

Taking control of your **Ankylosing Spondylitis**

A practical guide to treatments, services and lifestyle choices



Arthritis
AUSTRALIA

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Taking control of your ankylosing spondylitis

“The key to living successfully with ankylosing spondylitis is understanding your condition and taking control of it as soon as possible”

Ankylosing spondylitis is a painful condition that affects people from all walks of life. While the symptoms develop over months or even years, the possibility of significant back problems makes this an unwelcome diagnosis. However, the good news is that most people can control their ankylosing spondylitis with treatment and continue to lead active and healthy lives. The key to living successfully with ankylosing spondylitis is understanding your condition and taking control of it as soon as possible.

This booklet shows you how to get on top of your ankylosing spondylitis. It offers information and practical advice to help you:

- understand what ankylosing spondylitis is and what it means for you;
- work with your health care 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; and
- 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!



Understanding ankylosing spondylitis

What is ankylosing spondylitis?

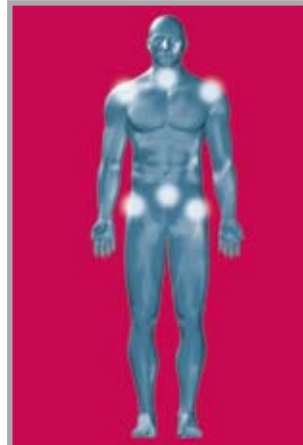
Ankylosing spondylitis is a disease which causes inflammation and pain in your spine (backbone). Early symptoms often include back and neck pain, which is usually worse early in the morning and when you first get out of bed. It can also affect other joints such as the shoulders, hips, knees, ankles and 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 in their cells. 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.

“Ankylosing spondylitis affects about 1–2% of Australians”



“Unlike other types of back pain, ankylosing spondylitis doesn't seem to be caused by particular jobs or lifestyle choices”

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 has yet to be determined. Unlike other types of back pain, ankylosing spondylitis doesn't seem to be 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 (hipbone). 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 (enthesitis).

People with ankylosing spondylitis may also experience short periods of eye inflammation (iritis or uveitis), which results 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.



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 work or carry out home duties, possibly with a change in working conditions to ensure adequate movement 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.

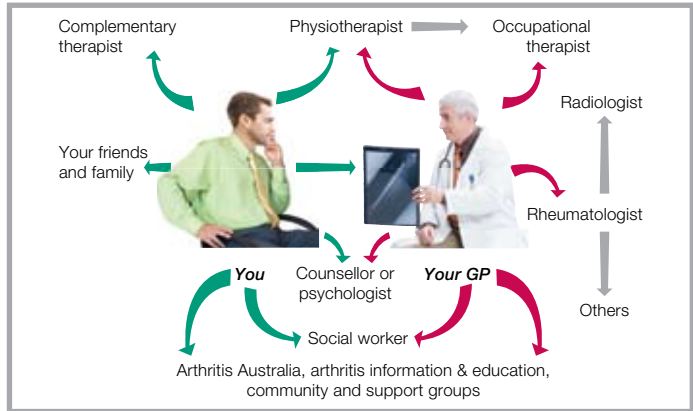
What about pregnancy?

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. For men, you should discuss your family's pregnancy plans with your doctor so that they can review your medications if necessary.

“While there is still no 'cure' for ankylosing spondylitis, there has been real progress in managing the disease during recent years”

Who can help?

“Your GP will refer you to a rheumatologist if they suspect that you have ankylosing spondylitis.”



Many support services are available for people with ankylosing spondylitis. Your GP will refer you to a specialist (rheumatologist) if they suspect that you have ankylosing spondylitis. You and your doctor can then coordinate most aspects of your care.

How can you help?

The first step is a positive attitude. By understanding your condition and how to stay on top of it, you can carry on living a normal life.

