more time to discuss things, you could ask for a longer appointment. If you wish you could invite a friend or family member to come with you too.

Managing daily tasks at home

Improving my mobility

Being physically active and fitter

Sleeping better

My mental health and emotional wellbeing

Keeping up relationships with friends and family

Improving my sexual relationships

Helping others to understand what I'm going through

Managing at work

Managing my studies

Support with money, benefits or housing

Managing my pain and other symptoms

Reviewing my medicines

Something else (write in what you would like to discuss):

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## 5 Helping you manage your symptoms

There are different things you can try that can help you manage your symptoms and live well with pain. Some of these options may help you do the things you enjoy, even if they do not reduce or remove your pain or other symptoms.

The next page lists some of the main options, which some people find helpful. This is followed by more detail about these options.

### What works for one person might not work for another

There are possible advantages and disadvantages with all the options but we cannot tell who might benefit or who might experience problems – everyone responds differently. You can try more than one at the same time. You may need to try a few things to find out what helps for you.

You may want to work with your health and care team to **adapt these options to your needs and circumstances**. If you find you are not getting any benefit, you can talk to them about stopping and maybe trying something else.

Depending on your personal circumstances, **some of the options may not be suitable for you**. If this is the case, your health and care team will discuss this with you.

You do not have to try any of these things if you do not want to or you feel now is not the right time.

You can continue as you are if you are happy to do so.

**Remember, you can come back to this document at any time, review your answers, and try different things.**

# Options to help you manage your symptoms

## Continue as I am

You may decide that you do not want to make any changes right now

## Things I can do myself (with support if I need it)

For more on these options, click here to be taken to page 11



## Things I may be able to try through my health and care team

For more on these options, click on the tabs below to go to that page:

### Support to identify and access things I can do for myself:

page 11



Physical activity in a group: page 13



Talking therapies: page 14



Acupuncture: page 15



Medicines: page 16



You can use this space to write down your initial thoughts about your options, or come back here once you have read more on the following pages.

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## 6 Things I can do myself

There are some things you can do yourself, which might help you manage your symptoms. You may want to try these things on your own or you may want to do them with the support of your family, friends, community groups (for example, charities) or your health and care team. Your GP practice may be able to offer you support from a social prescriber or a health and wellbeing coach to help you with some of the things listed here. **You do not have to have any support, but it is there if you need it.**

If you are worried about trying something new, or you would like advice on what to try, you could talk to your health and care team. You may also find it useful to get support from other people who are in a similar situation: see [‘Where can I go for further information’](#) on page 19 for organisations who can connect you. You can try these alongside other things you are trying through your health and care team, or you can just try these things on their own.

Different things help different people. You may want to try several things to see what is helpful for you at the moment. For example, you could try:

- learning more about your condition
- setting goals and action planning – this means identifying what you would like to be able to do, and breaking it down into smaller chunks so you can work towards it
- connecting with other people who are in a similar situation
- managing your energy levels – prioritising what needs to be done and building up your activity levels gradually (this is sometimes called pacing)
- planning how to manage a change in symptoms such as a flare-up – this is when your symptoms get worse than they had been
- keeping as active as you can (see [information box](#) on the next page)
- relaxation skills, such as meditation and breathing exercises
- trying ways to improve your sleep
- doing things you enjoy, such as spending time with friends and family, or taking part in hobbies
- accessing talking therapies for free on the NHS – see the section on [talking therapies](#) on page 14 for more information
- living a healthy lifestyle and trying to eat healthily to see if this helps

You can find lots of useful resources to help you find out more about things you can do yourself in the '[Where can I go for more information](#)' section of this decision aid on page 19.

### Info box: Physical activity and keeping as active as you can

This could be taking part in some physical activity or just being more active in your daily life, like moving around your home or walking more. You could take part in some physical activity in a group with an instructor or leader – they will help you manage your activity levels, to make it suitable for you. See [physical activity in a group](#) on page 13 for more information

Or, if you prefer not to join a group, you can keep active alone, for example by doing some online fitness activities, going for a walk or a swim, or just moving more in your day-to-day life. If you do too much too soon, your symptoms could worsen, or 'flare'. Here are a few tips to help prevent this from happening:

- start slowly at a level that feels comfortable for you, and doesn't trigger a flare or make you 'crash' afterwards
- give yourself enough time to recover between activities
- go at your own pace and build up gradually – be careful not to push yourself too hard or too quickly
- listen to your body, and how it feels, to find out what feels right for you

#### Advantages

The risk of harm is very low and there are no side effects from medicines.

