Taking control of your Fibromyalgia

Arthritis AUSTRALIA

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How can this booklet help you?

This booklet is designed for people who have been diagnosed with fibromyalgia.

It will help you understand your condition so that you can better manage your symptoms and continue to lead an active and healthy life.

This booklet offers information and practical advice to help you:

- understand what fibromyalgia is and what it means for you
- work with your healthcare team to reduce symptoms such as pain and tiredness
- choose activities that can help you manage your situation
- understand if and when medicines can help
- find support to cope with the emotional impacts of fibromyalgia

The information inside is based on the latest research and recommendations. It has also been reviewed by Australian experts in the field to make sure the contents are current and relevant to your needs. So go ahead - take control of your fibromyalgia management!

This resource is designed as a self management guide for people diagnosed with fibromyalgia. We acknowledge that severity of symptoms vary widely among people who have been diagnosed with fibromyalgia, and it can affect all aspects of a person's life, including the ability to work, and to undertake daily activities. Sometimes more support is required, and we have included details of organisations that may be able to assist you on pages 31 and 32.

What is fibromyalgia?

Fibromyalgia is a condition where the main symptom is long-lasting (chronic) pain that affects the whole body. This pain is not brought on by an injury.

Fibromyalgia is not rare and affects around two people out of every 100. Anyone can develop fibromyalgia, but it is twice as common in women. It is also more common in people who are middle-aged and in people with other painful bone and joint conditions, such as rheumatoid arthritis.

Fibromyalgia is a poorly understood and sometimes frustrating condition. People often have to wait many years to get a diagnosis. Fortunately, doctors are getting better at recognising fibromyalgia. As a result, people are getting help sooner these days.

For a person to be diagnosed with fibromyalgia, they must have had pain for three months or more.

Along with widespread pain and tenderness, people with fibromyalgia also often:

- feel very tired and have no energy
- have trouble getting to sleep or staying asleep
- have problems concentrating or remembering things. Some people call this “fibro fog”

Some people may also:

- have other body symptoms such as headaches, irritable bowel symptoms (tummy pain or bloating), dizziness, and/or numbness or tingling in the hands and feet
- be hypersensitive to certain sounds, or light, or the temperature
- sometimes feel frustrated, worried and ‘down’

The symptoms of fibromyalgia often overlap with those of chronic fatigue syndrome.

The pain and other symptoms of fibromyalgia can vary, and some days people will feel better than others.

What fibromyalgia is not

In the past, fibromyalgia was often misunderstood. Some people even believed it was not a 'real' condition.

We now know that the pain and symptoms of fibromyalgia are real and not:

- due to psychological or emotional problems
- due to you being unfit and not getting enough exercise
- 'all in the head' or imagined

What causes fibromyalgia?

The exact cause of fibromyalgia remains unknown.

For a long time, doctors thought there were only two types of pain - pain caused by tissue damage (such as after an injury or surgery) or pain caused by nerve damage (an example is the condition shingles).

Medical experts now realise that these descriptions do not explain all painful conditions. They have identified a third type of pain, resulting from increased sensitivity of the pain system. In *hypersensitive* pain, the body signals that it is in pain even though there is no clear sign of any tissue or nerve damage. Fibromyalgia is a hypersensitive pain condition.

Research shows that people with fibromyalgia are extra-sensitive to warning signals and their bodies respond to them differently. Some people say fibromyalgia is like having an oversensitive alarm system, which sounds its alarm even when the body is not under threat.

Both the *central nervous system* (brain and spinal cord) and the *peripheral nervous system* (nerves that transfer information between your brain and the rest of your body) seem to be extra-sensitive to these warning signals.

This hypersensitivity of the nervous system may also explain why many people with fibromyalgia can also be oversensitive to noise or light.

There are some things that increase the likelihood of you developing fibromyalgia. These are:

- Being born female, as we mentioned earlier
- Growing older: fibromyalgia is more common in people who are middle-aged or older
- Genetics: fibromyalgia may tend to run in some families
- Inflammation: When your immune system is challenged, it can make your nervous system more sensitive. This may trigger the development of painful conditions such as fibromyalgia

If you have rheumatoid arthritis or systemic lupus erythematosus (SLE or 'lupus') you may be more likely to get fibromyalgia. People with osteoarthritis, chronic low back pain and inflammatory bowel disease (such as ulcerative colitis or Crohn's) sometimes develop fibromyalgia as well.

- Other painful conditions: People with migraine, dysmenorrhoea (bad period pain) or irritable bowel syndrome (IBS) seem at increased risk of fibromyalgia
- Stress: stressful life events can trigger fibromyalgia, but the reasons why are unclear. People can also develop fibromyalgia without experiencing stressful events
- Anxiety and depression: people with fibromyalgia often feel anxious or depressed but it's not always easy to tell which condition came first. Sometimes, living with fibromyalgia may worsen these conditions

How might fibromyalgia affect me?

