

# Taking control of your Ankylosing Spondylitis

A practical guide to treatments,  
services and lifestyle choices



# How can this booklet help you

This booklet is designed for people who have ankylosing spondylitis.

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 ankylosing spondylitis is and what it means for you
- work with your healthcare team to manage the disease and reduce symptoms
- choose foods and activities that are appropriate to your situation

- understand how your medicines can help in the short and long term
- find support to cope with the emotional and lifestyle impacts of the disease.

The information inside is based on the latest research and recommendations, and has been reviewed by Australian experts in the field to make sure it is current and relevant to your needs. So go ahead — take control of your ankylosing spondylitis!

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Australian Rheumatology  
Association



## Medical and consumer consultants

Dr Paul Bird, Rheumatologist

Ms Tanya deKroo, Information Resources Coordinator, Arthritis Australia

Mr Matthew Leibowitz, person living with ankylosing spondylitis

Dr Mona Marabani, Rheumatologist and President of Arthritis Australia (2007-2010)

Ms Jean McQuade, Manager, Health & Education Services, Arthritis WA

Dr Peter Nash, Rheumatologist

Mrs Judith Nguyen, Arthritis Australia, Board Member

Dr Peter Youssef, Rheumatologist and Chair of Arthritis Australia Scientific Advisory Committee

# Understanding ankylosing spondylitis

## What is ankylosing spondylitis?

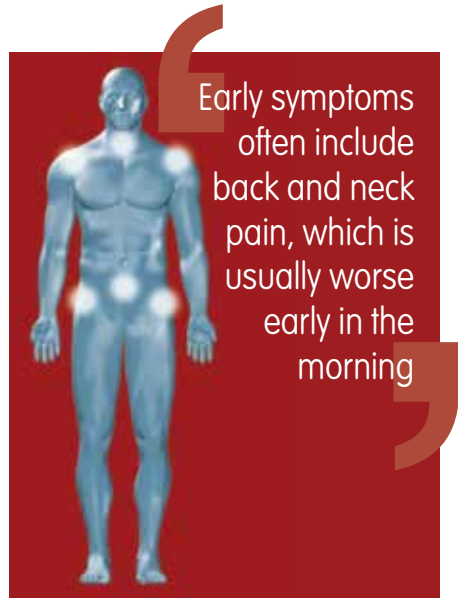
Ankylosing spondylitis is a disease which causes inflammation and pain in your spine (backbone).

Early symptoms often include back and neck pain, which is usually worse early in the morning and when you first get out of bed. This type of back pain is worse after rest and improves with exercise or activity. It can also affect other joints such as the shoulders, hips, knees, ankles and the joints between your ribs and breastbone. There may also be symptoms away from the spine, including bowel irritation and sore eyes.

Ankylosing spondylitis affects about 1–2% of Australians. The disease usually first appears between the ages of 15–40 years and is about three times more common in men than in women.


## What causes ankylosing spondylitis?

The exact cause of ankylosing spondylitis is not known. It seems that in almost all cases, the disease runs in the family, particularly in people who carry the HLA-B27 gene.



Early symptoms often include back and neck pain, which is usually worse early in the morning

However, only about one in every eight people who have the HLA-B27 gene will develop ankylosing spondylitis, so having the gene does not necessarily mean that the disease will be passed on from parents to their children. For people who carry HLA-B27 and have a parent, brother or sister with ankylosing spondylitis, the risk of developing the disease is about one in five.



Recently, two new genes (IL23R and ARTS1) have been found to be associated with ankylosing spondylitis, but what this means for passing on the condition is yet to be determined. Unlike other types of back pain, ankylosing spondylitis is not caused by particular jobs or lifestyle choices, and is usually not the result of particular injuries, infections or other medical conditions.

## How will ankylosing spondylitis affect me?

Ankylosing spondylitis affects different people in different ways. A common early symptom is deep aching in or across the buttocks. This is due to inflammation of the joints between the tailbone and pelvis (sacroiliac joint). Pain in the front of the chest or between the shoulder blades is also a common early symptom.

Other parts of the body may also be affected by pain, stiffness and swelling. These include the leg joints, hips, shoulders and the places such as the heels where muscles and tendons attach to your bones (called enthesitis).

People with ankylosing spondylitis may also experience short periods of eye inflammation (iritis or uveitis), which result in red, sore eyes, blurry vision and permanent damage if left untreated. The lining of your bowel may also be affected, causing symptoms of inflammatory bowel disease such as diarrhoea and bloating.



