Rheumatoid Arthritis

Consumer care guide

Arthritis AUSTRALIA

What is this guide?

This booklet is endorsed by the Australian Rheumatology Association, Australian Podiatry Association, Juvenile Arthritis Foundation Australia, and the Pharmaceutical Society of Australia

Australian Rheumatology Association

Apoda Australian Podiatry Association

Pharmaceutical Society of Australia

JAFA Juvenile Arthritis Foundation Australia

After being diagnosed with rheumatoid arthritis (RA), many people find themselves unsure of what to expect or what to do next.

This guide was designed alongside people with RA. It includes the things they wished they knew when they were first diagnosed.

We hope that this guide gives you the knowledge to work towards high quality care, making informed decisions alongside your healthcare team.

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The basics

This section covers the basics of RA, which are important to know when making informed decisions about your treatment and care. It explains what RA is, why you have it, the types of RA, treatment options and co-occurring conditions that some people may experience.

What is RA?
What does RA look like?
How is RA managed?
Medicines for RA
Co-occuring conditions

What is RA?

RA is an autoimmune disease that causes pain and swelling of the joints. The normal role of your body's immune system is to fight off infections to keep you healthy. In an autoimmune disease, it targets your own healthy tissues by mistake.

In RA, the immune system targets the lining of the joints, causing inflammation and joint damage. RA usually affects the smaller joints in the hands and feet. However, it can affect any joint in the body, such as the hips and knees, shoulders and jaw.

With early diagnosis and the right treatment plan, people with RA can lead full and active lives.

Why do I have RA?

We don't know what causes RA, but it is more common in people who smoke and/or have a family history of RA.

What are the types of RA?

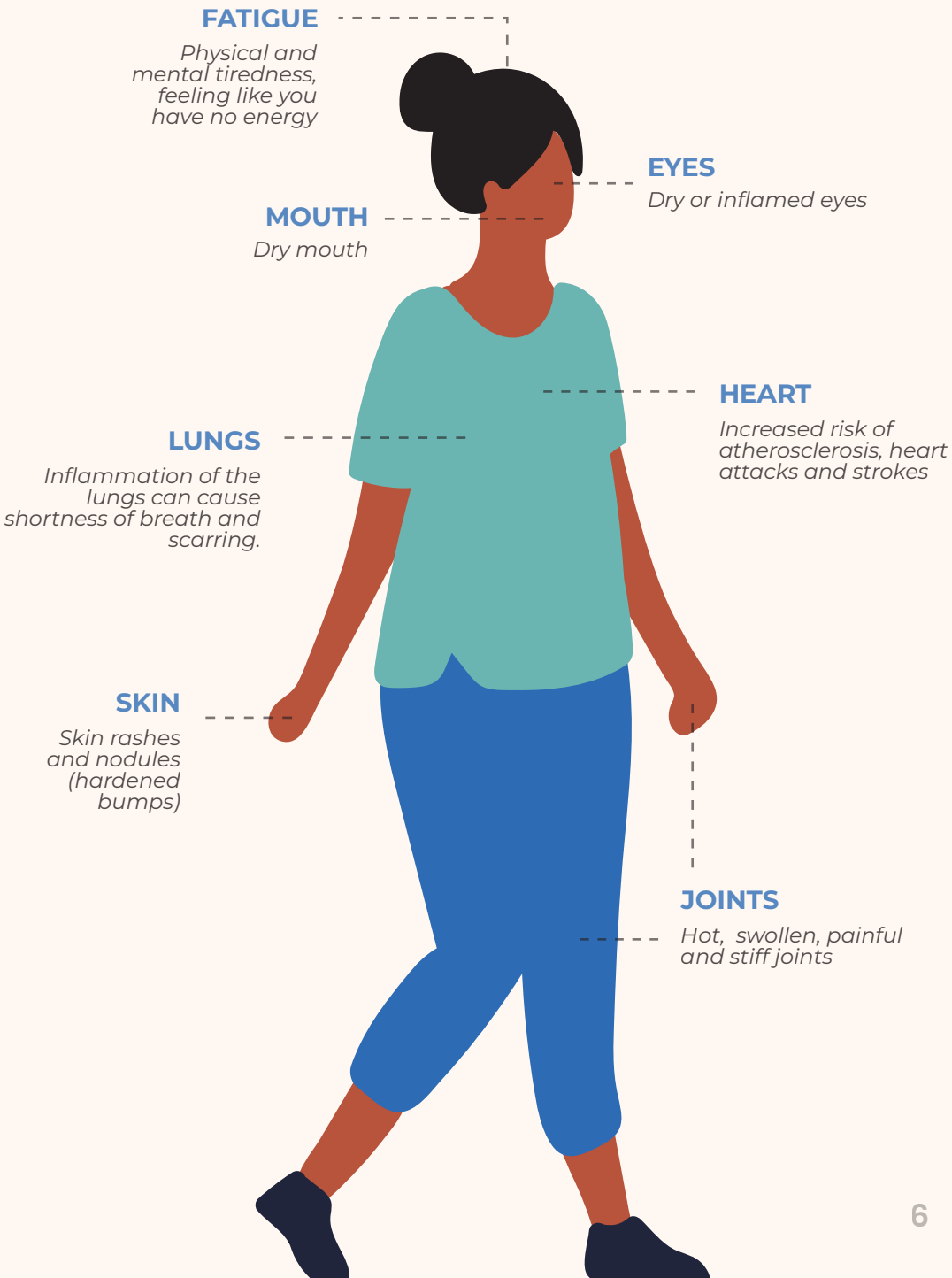
There are two main types of RA.