All people with fibromyalgia will at some time experience long-term pain that affects most of their body. Most will also have extreme tiredness and sleep and concentration problems.

However, no two people will have the same symptoms and some people may have worse pain than others.

Symptoms can even vary in the same person - people may have good days and bad days, sometimes for no obvious reason.

By the time people are diagnosed with fibromyalgia they often feel overwhelmed and frustrated. They may have suffered through years of ineffective treatments.

While traditional physiotherapy treatments such as massage, stretching and joint manipulation are good for many types of muscle and joint pain, they don't always work well for fibromyalgia. Common pain relievers, such as paracetamol, are often not effective either. Strong *opioid* pain relievers can even make the pain of fibromyalgia worse.

It is important to understand that while the pain you feel is real, it is not caused by an injury to your body. Fibromyalgia is not damaging to your joints, muscles, or other body tissues. While your symptoms may fluctuate, your overall condition should not steadily worsen over the long term.

Remember that it's helpful to think of fibromyalgia as an alarm system that has become oversensitive and is sounding an alarm when your body is not damaged.

While there is no 'cure' for fibromyalgia, treatments can help to 'turn down' that alarm so that pain and symptoms intrude less on your everyday life. These may include gentle exercise, improving sleep, learning coping strategies and (sometimes) medicines. We discuss these in the next sections.

How will my doctor diagnose fibromyalgia?

Doctors will look at many factors to help them decide whether a person has fibromyalgia.

Your general practitioner (GP) or specialist may:

- talk to you about your symptoms, and how long you have had them. To be diagnosed with fibromyalgia you must have experienced widespread pain and other symptoms, such as tiredness and/or poor sleep, for several months
- ask you more questions about your general health and your family history, including whether anyone in your family has a similar pain condition
- carefully examine you. The doctor will apply pressure to your muscles, joints, and tendons to see where there is tenderness. They may also look for signs of nerve pain such as *allodynia* (when people can feel pain from gentle touch) and 'pins and needles'.

Because there is no special test to diagnose fibromyalgia, blood tests and imaging, such as X-rays, CT or MRI scans, should be kept to a minimum. But if the doctor suspects you may have another condition, they may order additional tests to rule that condition in or out

Who can help?

GP

Psychologist

Counsellor

Exercise physiologist

Pharmacist

Physiotherapist

Your friends & family

Dietitian

Rheumatologist

Sleep specialist

Nurse

Arthritis Australia & Arthritis Affiliate Offices

Occupational therapist

Pain specialist

The good news is that fibromyalgia can be effectively managed – and a team approach is the best way to help you manage it. You may hear this referred to as multidisciplinary care.

This involves you and your healthcare team working together with support from family, friends, and community organisations.

How can you help?

Remember, the most important member of your healthcare team is you. By understanding your condition and learning how to manage it, you give yourself the best chance of living a fulfilling life.

Work closely with your healthcare team to develop a management plan. As soon as possible after diagnosis, you should receive education about fibromyalgia, discuss treatment options and the best ways to self-manage the condition. Reading this booklet should also help.

Sometimes it takes some trial and error to find the treatments that are going to best work for you. There is no 'one size fits all' treatment and different people will find different treatments more effective.

Any plan should centre around your needs and priorities, so before appointments try to think about what's most important to you. You may wish to take another person, such as a partner or friend, along to these appointments as support. Often there is a lot to take in, so it can help to have another set of eyes and ears with you.

It's best not to go into treatment expecting to be pain-free. The main aim of treatment is to help you to manage your pain so that you can still do the things you enjoy in life.

Fibromyalgia doesn't have to get in the way of working, travelling or relationships. Contact your State/Territory arthritis office on 1800 011 041 for guidance. They can provide information on exercise programs and other fibromyalgia management services.

Working with your GP

Your GP is an important partner in managing your fibromyalgia. They can also help you link in with other specialists, health professionals and services. Your GP may make the initial diagnosis of fibromyalgia themselves or they may refer you to a rheumatologist for diagnosis.

Once your fibromyalgia is fully assessed, your GP or specialist may prepare a care plan with you to manage the services and treatments you require. They may prescribe medicines to improve your symptoms and will also see you regularly to check on your progress.

Your GP may employ a practice nurse, who may coordinate your care and access to services, and provide guidance and support.

How do I find a GP?

If you don't have a regular GP, speak to your local medical practice or medical centre.

Sometimes it takes time to find the right GP. You may have to ask around to find someone you feel understands your needs.

When you find the right GP, try to stick with them if possible, as this leads to the best consistent care.

When should I see my GP?

- You should aim to visit your GP at least every 3 - 4 months once your treatment is underway
- Visit your GP immediately if you notice a sudden worsening or change in your symptoms

How can a rheumatologist help?

Rheumatologists are doctors who specialise in diseases of the muscles and joints. Not every person with fibromyalgia needs to see a rheumatologist, but many will.