Ankylosing spondylitis affects different people in different ways

### If left untreated, ankylosing spondylitis may lead to permanent stiffening of the spine

Not everyone with ankylosing spondylitis will develop all of these symptoms and, in some cases, the symptoms may come (flare) and go (remission) over many years. For other people, the symptoms and disability may slowly worsen over time.

If left untreated, ankylosing spondylitis may lead to permanent stiffening of the spine and damage to other joints and parts of the body. In particular, there may be new bone growing around the spine, which can lead to pain and disability as the back becomes increasingly stiff. In severe cases, this extra growth can fuse the bones in the spine together, stopping the spine from moving and causing a permanently forward-stooped posture.

Most people with ankylosing spondylitis continue to study, work or carry out home duties, although some may need a change in study and working conditions to avoid long

periods of sitting and allow adequate movement or activity throughout the day.

While there is still no 'cure' for ankylosing spondylitis, there has been real progress in managing the disease during recent years. Effective treatment as soon as possible can help reduce your symptoms and minimise any disability associated with spine and joint problems.



## How will my doctor diagnose ankylosing spondylitis?

A rheumatologist (specialist) will look at the results from many tests to help them decide whether you are likely to have ankylosing spondylitis. Your rheumatologist will:

- talk to you about your symptoms, including how old you were when you first noticed them, where and when you feel back pain, and whether it feels better or worse when you move
- ask if anyone in your family has had ankylosing spondylitis, back problems or other types of arthritis
- carefully examine your spine, eyes, shoulders, hips, knees and feet to check how well they can move, and to look for signs of inflammation such as tenderness, warmth or swelling
- take a blood sample to help decide if your symptoms are caused by inflammation and to test for the HLA-B27 gene
- possibly send you to a radiologist for an x-ray or other scan such as a CT or an MRI of your spine and pelvis.

## What about pregnancy?

For women, the disease should not interfere with pregnancy, but you will need to discuss your medications with your doctor to minimise potential harm to your unborn baby. Some arthritis medicines can still be used during pregnancy if necessary, but many can harm the foetus and should not be taken while trying to conceive, when pregnant or during breastfeeding. For men, you should discuss your family's pregnancy plans with your doctor so that they can review your medications if necessary.

Arthritis Australia's new website [www.empowered.org.au](http://www.empowered.org.au) presents a detailed section on pregnancy, including hearing directly from women with arthritis about their journeys to motherhood.

*Arthritis, pregnancy and the path to parenthood* details the experiences of Suzie May, a young Australian woman with rheumatoid arthritis, and other men and women from around the world as they fulfil their goal of becoming parents, despite their arthritis. This practical guide can help you understand the potential challenges you may face and give you strategies to overcome these challenges. The book is available at [www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au)

# Who can help?



The good news is that ankylosing spondylitis can be effectively managed – and a team approach is the best way to combat it. This involves you and your healthcare professionals together with support from family, friends and community organisations.

## How can you help?

Remember, you are the most important member of your healthcare team. By understanding your condition and learning to manage it, you can carry on living a normal life. Work closely with your healthcare team to develop a management plan for your condition, including medicines and other treatments. This will help you be actively involved in your care and decision-making about treatments. With the right treatment and advice,

ankylosing spondylitis doesn't have to get in the way of working, travelling, relationships, pregnancy or parenting.

Understand how your treatments will help and how to get the most out of them.

Contact your State/Territory Arthritis Office on 1800 011 041 for guidance. They can provide information and introduce you to support groups, exercise programs and other arthritis management services.

Arthritis Australia has developed a new website [www.empowered.org.au](http://www.empowered.org.au) with a range of resources designed to help you live, and live well, with ankylosing spondylitis. You can also see Arthritis Australia's range of information sheets for more about treatments for ankylosing spondylitis at [www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au)



# Working with your GP

## How can my GP help?

Your GP is an important partner in managing your ankylosing spondylitis. They can also help you to access other specialists, health professionals and services.

Once your ankylosing spondylitis is fully assessed, your GP or specialist may prepare a care plan to manage the services and treatments you require.

They will also see you regularly to check on your treatment and its progress.