In **seropositive** RA, proteins made by the immune system can be picked up in the body by blood tests. The best known of these is rheumatoid factor (RF). Some people without RA can also test positive for RF. Up to 5% of older people have RF without having RA.

In **seronegative** RA these proteins are absent. This can make it harder to diagnose. Around 1 in every 4 to 5 people with RA will be seronegative.

Is there a cure for RA?

Right now, there is no cure for RA. However, treatment has improved greatly over the past 20 years. Newer medicines are very helpful, especially when we start them in early RA.



What does RA look like?

The most obvious symptoms of RA include swelling, heat, stiffness and pain in your joints. Symptoms are often worse in the morning or after you have been inactive for a while. Usually the joints on both sides of the body are affected.

However, RA can affect more than just the joints and cause other symptoms such as fatigue. Some people with RA may have skin rashes, dry mouth, and dry or inflamed eyes. Inflammation of the lungs can cause scarring and shortness of breath. Fortunately, many of these other body problems are becoming less common with modern treatments.

Inflammation may also affect the heart and blood vessels, which can increase the risk of atherosclerosis (hardening of the arteries), heart attacks and strokes. Your doctor or healthcare professional can watch for complications with regular blood tests or check-ups, to help prevent many of these problems occurring.

How is RA managed?



Medicines

Modern medicines for RA can reduce inflammation, decrease pain and stiffness and prevent joint damage.



Team-based care

Your care is likely to involve many different healthcare professionals, although how this will work will vary from person to person. If you attend a clinic in a public hospital, most of your team-based care will be organised through the clinic.

More people will see a private rheumatologist. In this situation, your GP may coordinate most of your care. They will communicate with your rheumatologist and arrange many of your tests and prescriptions. They may also refer you to allied health professionals, such as a physiotherapist or occupational therapist (OT), for support in the home or community.



Counselling

Many people find that counselling can help when dealing with the emotional aspects of RA. A psychologist or social worker may also be an important person in your healthcare team.



Exercise, healthy eating and lifestyle

One of the best things you can do for yourself is get some exercise every day. You can also play an active role by not smoking, reducing stress, and eating a healthy diet.



Surgery

In some cases your doctor may recommend surgery – such as an arthroscopy or joint replacement.

Medicines for RA

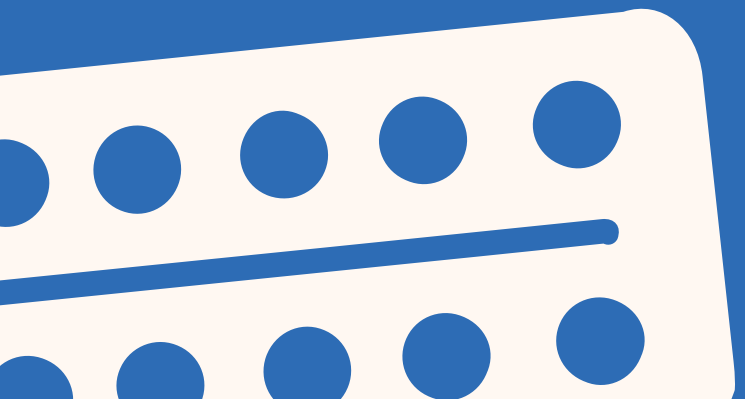
There is no cure for RA but medicines can help reduce joint inflammation. They can relieve pain and stiffness and slow progress of RA. This section describes some of the most common medicines used to treat RA.

Analgesics

pain relievers

Your doctor may suggest analgesics (or pain relievers) to help with pain. They are helpful for short-term relief, but will not slow progression of RA or prevent joint damage. Common pain relievers include paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs). NSAIDs also reduce inflammation and may help with stronger pain that paracetamol doesn't relieve. Some pain relievers are available over the counter. For others you will need a prescription.