Your GP may refer you to a rheumatologist:

- for diagnosis, especially if the cause of your symptoms is unclear
- if your symptoms are not improving or are worsening
- if you and your GP wish to seek advice about newer treatments

The rheumatologist may recommend non-drug therapies, prescribe medicines where appropriate, and provide self-management advice on the best way to deal with your condition.

If your fibromyalgia is complicated by another bone and joint condition, such as rheumatoid arthritis, 'lupus' or osteoarthritis, a rheumatologist will be able to help you manage both conditions.

Because every person's fibromyalgia is different, your rheumatologist will probably select different treatments over time to find the best one for you.

How do I find a rheumatologist?

You will need a referral from your GP to see a rheumatologist. Your GP will refer you and will stay in touch with the rheumatologist to coordinate your care.

Your GP may recommend a rheumatologist, or you can contact the Australian Rheumatology Association on (02) 9252 2356 or visit www.rheumatology.org.au to find a rheumatologist in your area (but you will still need a referral letter from your GP).

When should I see my rheumatologist?

- Some people may only need to see a rheumatologist once, at diagnosis. Other people may need to see their rheumatologist on a more regular basis
- You may also need to return to the rheumatologist if your symptoms continue to be severe despite your treatment, or are really interfering with your life

Other health professionals

How can other health professionals help?

A physiotherapist ('physio') can provide treatments such as movement therapy and activities in water, to help get you safely moving again. Physiotherapists can also advise on the ways you can manage your condition day-to-day. Physiotherapists can help educate people about fibromyalgia and act as a health coach, encouraging self-management strategies such as relaxation and stress management.

Some physiotherapists may also offer 'psychologically informed therapy', combining physiotherapy with psychological methods such as cognitive behavioural therapy (see page 13) to best assist you in the management of your condition.

An **exercise physiologist** can also give you advice about exercise, including how to get started safely and the best type of activities for your health and ability. If you need to lose weight, they can also design a movement program to work alongside a healthy diet.

A **dietitian** can support you to improve your health by providing expert nutrition and dietary advice. If you are above a healthy weight, losing weight can help with the pain of fibromyalgia. A dietitian can help you with this.

An **occupational therapist** (OT) can show you ways to make daily tasks, such as cooking and showering, easier and provide advice on home supports such as a shopper or cleaner.

A **nurse** can help you learn more about your condition, understand your treatments and provide support.

A **pharmacist** can give you information about your medicines, side effects and interactions, as well as help you to manage your medicines (e.g., checking dosage, managing repeats).

A **pain specialist** is a doctor who specialises in diagnosing and treating people with difficult to manage pain. They can counsel patients and their families, support safe medicine use and advise on other therapies. Many pain specialists work in multidisciplinary pain clinics in public and private hospitals. Not every person with fibromyalgia will need to see a pain specialist.

A **sleep specialist** is a doctor or psychologist who diagnoses and treats sleep disorders. Not every person with fibromyalgia will need to see a sleep specialist, but some people may have other sleep disorders such as obstructive sleep apnoea or restless legs that may need specialist treatment.

Psychologists and **counsellors** can help you with any worries, fears, or feelings of sadness that can stand in the way of changing the way you live with pain. If you're finding it difficult to introduce self-management changes or challenge your beliefs about your pain, they can help with this too.

See the section on *Seeking support* on page 26 for more information on the help they can provide.

The toll-free Arthritis Infoline: 1800 011 041 and your local arthritis office can advise you on a range educational and service supports, including self-management, community programs, seminars, support groups, and resources to help you live well with fibromyalgia. These will vary from place to place, but many may also be available online through telehealth.

Different people will have different preferences about the type of health professionals or therapists they wish to see. There is no 'right' or 'wrong' but make sure your health professional is qualified and registered.

You can check the registration of many types of health professionals with the Australian Health Practitioner Regulation Agency (AHPRA) at www.ahpra.gov.au or by calling 1300 419 495.

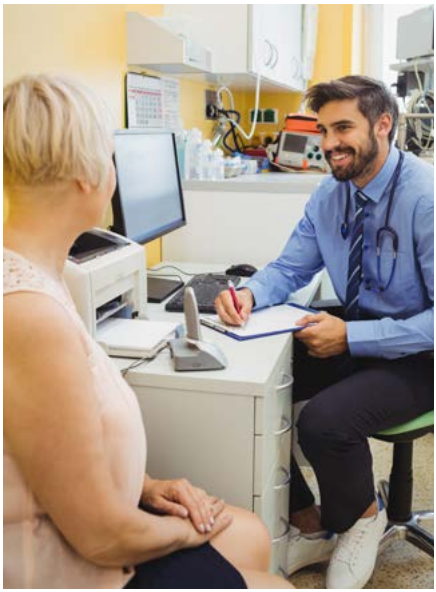
How do I find a health professional?