Understand how your treatments will help and how to get the most out of them. Your doctor or therapist can address your concerns and provide practical advice. You can obtain information sheets about treatments from Arthritis Australia or the Australian Rheumatology Association (www.rheumatology.org.au).

Read brochures such as this one and speak to your health care team. Call the Arthritis Information line on 1800 011 041 or visit www.arthritisaustralia.com.au.



Get in touch with people who understand your condition and needs, such as Arthritis Australia, for practical or emotional support to help you through difficult patches and to stay positive.

Working with your GP

How can my GP help?

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

Once your ankylosing spondylitis is fully assessed, your GP or rheumatologist 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 doctor 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”



Specialist care

“Because every person’s ankylosing spondylitis is different, your specialist will probably select different treatments over time to find the best one for you”

How can the specialist help?

Rheumatologists are doctors who specialise in diseases of the joints, including ankylosing spondylitis. They can make a full assessment of your condition to guide your care (see box on the next page). All people with suspected or diagnosed ankylosing spondylitis should visit a rheumatologist, and in some cases the specialist will organise your ongoing care.

The rheumatologist will refer you to a physiotherapy clinic and will probably start you on medicine to slow down the disease and reduce pain. Because every person’s ankylosing spondylitis is different, your specialist 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), a gastroenterologist (gut specialist), a dermatologist (skin specialist) or an orthopaedic surgeon (a specialist in bone and joint surgery).

How do I find a specialist?

- Your GP can refer you to a rheumatologist – they will then stay in touch to coordinate your care
- You can also contact the Australian Rheumatology Association on (02) 9256 5458 or visit www.rheumatology.org.au



When should I see my specialist?

- At first you will probably see the rheumatologist every 4–6 weeks
- After that you may need to visit about every 3 months, depending upon your treatment

Making a diagnosis of ankylosing spondylitis

Specialists need to 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 (ESR and CRP tests), and to test for the HLA-B27 gene; and
- 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.

“You might also visit an OT, or they may come to your home or workplace”

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.

You might also visit an occupational therapist (OT), or they may come to your home or workplace. OTs can provide advice on how to do things in ways that reduce strain and pain for your back.

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 reassess 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 local therapist directly
- For physios, visit the Australian Physiotherapy Association website (apa.advsol.com.au) or look under 'Physiotherapist' in the Yellow Pages
- For OTs, visit the Australian Association of Occupational Therapists website (www.ausot.com.au) or look under 'Occupational Therapist' in the Yellow Pages

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

“You will probably need to return to your physio on a regular basis, particularly in the early stages of the disease”

Healthy moves for your spine and joints

“Contact your local state or territory Arthritis Office on 1800 011 041”

While health care 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.

Quitting smoking is an important first step to help your joints – call the Quitline on 131 848 or visit www.quitnow.info.au. Talk to your doctor or other care team members before making lifestyle changes.

Your local state or territory Arthritis Australia office can provide information and introduce you to support groups, exercise programs and other arthritis management services. Contact them on 1800 011 041.

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 – 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 fruits, 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.

It might also be useful to increase your intake of Omega-3 fatty acids, which can be found in fatty fish like sardines and salmon, plus canola oil and walnuts. If you cannot eat these foods regularly, daily fish oil supplements that contain around 3g of Omega-3 may be a useful substitute. There is also evidence that you should reduce foods high in Omega-6 fatty acids, such as sunflower oil, peanuts and almonds.

The Australian Government publishes a useful guide to healthy eating called Food for Health – you can find it at www.nhmrc.gov.au/publications/synopses/_files/n31.pdf. For help in working out the best things to eat, you can ask your GP to refer you to a dietitian or contact one directly via the Dietitians Association of Australia – call (02) 6163 5200 or visit www.daa.asn.au.

“There is also evidence that you should reduce foods high in Omega-6 fatty acids, such as sunflower oil, peanuts and almonds”



“Regular stretching exercises can help to stretch and strengthen your muscles”

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 or doctor can suggest suitable exercises to stretch and strengthen your muscles. These exercises will help improve your posture and maintain the mobility of your spine. You should aim to do this stretching program daily or at least five times per week.