You can try these things straight away.

#### Disadvantages

It may take time to learn about the different options to find out what you want to try.

At first, you may find it difficult to try something new on your own. But you should find it easier over time.

#### Other things to think about

You can try different things at different times. You may find what helps you changes over time.

You do not have to do everything in one go.

# 7 Things I can try through my care team

## Physical activity in a group

### What does this involve?

This involves physical activity or fitness activities in a group with an instructor or a leader.

There are different types of group physical activity you can try. Finding the right activity for you is important – choose an activity you enjoy and one that you will be able to do regularly. If a particular activity has not helped you in the past, you may find it helpful to try a different type of activity. If you have not tried group physical activity before, you may find being with other people who are in a similar situation helpful. You may also find the support from the instructor or leader helpful - they are there to support you to move safely, at a level suitable for you.

(Also see the [Info box on physical activity](#) on page 12.)

Advantages	Disadvantages	Other things to think about
Studies show it can reduce some people's pain and improve their quality of life. It can also increase stamina and strength, allowing you to do more things.	In the short term, it can cause some discomfort. But then your pain should settle.	You'll need to take part in several sessions to get the most benefit. For example, this could be 6 to 12 sessions over 2 to 3 months.
Studies show the benefits last in the longer term as well as the shorter term.	It can take a few months before you see any improvement.	Programmes may be offered free or at a reduced cost.
It improves general health and fitness. It can also improve your mood and feeling of wellbeing.	There may be a waiting list before you can join a programme.	You may need to travel to the group. But you can take part in some fitness programmes online.
The risk of harm is very low and there are no side effects from medicines.	If you do too much too soon, symptoms can flare.	You can continue the activity after the programme ends if you enjoy it and it helps.

# Talking therapies

## What does this involve?

Pain can have an impact on how we think, feel and behave. Our thoughts and mood can also affect how we feel pain. This does **not** mean that your symptoms are not real or are “all in the mind”.

Cognitive Behavioural Therapy (CBT) and Acceptance and Commitment Therapy (ACT) are talking therapies that may help you manage your symptoms. Although they cannot cure the pain or other symptoms, they can help you cope better and may be able to reduce the impact of your symptoms on your daily living.

Even if talking therapies have not helped you in the past, you may still find it helpful to try them again, especially if things in your life have changed.

You can refer yourself for some talking therapies for free on the NHS. You can find more details here <https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/nhs-talking-therapies/>. These therapies may not be designed specifically for people with chronic pain, but you may still find them helpful.

Advantages	Disadvantages	Other things to think about
Studies show talking therapies can improve some people's quality of life and they may help sleep, pain and anxiety.	Taking part involves exploring your emotions. You may sometimes feel anxious or emotionally uncomfortable, especially at first.	You will need to commit yourself to the process to get the most out of it. You may have to do 'homework' between sessions, such as thinking differently about things or planning changes in your life that could help you.
You'll learn skills you can use any time in all kinds of situations.	It may take a few sessions before you see any benefit.	The course of treatment usually lasts between 6 and 10 sessions, with each session lasting 30 to 60 minutes.

Advantages	Disadvantages	Other things to think about
Studies show the benefits last in the longer term as well as the shorter term.	There may be a waiting list before you can start the sessions.	Courses can be done as a group, one-to-one, face-to-face, over the phone, online, or via an app.
The risk of harm is low and there are no side effects from medicines.	Therapies can be accessed in different ways, but may not all be available locally.	If the therapy is in-person, you may need to travel to get to sessions.

## Acupuncture

### What does this involve?

During acupuncture a therapist inserts very fine sterile needles at specific places on the body (these may not be where your pain is). Once positioned, they may be left in place for just a few minutes or up to 30 minutes or so.