- Your GP or specialist can write you a referral, or you can contact a private health professional directly (see page 12 for information about finding a private health professional)
- If you have private health insurance, your health fund may cover part of the cost of seeing certain private health professionals
- If your GP refers you to an allied health professional as part of a Chronic Disease Management (CDM) plan, you may be able to have up to five sessions per year (partly) funded by Medicare. Ask your GP for more information
- You may be able to see a health professional through the public health system (such as at a community health centre or public hospital). There is often a waiting list, and you will usually need a referral from your GP. Their services are usually free or low cost

When should I see a health professional?

- Your GP or rheumatologist may refer you to one or more health professionals soon after your diagnosis with fibromyalgia
- Ask your GP or rheumatologist about seeing a health professional if you notice your physical condition or abilities change

Visit www.arthritisaustralia.com.au to view our factsheet: Working with your Healthcare Team



Healthy moves in self-care

While health professionals can offer a range of treatments to help you manage your fibromyalgia, there are many things you can do too.

If you smoke, quitting smoking is an important first step to help you stay as healthy as possible - call the Quitline on 13 78 48 or visit www.quitnow.gov.au. It's important that you are actively involved in managing your fibromyalgia, alongside your healthcare team. People who take an active role in their management do better in the long run.

Talk to your doctor or other healthcare team members before making big changes. You don't need to do everything at once.

Goal setting

Effective self-management of fibromyalgia involves goal setting. The focus of these goals should be on helping you to live the life you want, rather than just reducing pain.

Goals should be **SMART** (specific, measurable, achievable, relevant, and time-based). For example, "I will increase my walking by X every X days, so that in 4 weeks I can walk to the end of the street and back" or "I will not use electronic devices 1 hour before bedtime".

Start with one or two goals of activities that are important to you, so you don't get overwhelmed. Remember to make these achievable. Then you won't get discouraged if you don't get there as fast as you hoped.

Pacing yourself

Pacing is an important part of self-management. Taking regular, short rest breaks throughout the day can help people with fibromyalgia manage their energy reserves.

It can be hard to adjust when simple things that you used to do easily, such as cleaning the house, become difficult. Try to break larger tasks down into small manageable bits with a rest break between. This way you can avoid overdoing things and suffering the next day (see *Managing a fibromyalgia flare* on page 28).

Simplify your life and prioritise the things that are important to you, remembering to include things that bring you enjoyment. Delegate tasks to other people, put off less important tasks, or stop doing them altogether if they're not essential.

It can be good for your mental health if you can continue to work and socialise within your limitations. Think about work and social activities ahead of time and have a plan so you don't overdo it. Balance your activities across the day or week.

By conserving your energy, you can gradually work towards achieving your SMART activity goals.

That said, it can be hard to set up goals and pacing strategies on your own. Ask your doctor or other health professional for help if you need it.

PainHEALTH has more information on pacing and goal setting. www.painhealth.csse.uwa.edu.au

Minding your emotions and thoughts

Learning some simple mind techniques can help you to cope with your pain and symptoms better. These may take practice but a trained professional such as a psychologist, will be able to help and guide you. Some GPs, nurses and physiotherapists are trained in these techniques too. There are also online resources and apps you can use.

Relaxation techniques, such as slow breathing, guided imagery (mental pictures) and progressive muscle relaxation, can help reduce stress, anxiety and muscle tension.

There are many relaxation methods. You may need to try a few until you find one that works for you.

It's good to learn to relax as much as possible in many places and times of day, even while you're doing other things. This can help you to use it when you need it and not have to wait until you get home or when you can lie down.

Mindfulness is a mental state where you focus on the present moment, without judging or being distracted by unhelpful thoughts. It can help with calming and making pain less troubling.

Distraction is when you focus on something other than the pain. This might be imagining a pleasant scene, or doing something you enjoy, such as listening to music, reading, or doing puzzles. Most people find they already do this, but it can help to remind yourself to use it when possible.

The Pain Management Network has information on these mind techniques. www.aci.health.nsw.gov.au/chronic-pain/chronic-pain

Staying active

How can I safely keep moving?

Regular physical activity benefits everyone, but it is even more important for people with fibromyalgia.

Slowly increasing your activity day-to-day can help you to function better, improve your quality of life, and reduce fatigue.

Low intensity activities can reduce your pain and stress levels and improve your sleep and mood. They can help you think clearer and improve strength and endurance, and overall health. Low-impact activities, such as walking, swimming, water aerobics or yoga, are best.

Strength training with light weights and resistance bands has also been shown to help. A program is more likely to be successful if it's designed around you - if you find an activity you enjoy you are more likely to keep it up.

If you need help to get moving safely, a physiotherapist or exercise physiologist can help you create a special movement program you can do at home or at the local gym or swimming pool.

Your State/Territory arthritis office may be able to advise about exercise programs in your local area, including community groups, swimming pools, sports centres or gyms which run programs suitable for people with fibromyalgia.

What if it hurts?