Examples of NSAIDs include:
ibuprofen, naproxen and celecoxib





Corticosteroids

steroids

Corticosteroids have a strong anti-inflammatory action and can reduce pain and swelling. They can help control symptoms while you are waiting for your DMARD medicine to work, or during a flare. However, they are best not to use long-term because of the risk of side effects, such as diabetes and osteoporosis (thinning of the bones) . They can be taken by mouth or injected into a joint or muscle to relieve inflammation.

Types of corticosteroids include:
prednisone, prednisolone, methylprednisolone

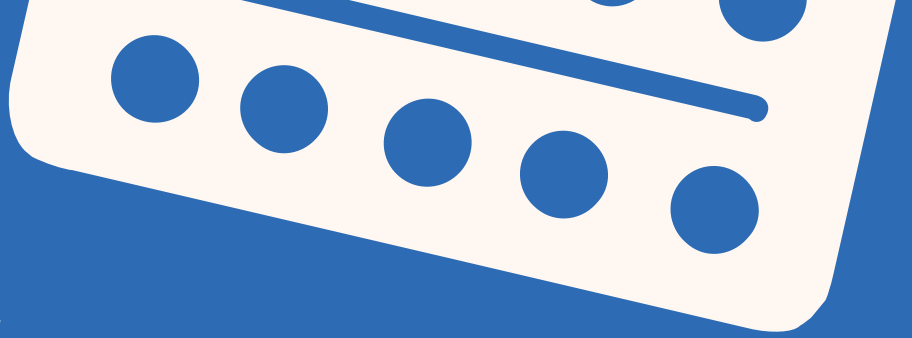
DMARDs

disease-modifying antirheumatic drugs

DMARDs reduce the activity of the immune system, to prevent it damaging healthy joints. They relieve symptoms and also slow progress of RA, lowering the risk of long-term damage to your joints. You will need to have blood tests to check how well they are working and to watch for possible side effects. DMARDs can take several weeks to work and it can take time to find the best DMARD or combination of DMARDs for you.

Types of DMARDs are explained on the following page.



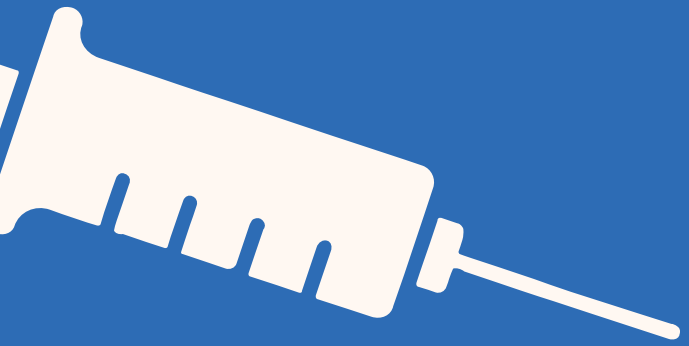


cSDMARDs

conventional synthetic disease-modifying antirheumatic drugs

cSDMARDs are used in early RA to reduce joint damage and improve symptoms. Of these medicines, methotrexate is most often used. It's usually taken once a week in the form of a tablet, or an injection just under the skin. Methotrexate may be prescribed alone, or combined with other DMARDs to get the best control of your disease and symptoms.

Examples of cSDMARDs include:
methotrexate, leflunomide, sulfasalazine, and hydroxychloroquine



bDMARDs

biological disease-modifying antirheumatic drugs

bDMARDs or 'biologics' are given by injection. They are made from living cells and block specific parts of the immune system. They are harder to make and cost more than conventional DMARDs. Your doctor can only prescribe them on the Pharmaceutical Benefits Scheme (PBS) if cSDMARDs are not working well enough.

Your doctor may offer you a biosimilar. This is a medicine that is a very close, but not identical, copy of an original biologic. They work in the same way as the original bDMARD, but have a different brand name.

Examples of bDMARDs include:
adalimumab, certolizumab, etanercept, golimumab, infliximab, abatacept, tocilizumab, rituximab

tsDMARDs

targeted synthetic disease-modifying antirheumatic drugs

To date, janus kinase (JAK) inhibitors are the only tsDMARDs available in Australia. They can be taken as a tablet, but are expensive and access is restricted under the PBS. bDMARDs and tsDMARDs cannot be used together but each can be used with cSDMARDs.

Examples of tsDMARDs include:
baricitinib, tofacitinib, upadacitinib



If you want to learn more, your pharmacist can provide you with a Consumer Medicine Information (CMI) leaflet with more detailed information about your medicine.

Co-occurring conditions

Other health conditions can occur with RA. The most common of these appear on this page.