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

## How do I find a GP?

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

## When should I see my GP?

- Once your treatment is underway, you should visit your GP at least every 2–3 months for review
- Visit your GP immediately if you notice a sudden worsening in symptoms or disability, particularly eye problems, knee pain or increased spinal pain

Your GP is an important partner in controlling and managing your ankylosing spondylitis



# Seeing a rheumatologist

## How can a rheumatologist help?

**Rheumatologists** are doctors who specialise in diseases of the joints, including ankylosing spondylitis.

All people with suspected or diagnosed ankylosing spondylitis should visit a rheumatologist, and in some cases the rheumatologist will organise your ongoing care.

The rheumatologist will refer you to a physiotherapist and will probably start you on medicine to slow down the disease and reduce pain. Because every person's ankylosing spondylitis is different, your rheumatologist will probably select different treatments over time to find the best one for you.

If there are specific problems in other parts of your body, your rheumatologist may refer you to other doctors such as an ophthalmologist (eye specialist), gastroenterologist (gut specialist), dermatologist (skin specialist) or an orthopaedic surgeon (a specialist in bone and joint surgery).

See [www.empowered.org.au](http://www.empowered.org.au) to learn more about rheumatologists, including what to expect at your first appointment and how to work with your specialist.

## How do I find a rheumatologist?

Your GP can refer you to a rheumatologist — they will then stay in touch to coordinate your care

- Your GP may recommend a rheumatologist
- You can also contact the Australian Rheumatology Association on (02) 9252 2334 or visit [www.rheumatology.org.au](http://www.rheumatology.org.au) to find a rheumatologist (but you will still need a referral from your GP)

## When should I see my rheumatologist?

- At first you will probably see the rheumatologist every 4–6 weeks
- After that you may need to visit about every three months, depending upon your treatment

All people with suspected or diagnosed ankylosing spondylitis should visit a rheumatologist



# Other health professionals


## How can a physiotherapist help?

An essential health partner for your ankylosing spondylitis is a **physiotherapist** (physio). Your physio will use various therapies, including mobilisation techniques, stretches and exercises, to keep your spine and joints as flexible, strong and pain-free as possible.


They will also suggest the best posture for your back and show you exercises that you should do at home to keep your spine mobile. They may also offer an intensive physiotherapy course, or encourage you to attend classes or group sessions for people with similar back problems.

## When should I see a physiotherapist?

- You should be referred to a physio or a physiotherapy clinic soon after your diagnosis of ankylosing spondylitis
- You will probably need to return to your physio on a regular basis, particularly in the early stages of the disease, so that they can reassess the mobility of your spine, adjust your exercises and help you stay motivated



Physiotherapists will use various therapies, including mobilisation techniques, stretches and exercises...



- If you take part in physiotherapy classes, these may happen every 1–2 weeks depending upon what is available in your area

## Occupational therapy

You might also visit an **occupational therapist** (OT), or they may come to your home or work. OTs can provide advice on how to do things, at home, work and when you're out and about, in ways that reduce strain and pain for your back.

## Rheumatology nurse

A **rheumatology nurse** is a specially trained nurse working with your rheumatologist that can help you learn more about your condition, understand your treatments and provide support.

## What changes might they suggest?

Your physio or OT may suggest changes to your furniture and posture to make your home and work more comfortable and better for your back. This can include finding an appropriate chair to provide good support for your spine.

If you will be sitting for a long time, sit up straight in your chair and move regularly — stand up and stretch every 20 minutes. When driving, a small cushion on the seat back will support your lower back, and you should also stop regularly for stretches.

Make sure that your bed is firm but not too hard, and use only one soft pillow. You may also need to re-assess with your physio or OT how you carry out your work or home duties to make sure that you continue to move your back without straining it.

## How do I find a therapist?

- Your GP or specialist can provide a referral, or you can contact a private therapist directly (see page 26 for information about finding a private therapist).
- 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 a health professional as part of a care plan, you may be able to have five sessions per year funded by Medicare. Ask your GP for more information.
- Most health professionals are available in 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.

Visit [www.empowered.org.au](http://www.empowered.org.au) to hear more about building your healthcare team and receive practical tips from various health professionals. Different people will have different preferences about the type of health professional or therapist they wish to see. There is no 'right' or 'wrong' but ensure 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](http://www.ahpra.gov.au) or by calling 1300 419 495.