Advantages	Disadvantages	Other things to think about
Studies show it can help some people's pain and improve their quality of life in the short-term (up to 3 months).	There is no good evidence to say that the benefits will last in the long term.	A course of treatment normally lasts for 3 to 8 sessions and each session typically lasts 10 to 30 minutes.
The risk of long term or serious harm is very low. There are no side effects from medicines.	It can produce some mild, short-term side effects like slight pain where the needles are inserted, bruising or bleeding. But not everyone gets these.	You will usually just have one course of treatment. This is because there is no good evidence to say that further courses are helpful.
If you get some benefit, even if just in the short term, it may allow you to try some other things such as being more active.	It may not be available in your area on the NHS. If it is, there may be a waiting list before you can start the sessions.	



# Medicines

## What does this involve?

Antidepressants are medicines which affect chemicals in the brain that involve the sensation of pain, as well as mood and emotions. They have been found to help some people who have chronic pain, even in people who are not depressed. At present, there is not much high quality evidence from research studies, so we cannot say for sure how much benefit people are likely to get or for how long.

Advantages	Disadvantages	Other things to think about
<p>Studies show they can help some people's pain and improve their quality of life in the short-term (up to 3 months).</p>	<p>Long term benefits have not been studied very well. It's not possible to say how long the benefits last.</p>	<p>Starting at a low dose and increasing slowly may help minimise side effects.</p>
<p>These can usually be prescribed by someone at your GP practice, so you do not need a referral to be able to try this.</p>	<p>Side effects can include dry mouth, drowsiness, constipation, diarrhoea and sexual problems. But not everyone gets these.</p>	<p>During treatment, the dose may need to be changed – it depends on how much benefit you are getting, and any troubling side effects.</p>
	<p>It may take a number of weeks before you get any benefit. It is difficult to say how long you need to wait because everyone is different.</p>	<p>Different types (classes) of antidepressants have different effects and side effects. If the first one does not suit you, you could try one from a different class.</p>
	<p>You may have withdrawal effects, or find your symptoms come back when you stop, change or reduce the dose of the antidepressant.</p>	



## Stopping antidepressants



If you are taking an antidepressant for pain and want to discuss reducing or stopping it, you can speak to your health and care team – they can review all your medicines and give you advice.

If you have been taking an antidepressant for more than a few weeks, you'll need to stop slowly – your health and care team will be able to advise you how to do this. If you do not, you may get withdrawal effects. This is because your body and brain have become used to the medicine. These effects may include sleep disturbance, feeling restless and changes to your mood.

## 8 Treatments that are not recommended

### Medicines that are not recommended

There is no good evidence that medicines used for short-term pain (for example, tension headache or pain caused by injury) will help with chronic primary pain. For example, paracetamol, or ibuprofen tablets or gel.

They may be helpful if there is another cause for your pain alongside your chronic primary pain (such as arthritis). But all medicines can cause side effects, especially if taken long term. So if you plan to take these medicines in the long term, it is important to talk to your health and care team about whether this is right for you.

Some other medicines have been used for chronic primary pain in the past but are no longer recommended. For example, gabapentin, pregabalin and opioids, such as morphine and codeine. This is because the evidence now shows that they do not usually help in chronic primary pain and they often have serious side effects.

If you are taking any of these for chronic primary pain, talk to your health and care team about whether they are really helping or not, and whether continuing to take them in the long term is right for you. If you are already taking them and do find them helpful, then you should not have to stop them unless your health and care team believes it is not safe for you to continue. For example, if you are having very harmful side effects.

### Other therapies that are not recommended

There is no good evidence that electrical therapies help with chronic primary pain, for example, TENS machines or ultrasound. But there is no evidence that they are harmful.