It can be scary to start moving. If you're already tired and in pain you may think that it will only make things worse, especially if you haven't been active in a long while.

If you can, see a physiotherapist or exercise physiologist, who can support your first steps. They can suggest safe activities suitable for your fitness level and make sure you are moving well.

If you need help finding a physiotherapist or exercise physiologist, your GP can refer you to one. Your GP may also be able to prescribe you a suitable pain medicine to help you get started.

You could also find it helpful to work with a psychologist with skills in pain management if fears and worries are interfering in your movement program. Ideally, your physiotherapist and psychologist (and GP) should work together with you to make sure you are getting the same message.

The key is to start slowly. Begin with very light activity, such as walking or exercising in water. Do even less than you think you will be able to manage at first. Then slowly, *over several months*, you can increase how hard you work and for how long. Don't try to rush or overdo it.

Some people find their pain and tiredness increases when they first start. If this happens, reduce the amount you are doing until you find a level that you can cope with.

Many people with fibromyalgia live with some level of pain all the time. But if the pain feels unusual or severe, or is worse than usual for more than two hours after an activity, you've done too much and should cut back at your next session.

You can read more in our Exercise and fibromyalgia information sheet.

Getting enough sleep

Most people with fibromyalgia also struggle with sleep. This can create a vicious cycle. A bad night's sleep makes people more sensitive to pain during the day. In turn pain can affect sleep at night.

Introducing good sleep habits can help. For example,

- reducing screen time in the hours before bed
- avoiding caffeine drinks (e.g., coffee and cola) late in the day
- waking up and going to bed at the same time each day

The Sleep Health Foundation has many helpful resources to help you to get a better night's sleep. www.sleephealthfoundation.org.au

PainHEALTH has a module on Sleep and Pain

Some of the medicines we use to treat fibromyalgia can also help with sleep. (See *Making the most of medicines* on page 22).

For severe insomnia, your GP may be able to refer you to a psychologist for cognitive behavioural therapy for insomnia (CBT-I). CBT-I combines sleep education with behavioural strategies (such sleep restriction and relaxation training) and cognitive (thinking) interventions that aim to change unhelpful thoughts about sleep.

CBT-I can also be delivered in group sessions, as well as by apps and self-help programs that are available online.

The Sleep Health Foundation has more information on CBT-I.

Eating well

What foods are good or bad for fibromyalgia?

There is no diet proven to 'cure' fibromyalgia, but eating a healthy diet may help you to feel better.

A balanced diet that is high in fruit, vegetables, healthy oils and omega-3 fats (such as in oily fish) and low in saturated fats, sugars, salt and processed foods is good for most people.

If you are above a healthy weight, losing weight can help with the pain of fibromyalgia.

The Australian Government provides advice about the amount and kinds of foods that we need to eat for health and wellbeing. Learn more about the Australian Dietary Guidelines at www.eatforhealth.gov.au

For help in working out the best things to eat, you can ask your GP to refer you to a dietitian or find one directly via Dietitians Australia - call 1800 812 942 or visit www.dietitiansaustralia.org.au

FODMAP diet

FODMAPs are sugars that aren't properly absorbed in the gut, causing symptoms in people with irritable bowel syndrome (IBS). FODMAPs are found naturally in many foods and food additives.

Some people with fibromyalgia also have IBS. People with bowel symptoms (such as pain, bloating, wind, and changed toileting habits) may wish to consider a low FODMAP diet for these symptoms.

A FODMAP diet can help identify certain foods that cause bowel symptoms, as well as those that can be tolerated, and you do not need to avoid in the long term.

Following an exclusion diet like FODMAP can be difficult. You should only start a FODMAP diet under the guidance of a dietitian who has special skills in managing IBS and using a FODMAP diet.

Research is continuing to see if a FODMAP or other diets can help with some other symptoms of fibromyalgia.

You can read more about the FODMAP diet at monashfodmap.com.

Making the most of medicines

Will medicines cure my fibromyalgia?

At present there is no medicine that can 'cure' fibromyalgia and the medicines we currently have available do not work for everybody. Medicines alone are rarely effective for fibromyalgia. They work best when they are combined with non-drug measures such as gentle physical activity, pacing and support.

It is important to have realistic expectations when you start a medicine for fibromyalgia. No medicine is going to make you pain free, but the right one may reduce your pain enough that you can get out and do more of the things you enjoy.

What is the right medicine for me?

All medicines have risks and benefits, so before you start treatment talk to your doctor about how each medicine should be helping you and what risks it might have. Make sure your doctor knows about any other health problems that you or your family members have, and what other medicines you are taking, including any vitamins, supplements or herbal medicines. This information will help them choose the best medicine for you.

Read about what side effects the medicine might have and what to do if you experience any unwanted effects from your medicine. Many fibromyalgia medicines need to be taken regularly to work properly and should not be stopped suddenly. Talk to your doctor if you have concerns about side effects, safety or cost.