# Healthy moves for your spine and joints

While healthcare professionals can offer a range of treatments for your ankylosing spondylitis, there are many things you can do too. The Australian Government's Healthy Active website provides straightforward suggestions for good eating and activity levels – visit [www.healthyactive.gov.au](http://www.healthyactive.gov.au)

Quitting smoking is an important first step to help your joints – call the Quitline on 13 78 48 or visit [www.quitnow.gov.au](http://www.quitnow.gov.au) Talk to your doctor or other care team members before making lifestyle changes.

## Eating well

### What foods are good or bad for ankylosing spondylitis?

There is very little evidence that particular foods are good or bad for people with inflammatory conditions such as ankylosing spondylitis and there is certainly no diet proven to 'cure' it. Eating a balanced diet that is low in saturated fat, sugar and salt, but high in fruit, vegetables and cereals is good for most people. This can help you lose weight (if required), which may reduce the strain on your lower back, hips, legs and feet.

The Australian Government provides advice about the amount and kinds

of foods that we need to eat for health and wellbeing, including Australian Dietary Guidelines, at [www.eatforhealth.gov.au](http://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 the Dietitians Association of Australia — call 1800 812 942 or visit [www.daa.asn.au](http://www.daa.asn.au)

For more information about diet visit [www.empowered.org.au](http://www.empowered.org.au)

## Fish oils

Current research suggests eating foods rich in Omega-3 fats can help reduce inflammation in some forms of arthritis. While these effects are modest compared with medicines, omega-3 fats do not have serious side effects. Foods rich in omega-3 fats include oily fish, like sardines and salmon, plus canola oil and walnuts. If you cannot eat these foods regularly, daily fish oil supplements that provide around 2.7g of omega-3 (EPA plus DHA) may be a useful substitute.



## Keeping active

### What exercise should I be doing?

Regular physical activity benefits everyone, and is one of the most effective treatments for ankylosing spondylitis. It helps to reduce your pain, strengthen your muscles, maintain good posture and improve your sleep and overall health.

Inflammation in your muscles, tendons and other tissues may make it harder for you to stand up straight, turn and bend or take a deep breath.

Regular stretching exercises can help, and your physio can suggest suitable exercises to stretch and strengthen

your muscles. These exercises will help your posture and help to maintain mobility in your spine. You should aim to do this stretching program daily or at least five times per week.

Regular physical activity benefits everyone, and is one of the most effective treatments for ankylosing spondylitis



## AS exercises with Michael Slater

Australian cricketing legend, Michael Slater, has partnered with Arthritis Australia to produce an AS exercise video. Slater, who has AS, demonstrates specific stretching exercises which have been designed to help people with AS manage their symptoms. The exercises were developed by physiotherapists and the video is endorsed by the Australian Physiotherapy Association and Australian Rheumatology Association. This video is available from the AS section of the Arthritis Australia website. Visit [www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au)

In addition to your stretching and posture exercises, it is important to do at least 30 minutes of moderate exercise on most days of the week for your general fitness. You can do this either in one go or break your exercise into smaller efforts (for instance, three 10-minute or two 15-minute blocks per day).

Activities that are likely to be good for your fitness and posture include swimming, walking, jogging, low-impact aerobics and tennis. If you prefer riding a bike or exercise bike, talk to your physio about how to modify your bike to maintain good posture. Your physio can also suggest other exercises that are appropriate for your situation.

Ask your State/Territory Arthritis Office about appropriate exercise programs in your local area, including community groups, sports centres or gyms that run programs specifically for people with arthritis.

The UK National Ankylosing Spondylitis Society publishes a useful guidebook that shows many practical exercises — you can find it at [www.nass.co.uk](http://www.nass.co.uk)

For more information about staying active visit [www.empowered.org.au](http://www.empowered.org.au)



### What if it hurts to exercise?

The level and type of exercise you will be able to do varies from person to person — while some people can aim to keep or improve their fitness through exercise, others may be aiming to remain mobile.

Some people will experience pain in their soft tissue and muscles when first exercising. If pain feels unusual or severe, or lasts for more than two hours after you have stopped an activity, it is probably best to avoid or change that activity. Applying a heat or cold pack to a sore area may ease swelling and/or pain.

Try to plan your exercise for times when you are experiencing the least pain — generally when you are least tired and your medicine is having maximum effect.