Not everyone will develop these conditions and many are easily managed with modern treatments. If we know to look out for them we can best manage your risk.

Some treatments for RA can also increase your chance of infection and certain cancers, especially skin cancer. Your healthcare team should explain to you how you can lower your risks.

If you have not been assessed for these conditions, speak to your GP, rheumatologist or other member of your healthcare team.

Heart and blood vessel disease

People with RA are at increased risk of heart and blood vessel disease, including heart attacks and stroke



Around **1 in 5** Australians with RA will develop these conditions.

Depression

Having RA can affect your mental and emotional health, sometimes leading to depression.



Approximately **2-3 in 10** people with RA will experience depression.

Diabetes

People with RA may have an increased risk of developing diabetes.



Around **3 in 20** people with RA report they also have diabetes.

Osteoporosis *(thinning of the bones)*

Australians with RA have more than double the risk of osteoporosis compared with those without RA.



Approximately **2 in 10** people with RA have osteoporosis.

Lung conditions

People with RA seem more likely to develop lung conditions such as chronic obstructive pulmonary disease (COPD) and asthma.



Around **1 in 3** Australians with RA report they also have lung disease.

1. AIHW (2023) Chronic musculoskeletal conditions : Rheumatoid arthritis, AIHW, Australian Government. 2. Ramos, AL., et al. (2019). Journal of Rheumatology, 46(6), 564–571. 3. Marrie, RA., et al. (2018) Arthritis Care & Research, 70(7), 970–978.

What to expect

This section offers a breakdown of what you can expect RA care to look like at different stages, including a timeline of the first few months of care.

It is based on the current Clinical Care Standard for RA, with added information and suggestions from other people with RA.

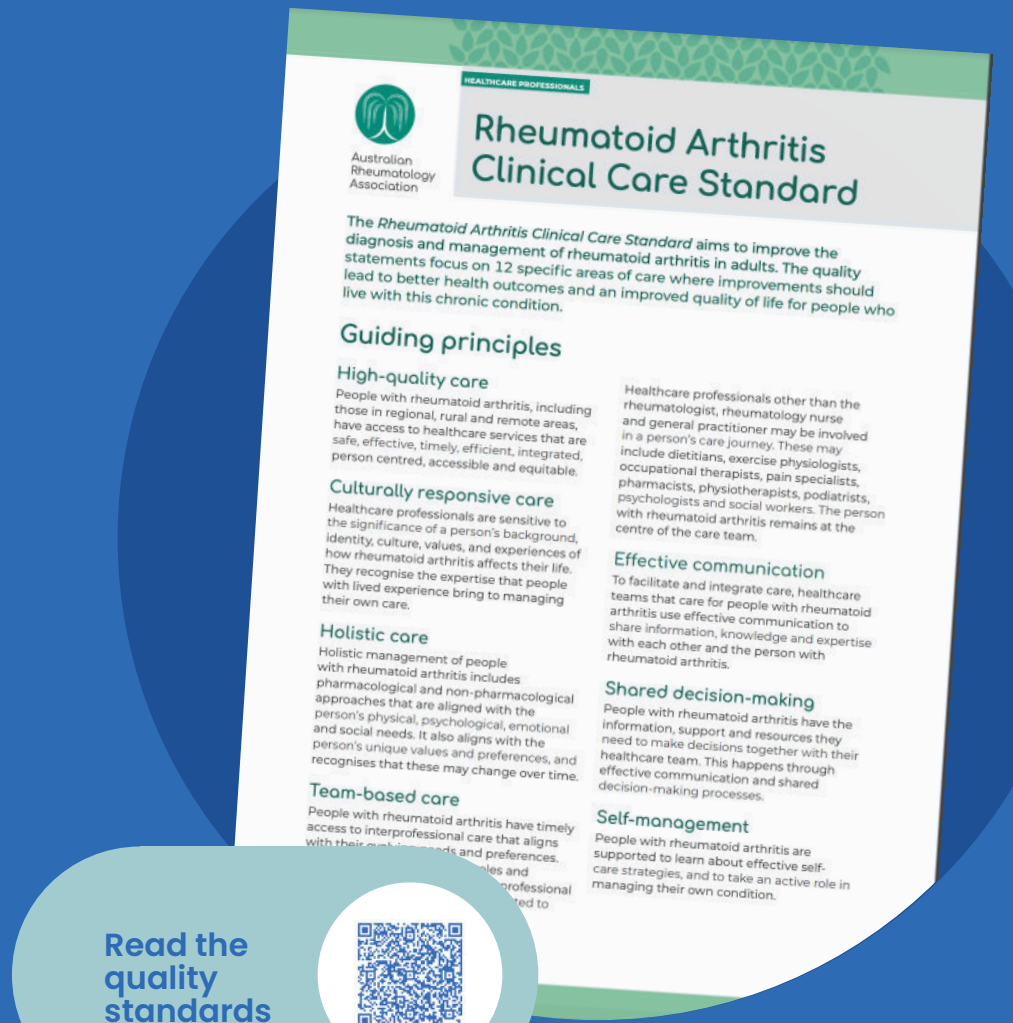
Clinical care standard
RA timeline
Priority populations
Stages of the disease
Life stages

Clinical care standard

The Australian Rheumatology Association (ARA) has developed a Clinical Care Standard to improve the quality of healthcare for people living with RA.