Each person responds differently to medicines, which means that you will need to work with your GP or rheumatologist to find the best medicine and dose for you. This can take time, but it is worthwhile to find the most effective medicine with the least side effects.

Your condition may also change over time, including how much pain or disability you experience, and whether you have symptom-free periods. This means that you may need to change or add medicines over the course of your treatment - you may not be on the same medicine forever.

How will the medicines help?

Common pain relievers (analgesics) such as paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs) like ibuprofen, diclofenac and celecoxib are usually not effective for the pain of fibromyalgia. Strong pain-relieving opioid medicines (e.g., oxycodone) are also rarely effective in the long term and in some people may even make the pain worse.

The medicines that doctors prescribe for fibromyalgia are many of the same ones we use for nerve pain. They are designed to 'calm down' the nervous system, reducing hypersensitivity. These include:

Duloxetine

Duloxetine is an antidepressant medicine that is often used these days for nerve pain. It is called a SNRI (serotonin-noradrenaline reuptake inhibitor) as it affects levels of two important neurotransmitters in the brain, called serotonin and noradrenaline.

It may be particularly useful for people with fibromyalgia who also have symptoms of depression. Common side events with duloxetine include headaches, nausea, dry mouth and diarrhoea.

Milnacipran is another SNRI that is sometimes used for fibromyalgia. It is an imported product which can only be prescribed by specialists for individual patients.

Amitriptyline

Amitriptyline is an older-style (tricyclic) antidepressant, which is also more often used for nerve pain these days. As well as reducing pain, amitriptyline may improve sleep. Side effects include drowsiness, dry mouth, constipation and weight gain, but taking the medicine at night can help with side effects.

Dosulepin (dothiepin) is another medicine in the tricyclic antidepressant family that is also sometimes used.

Pregabalin and gabapentin

Pregabalin and gabapentin are medicines in the same family. While they are also used for epilepsy, they are more often used to treat nerve pain these days. Both medicines have been shown to help relieve pain in some people with fibromyalgia, although not everybody will get benefit. As well as reducing pain they can help with sleep. Common side effects include dizziness, dry mouth, sleepiness and weight gain.

Other medicines

Tramadol is a weak opioid pain reliever which has some SNRI effects (like duloxetine). This makes it effective in some types of nerve pain. It does not have many of the disadvantages of strong opioids and is sometimes used in fibromyalgia for severe pain that does not respond to other treatments.

Naltrexone is an opioid antagonist (blocker). When given at a very low dose it has been shown to help some people with fibromyalgia, reducing pain and helping with sleep and tiredness. Side effects can include tummy cramping, diarrhoea and vivid dreams.

Medicinal cannabis is often raised as an option, but more research is needed before doctors can widely recommend its use. Despite this, many people with fibromyalgia are interested in trying medicinal cannabis products for their pain. Talk to your doctor if you're wondering whether medicinal cannabis might be right for you.

Most medicinal cannabis products are unapproved medicines in Australia and have not been assessed for safety, quality or effectiveness. The Therapeutic Goods Administration has a medicinal cannabis hub where consumers can find out more information about obtaining medicinal cannabis products.

You can read the Australian Rheumatology Association's position on medicinal cannabis on the 'For Patients' menu at www.rheumatology.org.au.

How do I find out more about these medicines, including side effects?

To understand more about your medicines and any risks or side effects that they may have, ask your doctor or pharmacist for a Consumer Medicines Information (CMI) leaflet.

CMI leaflets provide easy to understand information including:

- what the medicine is for and how it is used
- things to consider before using the medicine
- possible side effects and what to do if they occur

Speak to your GP or specialist if you have concerns about the long-term effect of medicines. Also talk to your doctor if you are planning on getting pregnant, as not all medicines can be taken during pregnancy or breastfeeding.

What other treatments can help?

There are many promises made for non-medical 'cures' or treatments to ease fibromyalgia – while some of these may help, many have not been proven to be effective.

If you are considering other treatments do some research first. Look at our section on *What about information from other websites?* (page 28) for tips on finding reliable sources of information. You can also contact your local arthritis office or visit our website at www.arthritisaustralia.com.au.

Research suggests that activities that combine **movement with meditation** such as yoga and tai chi, can assist with sleep and fatigue in fibromyalgia.

Hydrotherapy may help with pain. This means exercising in water or simply relaxing in hot baths or mineral spring baths (called balneotherapy).

Because herbal, homeopathic, Ayurvedic or Eastern medicines may affect the treatments prescribed by your doctor, please tell your GP and specialist what other treatments you are thinking about using.

Ensure your practitioner is qualified and registered. Most therapies have a professional association you can contact. Some qualifications, for example Chinese Medicine Practitioners, can be checked at the Australian Health Practitioner Regulation Agency (AHPRA) www.ahpra.gov.au or by calling 1300 419 495.