Applying a heat or cold pack to a sore area may ease swelling and/or pain

# Making the most of medicines

## Will medicine cure my ankylosing spondylitis?

At present there is no 'cure' for ankylosing spondylitis. However, along with exercise, early use of the right medicines can help slow down the damage caused by the disease, relieve pain and stiffness, and reduce long-term disability. The aim of treatment is remission — to be symptom-free and return to normal function.

## What is the right medicine for me?


All medicines have risks and benefits, so before you start treatment talk to your doctor and pharmacist 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, as this can help them choose the best medicine for you.

You should also make sure that you understand what side effects the medicine might have, including what to do or who to speak to if you experience any unwanted effects from your medication.



Many medicines for ankylosing spondylitis 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.

All medicines have risks and benefits, so before you start treatment talk to your doctor and pharmacist



Each person responds differently to medicines, which means that you will need to work with your specialist and GP to find the best medications and doses for you. This can take time, but by finding the most effective medicines with the least side effects, you can hope to really make a difference in controlling your ankylosing spondylitis. This means that you may need to change or add medicines over the course of your treatment.

Some medicines may only be used once exercise or other medicines are no longer effective in controlling your ankylosing spondylitis.

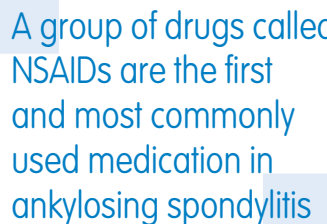
### **How will the medicines help?**

For many people with ankylosing spondylitis, the combination of regular medication and exercise can control symptoms and reduce the long-term effects of the disease.

A group of drugs called NSAIDs (anti-inflammatory drugs) are the first and most common type of medication that people with ankylosing spondylitis use. NSAIDs can help relieve pain, reduce swelling

and stiffness, and may limit harmful changes to the bones of the spine and pelvis.

Sometimes, disease-modifying arthritis medications called DMARDs will be used to control symptoms in joints other than the spine or pelvis, such as the hip or knees. A short course of corticosteroid tablets may also help reduce the pain and stiffness in joints.



A group of drugs called NSAIDs are the first and most commonly used medication in ankylosing spondylitis

If other treatments have not controlled your disease, another type of medicine called a biologic may be prescribed by your rheumatologist. These medicines can reduce pain and inflammation in the spine and other joints, improving your mobility and quality of life.

Regular blood tests may be necessary to test the effectiveness of the drugs you are taking and to check for any unwanted side effects.

### What side effects do these medicines have?

To understand more about your medicines and any risks or side effects that they may have, read the Consumer Medicine Information (CMI) leaflet that is available from your doctor or pharmacist. 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; and possible side effects and what to do if they occur. Speak to your specialist or GP, especially if you have concerns about the long-term effect of medicines, or whether they should be taken during pregnancy or breastfeeding.

If other treatments have not controlled your disease, another type of medicine called a biologic may be prescribed by your rheumatologist.

The Australian Rheumatology Association and Arthritis Australia publish medicine information sheets. Call the Arthritis Helpline on 1800 011 041 for copies or visit [www.rheumatology.org.au](http://www.rheumatology.org.au) or [www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au)

For detailed information about the medicines used to treat ankylosing spondylitis, visit [www.empowered.org.au](http://www.empowered.org.au)

Biosimilar medicines are beginning to enter the Australian market. These are copies of biologic medicines that are very similar, but not identical to, the original medicine. To make sure you get the medicine that is right for you, talk to your rheumatologist about whether you should keep taking the same brand of biologic or whether it could be substituted. Visit [www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au) to find out more.

## What other treatments can help?

Very few non-medical ‘cures’ or treatments have been scientifically proven to help reduce symptoms of ankylosing spondylitis. Acupuncture has been found to relieve long-term back pain, but not specifically back pain related to ankylosing spondylitis.

Ensure your practitioner is qualified and registered. There are professional associations for most therapies that you can contact for more information, or they can help you find an accredited practitioner. Some qualifications, for example Chinese Medicine Practitioners, can be checked at the Australian Health Practitioner Regulation Agency (AHPRA) [www.ahpra.gov.au](http://www.ahpra.gov.au) or by calling 1300 419 495.

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

You may feel concerned that your doctor or other members of your healthcare team will disapprove of

complementary therapies. However it is very important to keep your healthcare team informed, even if they do not approve. 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.

See Arthritis Australia’s *Complementary therapies* information sheet for more about the safe use of these types of treatments at [www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au) or visit [www.empowered.org.au](http://www.empowered.org.au)

You should also talk to your specialist or GP before having treatment from a chiropractor or osteopath. Manipulation of the spine may not be a suitable treatment option for people with ankylosing spondylitis.