It includes 12 quality statements which describe the standard of care that all adults with RA should expect to be offered, regardless of where they live. It also includes 7 guiding principles, which should always apply to your care.

We'll be referring to the Standard in this section of the care guide (***What to expect***) and in ***What you can do*** at the end of the guide. This will give you the information you need to advocate for high quality care.



Read the quality standards

RA timeline

It is normal to feel out of control when you are first diagnosed with RA and are not sure what to expect. This timeline lists milestones outlined in the RA Clinical Care Standard, as well as key moments in between. It gives you a snapshot of what care should look like in the first few months. The RA journey often begins many months or years beforehand. However, this timeline begins at the moment a person is first referred. These timeframes indicate what rheumatology teams across Australia are aiming for. As yet, many RA journeys do not look like this. Use this timeline when talking to your healthcare team.





Referral

When you present to a doctor with symptoms of RA, they should order tests and identify that RA is a possible diagnosis. They should then immediately refer you to a rheumatology service.

week 4



Rheumatology appointment

If your doctor suspects you have RA, you should be seen by a rheumatology service within 4 weeks of referral. A rheumatologist will be able to assess you and may diagnose you with RA.



Pre-treatment tests

Although DMARDs are very good for treating RA, it is important to do screening tests before treatment is started to ensure they are safe for the person to use. Some of these blood tests and scans will need to be repeated throughout your treatment, to check for side effects and monitor your condition.

week 8



DMARDs

After you get your RA diagnosis , you should start taking DMARDs within 4 weeks. This will allow time for your rheumatology team to teach you about the medicine and order pre-treatment tests.



Specialist advice

You should have a clear pathway to specialist advice and support from your rheumatology team between appointments. You will need someone to contact in case your symptoms worsen or you get side effects from treatment.

1-3 months



Review appointment

You should expect to see your rheumatology team every 1-3 months to keep track of disease activity. This will happen until your treatment goals are met. After treatment goals are met, you will see your rheumatology team for review appointments every 6 to 12 months.

Priority populations

The next section will cover information about what you can expect at different stages of RA. Everyone has the right to be respected and receive personalised care at every stage. However, we know that there are groups with different health needs who may need extra support.

This includes:

- Aboriginal and Torres Strait Islander peoples
- Culturally and Linguistically Diverse (CALD) people
- Lesbian, gay, bisexual, transgender, intersex, queer, asexual and other sexually or gender diverse (LGBTIQA+)
- people living with disability
- those who live in rural or regional areas

If you need extra support, speak to your rheumatology team about your needs and any concerns, and what extra support may be available. Examples may include translation services or support from an Aboriginal Health Worker.

Healthcare services should commit to provide culturally safe care. Healthcare professionals should also develop their cultural competence. They should listen to the cultural needs of each person as part of their care journey and always use culturally appropriate language.

Stages of the disease

RA is a life-long disease, but with the right treatment, symptoms may come and go, or even disappear for a time. This section talks about the main stages of the disease: from early care after diagnosis, to active disease when the focus is on controlling inflammation, to well-controlled disease when you can turn your attention to other things in life.



Early care

Learning about RA and getting the help you need

Active disease

When pain, stiffness and active inflammation are present

Well-controlled disease

When symptoms are mild or absent

Early care

The first few months after diagnosis are full of many new experiences and emotions. These early days are crucial – both for you as you begin to navigate what RA means for you, and for your rheumatology team as they work to control the disease. Following are some of the most important actions for you and your care team to take during this time

What your rheumatology team should do:



Establish your care team

Early in your care, your healthcare team should be set up, with you at its centre. This may include your rheumatologist, general practitioner (GP) and sometimes a rheumatology nurse. Often your GP will be key. They may organise much of your care and see you between specialist appointments to check on your progress. Depending on your needs, your team might include a physiotherapist, an occupational therapist, a podiatrist, an exercise physiologist, psychologist, a pharmacist, a dietitian or a pain specialist.