You may be worried that your doctor or other members of your healthcare team may disapprove of these other therapies. However, it is very important to keep your healthcare team informed.

Your healthcare team, particularly your doctor and pharmacist, can't give you the best professional advice without knowing all the treatments you are using. This includes vitamin supplements, herbal medicines and other therapies.

Seeking support

Why me?

It's perfectly normal to wonder why you have developed fibromyalgia and to feel angry, sad, frightened or puzzled about it.

One of the best things you can do for yourself is understand more about the condition and the best ways to manage it yourself. Talk to your rheumatologist or GP if you're unsure about anything. Reading this booklet should help.

However, sometimes the symptoms can get you down, especially if pain and exhaustion are affecting your everyday life. It may also feel as though people around you – even close friends or family – don't understand what you're going through.

Feeling motivated to change your mindset or habits when you have these symptoms is understandably challenging. Sometimes it can feel too hard to do everything expected of you.

Who can help?

There are many people who can help when your fibromyalgia is troubling you. A first step can be to try to talk honestly with your partner, family member, or a trusted friend about how you feel. Give them a chance to talk too – they may feel that they don't know enough about your situation and how to help you. This may leave them feeling helpless and even guilty. So, talking with them could help both of you.

Visit your GP if you are worried that unwanted feelings are too strong or have been there for a long time. Your GP may be able to suggest ways of coping or may prescribe medicines if you are especially worried or depressed.

Your GP may also refer you to a psychologist or counsellor. They will have more time to ask you about your worries, troubling feelings and moods. They should then be able to help you work out ways to manage things more effectively.

Psychologists may offer a course of cognitive behavioural therapy (CBT), a 'talking therapy'. CBT can teach you to recognise and change unhelpful ways of thinking and reacting, as well as working out more helpful responses to pain and stress. It has been shown to help people with troubling pain to manage better and to reduce distress.

Psychologists can also help you to deal with stressful situations (at work and home) that might be adding to the burden of your condition.

They can also help you understand and challenge your mindset and habits that make self-management changes feel difficult. It can be even more helpful if your physio, GP and psychologist work in a coordinated way with you, rather than separately.

Your GP can arrange a Medicare Mental Health Care Plan. This allows you ten subsidised visits per year to a psychologist of your choice.

If you want to contact a psychologist directly, call the Australian Psychological Society on 1800 333 497 or visit www.psychology.org.au

Whichever way you find a psychologist, it's a good idea to ask them about their experience in helping people with chronic pain conditions.

Beyond Blue provides information and advice about depression, anxiety available treatments and where to get help. Visit www.beyondblue.org.au or call 1300 22 4636.

Lifeline provides a 24-hour confidential telephone crisis support service for anyone across Australia experiencing a personal crisis. Call 13 11 14.

What other assistance is available?

If you find yourself unable to work, your doctor may put you in touch with a social worker, who can help explain the financial and health services that are available to you. These can include any pensions or allowances that you might be eligible for, plus any financial assistance such as Health Care Concession Cards or low-cost treatment programs.

Your local council, community health centre, community group or religious organisation may also offer programs that include practical advice, activities, social networks or just someone to talk to.

If you can find the right group, talking to other people with fibromyalgia can be a positive experience. However, not all support groups suit everyone. You don't have to stay in a group if you find it's not a good fit for you.

Some state affiliate organisations of Arthritis Australia may be able to provide information on support groups. Contact your State/Territory arthritis office - call 1800 011 041 or visit www.arthritisaustralia.com.au.

Fibromyalgia Australia and state-based fibromyalgia organisations may also have useful information and resources.

Managing a fibromyalgia flare

You can do everything right, but still occasionally you may experience a flare. A flare is a sudden, temporary worsening of fibromyalgia symptoms. Usually this means more severe pain, but some people also experience 'flu-like' symptoms, 'fibro fog' and overwhelming tiredness. For some people, symptoms are so bad that everyday tasks become impossible.

Flares can be unpredictable and the time they last can vary. They can happen at any time, with little or no warning. Often there is no obvious cause, but sometimes they can occur alongside a viral infection. Some people report that stress, 'overdoing it', poor sleep, and even weather changes can bring on flares.

If you are worried, see your GP to review your treatment plan. They can also help design an action plan to use with any future flares.

If you have any new or different symptoms, these should be investigated as they may be the sign of a new illness, rather than a flare.

Remind yourself that the flares are to be expected and will eventually pass. In the meanwhile, give yourself permission to take it slow.

What about information from other websites?

The web can be a useful source of information and support. However, not everyone who puts information on the web is a qualified health practitioner.

Some organisations make unrealistic promises in order to sell their products. Treatments and therapies from overseas may also not be relevant or approved in Australia. Always check information from the web with a trusted member of your healthcare team.

The Australian Government's Health Direct website www.healthdirect.gov.au is an excellent starting point for web searches, as every site that Health Direct links to has been checked for quality.