Manipulation of the spine may not be a suitable treatment option for people with ankylosing spondylitis

# Seeking support

## Why me?

It's perfectly normal to wonder why you have developed ankylosing spondylitis, and to feel angry, sad, frightened or confused about it. By taking control of your condition and working with your healthcare team, you can approach the disease with a positive attitude. However, sometimes the condition can get you down, especially if pain, stiffness or disability 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.

## Who can help?


There are many people who can help you deal with the emotional side of ankylosing spondylitis. Your first step is to try to talk honestly with your partner, parents or children about how you feel. Give them a chance to talk too — they might have worries or feel that they don't know enough about your disease and how it is affecting 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.

Visit [www.empowered.org.au](http://www.empowered.org.au) to hear directly from people with ankylosing spondylitis and similar conditions on how they learned to deal with the emotional ups and downs of living with arthritis.



They may also refer you to a counsellor or psychologist, who can talk to you about your worries, feelings and moods, then suggest practical ways to work through them. If you want to contact a psychologist directly, call the Australian Psychological Society on 1800 333 497 or visit [www.psychology.org.au](http://www.psychology.org.au)

beyondblue provides information and advice about depression, anxiety, available treatments and where to get help. Visit [www.beyondblue.org.au](http://www.beyondblue.org.au) or call 1300 22 4636.

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


## **What other assistance is available?**

There are many resources available to help people with ankylosing spondylitis. 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 entitled to, 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. There are also Independent Living Centres in each state that provide advice on products and services, including aids and devices, that can help with day-to-day activities. Visit [www.ilcaustralia.org.au](http://www.ilcaustralia.org.au) or call 1300 885 886 to find your closest centre or more information.

Contact your State/Territory Arthritis Office to find out about their wide range of resources, management programs and support groups — call 1800 011 041 or visit [www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au)



Contact your State/Territory Arthritis Office to find out about their wide range of resources, management programs and support groups



Arthritis Australia has a new website [www.empowered.org.au](http://www.empowered.org.au) that allows you to hear directly from people living with ankylosing spondylitis and similar conditions about how they have managed to survive, and thrive, with arthritis. Arthritis Australia also has a designated AS section on its website, which includes Australian cricketing legend, Michael Slater's story about his 20-year journey with AS, as well as other personal stories from people living with the condition. A new AS exercise video, featuring Michael Slater and physiotherapists can be downloaded. Visit [www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au)

## 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.

Treatment options and practices 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](http://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 and accuracy of information.

The Australian Government's Healthinsite is an excellent starting point for web searches



# Glossary of terms

|                               |                                 |   |
|-------------------------------|---------------------------------|---|
| <b>Analgesic</b>              | an-al-jee-zik                   | A medicine that helps relieve pain.   |
| <b>Ankylosing spondylitis</b> | an-kee-lo-zing spon-dee-ly-tiss | A disease where the joints in the spine become inflamed and, if untreated, may lead to the spinal bones joining together.   |
| <b>Arthritis</b>              | are-thry-tiss                   | Inflammation of one or more joints, including those between the bones of the spine.   |
| <b>Corticosteroid</b>         | core-tick-o-ster-oyd            | A type of medicine that is very effective in reducing inflammation.   |
| <b>Dietitian</b>              | die-et-ish-un                   | A health professional who can recommend what foods you should and shouldn't eat.  |
| <b>DMARD</b>                  | dee-mard                        | A range of medicines that are known as disease-modifying anti-rheumatic drugs. These help reduce damage to your joints as well as relieving symptoms.   |
| <b>Enthesitis</b>             | en-thee-sy-tiss                 | Inflammation of the places where your muscles and tendons join your bones.  |
| <b>Inflammation</b>           | in-fla-may-shun                 | The body's response to damage or infection, which mistakenly affects your spine and other joints in ankylosing spondylitis. Inflammation can cause pain, swelling, warmth, redness and difficulty moving the joint. |
| <b>NSAID</b>                  | en-sayd                         | A group of medicines known as non-steroidal anti-inflammatory drugs. These can reduce inflammation, swelling and stiffness.   |
| <b>Occupational therapist</b> | OT                              | A health professional who looks at your activities at home or work, then suggests changes or devices to make everyday life easier on your spine.  |
| <b>Physiotherapist</b>        | fizz-ee-o-ther-a-pist           | A health professional who uses treatments to keep your spine mobile, and can suggest exercises for you to use at home.  |
| <b>Rheumatologist</b>         | roo-ma-tol-o-jist               | A doctor who is a specialist in treating problems of the joints. Your rheumatologist will probably start and review most of your medicines and treatments.  |