Develop a management plan

Your care team should work with you to develop a management plan that considers your wishes and what you want from life. It should respect your culture and sense of wellbeing and not just focus on your disease. This plan should explain the expected goals of treatment, and the details of important people in your care team, including who to contact if your condition worsens.



Provide RA education

Your care team should support and educate you about RA, and refer you to reliable consumer information and support services where you can learn more. If English isn't your first language, you may want to ask for an interpreter be present during education sessions. Any education should include information on your medicines, blood tests and vaccinations, and ways you can maintain a healthy lifestyle. You should also be given information on managing your pain and what to do in the event of a flare.

What you can do:



Speak up for your needs

Remember, the most important member of your care team is you. If you feel your needs are not being respected, you have the right to raise this at any time.



Get to know your care team

It is important that you are familiar with the members of your care team, and know who to contact, when and why. If you need extra support, you can ask for other allied health or support workers to be added to your team. For example, First Nations people may wish to ask for an Aboriginal Health Worker to be included.



Keep moving

Some people think that an RA diagnosis means you have to stop everything you used to do, but it's important for your health to stay physically active. If you need support to remain active, a physiotherapist or exercise physiologist can help.



Involve your support people

If speaking up for yourself doesn't come naturally to you, or you feel overwhelmed at appointments, you could think about taking a support person, such as a family member or friend, along with you. Even if they don't speak, having someone there for moral support can help. A support person can also help by taking notes during appointments, so you don't forget anything.



Seek out RA education

Try to take time to learn about your condition and its management, so you can make informed, shared decisions with your team. If you haven't had a RA education session with a member of your rheumatology team within 2 weeks of diagnosis, ask your team to schedule a session. If you have not been given educational resources see page 38 of this guide for our top picks. Some people like to keep a folder of these resources along with a diary of important milestones.

Active disease

When you first present to your doctor, your RA will be in its active state, where symptoms such as swollen and tender joints and other signs of active inflammation are present. Without treatment, permanent joint damage can occur.

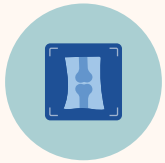
Starting DMARDs early increases your chance of remission and can delay progression of your disease.

What your rheumatology team should do:



Control inflammation

Your care team will aim to control inflammation as quickly as possible. People with active RA should start taking DMARDs within 4 weeks of diagnosis. It can take several weeks for some DMARDs to start working, so your care team may also prescribe some corticosteroid tablets or injections to quickly relieve your symptoms.



Pre-treatment screening tests

Before starting your treatment, your care team will refer you for some pre-treatment blood tests to make sure your DMARD medicine is safe for you to use. Blood tests and scans will need to be repeated throughout your treatment to check for side effects.



Track your progress

While you have active RA, your care team should check on your disease activity every 1-3 months and adjust your medicines in response to this. They do this by examining your joints, asking you questions about your pain and mobility, and through blood tests that check for markers of inflammation in the body.



Manage your medicines

With the right DMARDs or combination of DMARDs, most people with RA will be able to reach a state where their disease is well controlled, with few or no symptoms or signs of inflammation. However, it can take time to find the right combination for you. Your care team should explain the risks and benefits of any treatment in ways that you can easily understand.



Consider your emotional and physical wellbeing

While getting your RA under control will be their priority, your care team should never lose sight of you as a person. They should regularly ask about pain and fatigue as well as your emotions and moods.

What you can do:



Take care of yourself

It's important to look after yourself until your condition is under better control. Talk to your care team if the pain and stiffness are getting you down. Your doctor can refer you to other members of your care team, such as a physiotherapist or psychologist for support.



Conserve your energy

If fatigue is a problem, conserve your energy by prioritising the things that are important to you, letting go of the less important things. Entrust tasks to other people, put off the less important ones, or stop doing them altogether if they're not essential.



Keep a diary

This is a good time to start a health diary, to keep track of your pain and symptoms and possible side effects to your medicines. This can help to guide discussions with your care team.



Play your part

You can play an active part in your care. Try to keep all appointments, have your regular blood tests, and take your medicines as prescribed.



Speak up if you're worried

Don't hesitate to contact your care team if your symptoms worsen a lot or you get side effects from your treatment at any time.

Well-controlled disease

Well-controlled RA means that you have no symptoms or only occasional mild symptoms, your RA doesn't affect your day-to-day life, and your joints are not being damaged by inflammation. This can also be called 'being in remission' or 'low disease activity'.

Once your RA is well controlled, your care team should continue monitoring your condition for disease activity and potential side effects from your medicines

What your rheumatology team should do:



Offer regular reviews

Once your RA is well controlled, your care team should continue monitoring your condition for disease activity and side effects from your medicines. In well-controlled RA, review appointments can be reduced to once or twice a year.