Please let us know your feedback on this resource by completing our quick survey - **https://www.surveymonkey.com/r/BW8XPFL**

Glossary of terms

Analgesic *an-al-jee-zik*
A medicine that helps relieve pain.

Arthritis *are-thry-tiss*
Inflammation of one or more joints.

Dietitian *die-et-ish-un*
A health professional who can recommend what foods you should and shouldn't eat for good health.

Exercise physiologist *fizz-ee-o-lo-jist*
A health professional who specialises in exercise and movement to prevent and manage chronic conditions.

Fibromyalgia *fai-bro-my-al-jah*
A condition marked by generalised pain and muscle stiffness. Extreme fatigue (tiredness) and sleep problems are also common.

Flare
A period of increased disease activity/ symptoms, that may last days, weeks or month.

Hypersensitivity
hy-per-sen-sih-tih-vih-tee
Extreme physical sensitivity to particular substances or conditions.

Inflammation *in-fla-may-shun*
The body's response to damage or infection, which mistakenly attacks your joints in inflammatory arthritis. Inflammation can cause pain, swelling, warmth, redness and difficulty moving a joint.

Occupational therapist
occ-u-pay-shun-al theh·ah·pist
A health professional who looks at your activities at home or work, then suggests changes to make everyday life easier with fibromyalgia.

Multidisciplinary
Involving input from different health professional disciplines

Opioids *o-pee-oyds*
A type of medicine used for severe pain.

Osteoarthritis *os-tee-o-are-thrytiss*
A condition that causes pain and reduced function in affected joints.

Pacing
Strategy for managing activity levels.

Physiotherapist *fizz-ee-o-ther-a-pist*
A health professional who specialises in assessing and treating conditions using physical methods such as manual therapy and movement to help manage pain.

Psychologist *sai-ko-luh-juhst*
A health professional who is trained in human behaviour, who can assist in the treatment of mental, emotional, and behavioural problems.

Rheumatologist *roo-ma-tol-o-jist*
A doctor who is a specialist in diagnosing and treating conditions of the bones, muscles and joints, including fibromyalgia.

Rheumatoid Arthritis (RA)
An autoimmune disease that causes pain and swelling of the joints.

Useful resources

Australian resources

For information and advice about fibromyalgia visit
www.arthritisaustralia.com.au
Ph: 1800 011 041

Fibromyalgia Australia

Fibromyalgia Australia works to improve research and services for Australians disadvantaged by Fibromyalgia, ME/CFS (Chronic Fatigue Syndrome) and associated conditions.
www.fibromyalgiaaustralia.org.au

PainHealth

Clinically supported information, tips, support and personal stories to help you manage musculoskeletal pain
https://painhealth.csse.uwa.edu.au/

For access to quality online information about fibromyalgia start at Health Direct
www.healthdirect.gov.au

For advice on healthy eating and appropriate exercise, visit Healthy Active
www.healthyactive.gov.au

For advice on quitting smoking, contact the Quitline on **13 78 48** or visit
www.quitnow.gov.au

To find a rheumatologist, contact the Australian Rheumatology Association
www.rheumatology.org.au
Ph: (02) 9252 2356

To find a physiotherapist, contact the Australian Physiotherapy Association
www.physiotherapy.asn.au
Ph: 1300 306 622

To find an occupational therapist, contact Occupational Therapy Australia
www.otaus.com.au
Ph: 1300 682 878

To find an exercise physiologist, contact Exercise and Sports Science Australia
www.essa.org.au
Ph: (07) 3171 3335

To find a dietitian, contact Dietitians Australia
www.dietitiansaustralia.org.au
Ph: 1800 812 942

To find a psychologist, contact the Australian Psychological Society
www.psychology.org.au
Ph: 1800 333 497

Please keep in mind that some issues and treatments from overseas may not be relevant in Australia.

Arthritis Australia

Arthritis Australia is a not-for-profit organisation that provides support and information for all Australians affected by arthritis.

Arthritis Infoline: 1800 011 041 | www.arthritisaustralia.com.au

Arthritis Australian Capital Territory
Building 18,
170 Haydon Drive
Bruce, ACT 2617
PO Box 908, Belconnen ACT 2616
02 6251 2055
www.arthritisact.org.au

Arthritis Northern Territory
Shop 18, Rapid Creek Business Village,
48 Trower Rd
Millner, NT 0810
PO Box 452, Nightcliff NT 0814
08 8948 5232
www.aont.org.au

Arthritis Queensland
WOTSO,
Level 2 Westfield,
Chermside QLD 4032
PO Box 2121, Lutwyche QLD 4030
07 38574200
www.arthritis.org.au

Arthritis New South Wales
Locked Bag 2216, North Ryde NSW 1670
02 9857 3300
www.arthritisnsw.org.au

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111A Welland Avenue
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08 8379 5711
www.arthritissa.org.au

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19A Main Road
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PO Box 780, Moonah TAS 7009
03 6228 4824
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