# Useful resources

## Australian resources

For more on ankylosing spondylitis including personal stories, and to download the Arthritis Australia/ Michael Slater exercise video

[www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au)

For more on living, and living well, with ankylosing spondylitis

[www.empowered.org.au](http://www.empowered.org.au)

For access to quality online information about ankylosing spondylitis, start at Health Direct

[www.healthdirect.gov.au](http://www.healthdirect.gov.au)

For advice on healthy eating and appropriate exercise, visit Healthy Active

[www.healthyactive.gov.au](http://www.healthyactive.gov.au)

For advice on quitting smoking, contact the Quitline

[www.quitnow.gov.au](http://www.quitnow.gov.au)

Ph: 13 78 48

To find a specialist, contact the Australian Rheumatology Association

[www.rheumatology.org.au](http://www.rheumatology.org.au)

Ph: (02) 9252 2334

To find a physiotherapist, contact the Australian Physiotherapy Association

[www.physiotherapy.asn.au](http://www.physiotherapy.asn.au)

Ph: 1300 306 622

To find an occupational therapist, contact the Australian Association of Occupational Therapists

[www.otaus.com.au](http://www.otaus.com.au)

Ph: 1300 682 878

To find a dietitian, contact the Dietitians Association of Australia

[www.daa.asn.au](http://www.daa.asn.au)

Ph: 1800 812 942

To find a psychologist, contact the Australian Psychological Society

[www.psychology.org.au](http://www.psychology.org.au)

Ph: 1800 333 497

## International resources

The public area on the website of the American College of Rheumatology contains many useful resources

[www.rheumatology.org/public](http://www.rheumatology.org/public)

The UK National Ankylosing Spondylitis Society provides specific information and publishes a useful guidebook that demonstrates many practical exercises for your condition

[www.nass.co.uk](http://www.nass.co.uk)

Arthritis Research UK also provides a wide variety of information for people with arthritis

[www.arthritisresearchuk.org](http://www.arthritisresearchuk.org)

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

## My contact details

My name:

Telephone:

## My GP

Name:

Telephone:

## My specialist

Name:

Telephone:

## My support team

Name:

Telephone:

Name:

Telephone:

## My medicines

| Name | Dosage | Instructions |
|------|--------|--------------|
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## Arthritis Australia

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

Contact your State/Territory Arthritis Office to find out about the range of awareness and education programs, support services and resources available.

Arthritis Helpline: 1800 011 041

[www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au)

### Arthritis ACT

Level 2B Grant Cameron  
Community Centre  
27 Mulley Street Holder ACT 2611  
PO Box 4017 Weston Creek ACT 2611

### Arthritis New South Wales

Suite 1.15 32 Delhi Road  
North Ryde NSW 2113  
Locked Bag 2216 North Ryde NSW 1670

### Arthritis Northern Territory

Shop 18 Rapid Creek Business Village  
48 Trower Road, Millner NT 0810  
PO Box 452 Nightcliff NT 0814

### Arthritis Queensland

1 Cartwright Street  
Windsor QLD 4030  
PO Box 2121 Windsor QLD 4030

### Arthritis South Australia

118-124 Richmond Road  
Marleston SA 5033

### Arthritis Tasmania

19A Main Road  
Moonah TAS 7009  
GPO Box 1843 Hobart TAS 7001

### Arthritis Victoria

263-265 Kooyong Road  
Elsternwick VIC 3185  
PO Box 130 Caulfield South VIC 3162

### Arthritis Western Australia

17 Lemnos Street  
Shenton Park WA 6008  
PO Box 34 Wembley WA 6913



Arthritis Australia Level 2, 255 Broadway Glebe NSW 2037

**Mail:** PO Box 550 Broadway NSW 2007

**Phone:** 02 9518 4441 **Fax:** 02 9518 4011

**Email:** [info@arthritisaustralia.com.au](mailto:info@arthritisaustralia.com.au)

**Web:** [www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au)

**Arthritis Helpline:** 1800 011 041

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