Even with well-controlled RA some people will still have pain. Your care team should ask you about your pain, and your emotional wellbeing, and refer you to other professionals if they have concerns.



Consider dose reduction

If your RA has been well controlled for at least 6 months, it may be possible to slowly reduce the dose of your medicines. This is a decision for you and your care team. Some people will be keen to reduce the dose of their medicines, while others will not wish to risk it. Ultimately the final say should rest with you.



Give you a flare plan

Flare ups can still occur, even when your condition is well controlled. Your team should talk to you about having a plan for flare ups, including who you can contact in the event of a flare.



Vaccination advice

People with RA are at increased risk of infection, so it's important all your vaccinations are kept up to date. Your care team should remind you, but talk to them if you're unsure.



Risk assessment

Your care team should continue to monitor for co-occurring conditions, particularly your risk of heart disease and osteoporosis, throughout your treatment journey.

What you can do:



Take your medicines as prescribed

Most people with RA will need to continue taking DMARDs throughout their life. You should never stop or reduce the dose of medicines you are taking without talking to your doctor first.



Consider lifestyle

With your condition well controlled, you should be feeling better. If you haven't already done so, this can be a time to really focus on your lifestyle through healthy eating, stopping smoking, and making sure you get good quality sleep. We discuss this more in the Living with RA section at the end of this guide.



Keep moving

While it can be hard to get started, keeping physically active is one of the best things you can do for your RA. Low intensity activities can reduce your pain and stress levels and improve your sleep, mood and overall health. We talk more about this in the Living with RA section in this guide.



Keep communication lines open

Always tell your care team about any other treatments you are using, including any vitamin supplements, herbal medicines and other therapies. Your care team can't give you the best advice without knowing all the treatments you are using.

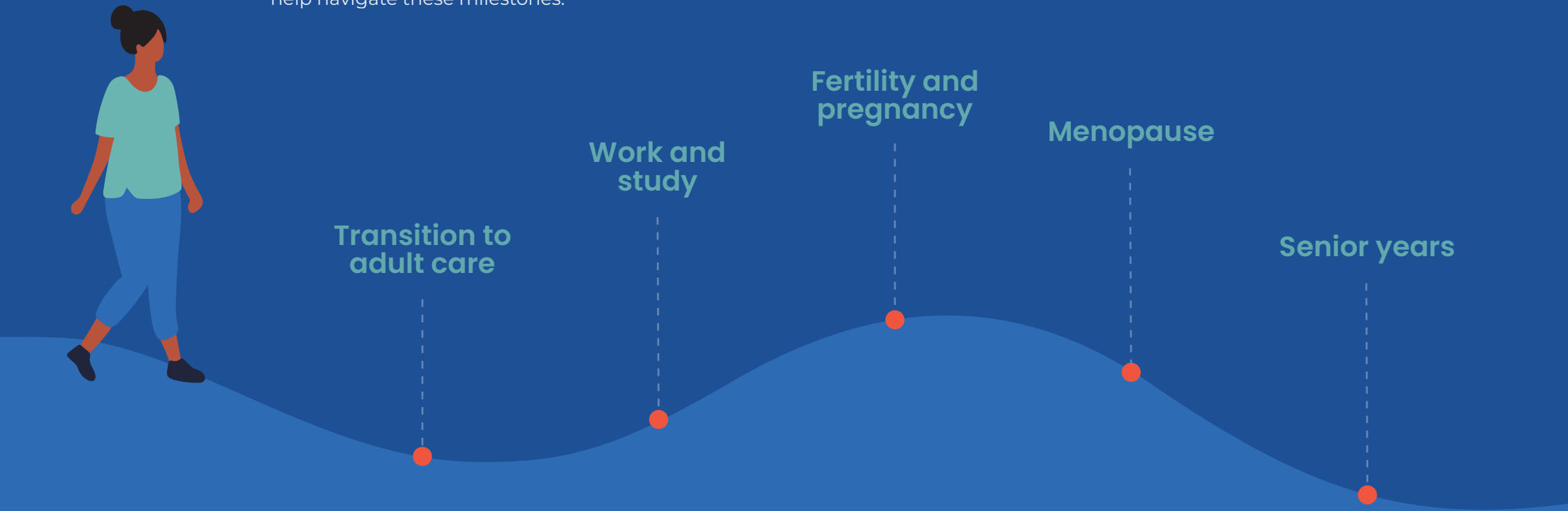


Continue to speak up

Remember that you are the most important person in your RA management team. If you haven't been offered a plan for flare ups, or you feel your needs are not being met in any way, you are within your rights to speak up.