# 9 Thinking about my options

**What have you tried already?**

No help

Some help

Very helpful

Not tried

Doing things myself

Group physical activity

Talking therapies

Acupuncture

Antidepressants

Other medicines

Something else

I tried these things:

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## 10 Making a decision

### Where can I go for more information?

**Pain concern** has a number of leaflets and other tools to help you manage your pain, including the [Self-Management Navigator Tool](#), upon which the 'What's important to you' and the 'What would you like to focus on today' sections of this patient decision aid were based. They also have a helpline and an online forum where you can get support or share your experience with like-minded people:



<https://www.painconcern.org.uk>

**Action on Pain** provide useful resources about chronic pain and also operate a helpline staffed by volunteers with experience of chronic pain:

<https://action-on-pain.co.uk/>

**Versus Arthritis** have information which you may find helpful, even if you do not have arthritis. For example, information on common aches and pains and advice on exercises to manage pain:

<https://versusarthritis.org/>

**The Chartered Society of Physiotherapists** have a list of resources on managing your pain:

<https://www.csp.org.uk/conditions/managing-pain-home/managing-your-pain>

To find out more about things you can do yourself, you may find the following websites useful:

**Live well with pain:**

<https://livewellwithpain.co.uk/what-is-self-management/>

**NHS 10 ways to reduce pain:**

<https://www.nhs.uk/live-well/pain/10-ways-to-ease-pain/>

Continued over page...

**NHS Fitness Studio exercise videos:**

<https://www.nhs.uk/conditions/nhs-fitness-studio/>

**NHS Live Well for advice on healthy living:**

<https://www.nhs.uk/live-well/>

**NHS Every mind matters** for help with mental health and wellbeing:

<https://www.nhs.uk/every-mind-matters/>

**Royal College of Occupational Therapists** for advice on managing your energy levels:

<https://www.rcot.co.uk/conserving-energy>

**Meditainment**, for a free pain management meditation course:

<https://www.meditainment.com/pain-management-meditation>

**Sleepio**, for a self-help sleep improvement programme (only available in certain regions):

<https://onboarding.sleepio.com/sleepio/nhs/120#1/1>

To find out more about acupuncture:

**NHS acupuncture:**

<https://www.nhs.uk/conditions/acupuncture/>

A **social prescriber** may be able to help you if your concerns are non-medical. For example, finance or housing worries. They can also link you to social activities or practical support to improve your wellbeing. Ask your GP surgery if it is available in your area. Find out more about social prescribing here:

<https://socialprescribingacademy.org.uk/>

The **Money and Pensions Service** can offer support and advice if you have concerns about money:

<https://maps.org.uk/en>

**Citizens Advice** can give you advice on a wide range of non-medical problems:

<https://www.citizensadvice.org.uk/>

## Making decisions

Think about which option or options are best for you at the moment.  
Remember:

- You do not have to do any of these options if you do not want to.
- You can try more than one option at the same time.
- You do not have to make this decision straight away.
- You can take some time to discuss it with family, friends, health and care professionals, and then decide.
- You can always try other options in the future.

## Things to check

At the moment:

I feel sure about the best choice for me Yes | No

I know enough about the potential advantages and disadvantages of each option Yes | No

I am clear about which potential advantages and disadvantages matter most to me Yes | No

I have enough support and advice to make a choice Yes | No

If you said 'no' to any of these, tell your health and care team and ask them for help

## My thoughts at the moment

I'm not sure what to do

I have further questions on the options

I would like to take some time to consider the options

The option(s) I am considering at the moment are:

Continuing as I am

Trying some things myself

Keeping active or physical activity

Talking therapy

Acupuncture

Taking an antidepressant

Having a medication review

Something else:

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You may want to say why you are considering these options here, if you think it will help your discussions with your health and care team

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# 11 How this decision aid was produced

## Who made this decision aid?

This decision aid was developed in line with the [NICE process guide for decision aids](#). It was produced with a project group of clinical and patient experts. A wide range of stakeholders was invited to comment on an earlier draft. This included people with lived experience. It is based on the best available evidence and the project group's experience and expertise. The sources of further information were identified by the project group. NICE is not responsible for the content of external websites. Omission of a website in this decision aid does not imply that NICE has made a judgment about its content.

## Information we used to make this decision aid

The 'What's important to you' and the 'What would you like to focus on today' sections were adapted from the [Self-Management Navigator Tool](#) © Pain Concern 2017. All rights reserved.

- [Chronic pain \(primary and secondary\) in over 16s: assessment of all chronic pain and management of chronic primary pain](#) (2021) NICE guideline NG193.
- Pain Concern (2023) [The Self-Management Navigator Tool](#). Accessed August 2023.

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