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 or doctor 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.

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 2 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.

“Some people will experience pain in their soft tissue and muscles when first exercising”



Making the most of medicines

“Make sure your doctor knows about any other health problems that you or your family members have”

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 whom 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.



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 medications 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 used by people with ankylosing spondylitis. 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.

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

“Speak to your GP or specialist, especially if you have concerns about your medicines”

If other treatments have not controlled your disease, a new type of medicine called a biological DMARD may be prescribed by your rheumatologist. These medicines can reduce pain and damage 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 GP or specialist if you have concerns about the long-term effect of medicines, and whether they should be taken during pregnancy or breastfeeding.

The Australian Rheumatology Association and Arthritis Australia publish medicine information sheets. Call the Arthritis Information line on 1800 011 041 for copies or visit www.rheumatology.org.au or www.arthritisaustralia.com.au.

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.

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

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.

“Very few non-medical 'cures' or treatments have been scientifically proven to help reduce symptoms of ankylosing spondylitis”

Seeking support

“By taking control of your condition and working with your health care team, you can approach the disease with a positive attitude”

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 health care team, you can approach the disease with a positive attitude. However, sometimes the condition can get you down, especially if pain, stiffness or disability is 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 feelings 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.



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.

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 – look under ‘independent living’ in your local White Pages.

Contact Arthritis Australia to find out about their wide range of resources, management programs and support groups: call 1800 011 041 or visit www.arthritisaustralia.com.au.

“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”

What about information from 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 health care team.

The Australian Government's HealthInsite (www.healthinsite.gov.au) is an excellent starting point for web searches, as every site that HealthInsite links to has been checked for quality and accuracy of information.

“Always check information from the web with a trusted member of your health care team”



Glossary of terms

Analgescic	an-al-jee-zik	A medicine that helps relieve pain.
Ankylosing spondylitis	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.
Arthritis	are-thry-tiss	Inflammation of one or more joints, including those between the bones of the spine.
Corticosteroid	core-tick-o-ster-oyd	A type of medicine that is very effective in reducing inflammation.
Dietitian	die-et-ish-un	A health care practitioner who can recommend what foods you should and shouldn't eat.
DMARD	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.
Enthesitis	en-thee-sy-tiss	Inflammation of the places where your muscles and tendons join your bones.
Inflammation	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.
NSAID	en-sayd	A group of medicines known as non-steroidal anti-inflammatory drugs. These can reduce inflammation, swelling and stiffness.
Occupational therapist	OT	A health care practitioner who looks at your activities at home or work, then suggests changes or devices to make everyday life easier on your spine.
Physiotherapist	fizz-ee-o-ther-a-pist	A health care practitioner who can provide massage and stretching to keep your spine mobile, and can suggest exercises for you to use at home.
Rheumatologist	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 access to quality online information about ankylosing spondylitis, start at HealthInsite

www.healthinsite.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

www.quitnow.info.au
Ph: 131 848

To find a specialist, contact the Australian Rheumatology Association

www.rheumatology.org.au
Ph: (02) 9256 5458

To find a physio, contact the Australian Physiotherapy Association

apa.advsol.com.au
Ph: 1300 306 622

To find an OT, contact the Australian Association of Occupational Therapists

www.ausot.com.au
Ph: (03) 9415 2900

To find a dietitian, contact the Dietitians Association of Australia

www.daa.asn.au
Ph: (02) 6163 5200

To find a psychologist, contact the Australian Psychological Society

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

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

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

www.arc.org.uk

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

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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 local state or territory Arthritis Office to find out about the range of awareness and education programs, support services and resources available

Freecall anywhere in Australia: 1800 011 041

www.arthritisaustralia.com.au

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27 Mulley Street Holder ACT 2611
PO Box 4017 Weston Creek ACT 2611

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