Life stages

RA is a lifelong condition but with the right treatment and advice it doesn't have to get in the way of working, travelling, relationships, pregnancy or parenting. The following section outlines some of the key stages in life and suggests practical actions that you can take to help navigate these milestones.



Transition to adult care



Acknowledging juvenile arthritis

People with arthritis in childhood should have ongoing care in adulthood. Juvenile arthritis comes with unique challenges. If these are not well understood by adult care rheumatologists, it can make the move to adult care hard. Your paediatric rheumatology team may be able to help with advice and support at this time. If you have recently transitioned to adult care and feel you don't have the right support, talk to your GP or member of your care team to find a rheumatologist who can better meet your care needs.

Communicating your needs

At first you may find it hard to talk with an adult care rheumatologist who you are not used to. It is important to raise any concerns you have with your new rheumatologist, even if they don't ask. This could include any concerns you have with your medical, psychological, or social wellbeing.

Establishing support networks

Transitioning to adult care can be hard on the emotions. Getting to know a new health care team while balancing your independence can be difficult. At this stage, it is healthy for parents to step back and let you take more control. Having support groups during this time can help and you may find it helpful to connect with other people with similar experiences. Talk to a member of your care team or call the Arthritis Infoline on 1800 011 041 about patient support groups that you can connect with.

Maintaining disease stability

It may feel like you are starting all over again when you move to an adult care rheumatologist who doesn't know your specific needs. They may ask a lot of questions about your medical history and treatment. It important they understand your treatment plan to avoid any changes that could cause your arthritis to flare. Speak with your GP or another member of your care team about the information you need to help at this time.

Work and study

Telling your employer

At first, RA may cause pain and some degree of disability, which can affect your ability to work. You will need to think about the effect this may have on your job and what you are comfortable telling your employer. However, if your RA has no effect on your ability to do your job you are not required to mention it.

Challenges in the workplace

Depending on which of your joints are affected, you may face challenges with typing, sitting, standing for long periods, lifting, bending and crouching. However, more than half of the people who develop RA are able to work for many years after their diagnosis.

Sick leave

You may need to take time off for medical appointments or treatment. There may also be times you are unable to work due to a flare. Your GP or rheumatologist should be able to provide a letter to your employer if you need to take sick leave. However, they are not required to reveal what your health condition is.

Reasonable adjustments

If time off work and pain start affecting your job, telling your employer you have RA may allow them to be more understanding. They may be able to offer you reasonable adjustments where possible. Examples include extra rest breaks, flexible work hours and working from home. Assistive technology such as an ergonomic keyboard, voice recognition software, and an adjustable standing desk can also help.

Study

If you're enrolled in further study (e.g. university or TAFE), most institutions have dedicated support for students living with disabilities. You may also be able to contact your faculty coordinator to discuss concessions around exams, assignments and attendance.



Fertility and pregnancy

Pregnancy planning

Whether you are male or female, when you're ready to start a family, you should talk to your rheumatologist at least six months before you start trying to conceive. Many arthritis medicines can be safely used before and during pregnancy but others should not be taken while trying to conceive, when pregnant or during breastfeeding. Your rheumatologist can advise which medicines are safe to use. Your chances of success are greatest when your arthritis is well-controlled, so never stop taking any of your medicines without your doctor's advice.

Planning your birth

Towards the end of your pregnancy, you should talk to your rheumatologist, obstetrician, or midwife about how arthritis may impact your baby's delivery. For example, you may find some positions are more comfortable for labour and delivery. You may also want to talk about whether you will be able to give birth vaginally and the likelihood of needing a caesarean.

Unplanned pregnancy

Some arthritis medicines may be harmful to an unborn baby, so you'll need effective contraception until you're ready for parenthood. If you or your partner fall pregnant unexpectedly, call your rheumatology care team straight away. Some medicines can harm an unborn baby and are not safe to take during pregnancy. Your rheumatologist can change you to a medicine that can be safely used during pregnancy.

During pregnancy

During pregnancy, your immune system goes through changes to allow your baby to grow and develop. Some women may find these changes can reduce their RA symptoms, while other women may find their symptoms increase. Speak to your rheumatologist if you experience worsening symptoms, such as extra pain and pressure on your lower joints, low back pain that makes it hard to to walk, swelling of your feet and hands, or fatigue.

This can be an emotional time, so enlist your partner and family for support.

After the birth and breastfeeding

This can be an overwhelming time, so don't be afraid to ask for support if you need it. It's a good idea to have an appointment booked with your rheumatology team for 4-6 weeks after the birth.

Some women can experience a flare in their symptoms at this time. If you notice your symptoms worsening, get in touch with your care team straight away for advice. Many arthritis medicines are safe to take during breastfeeding as they do not pass into breast milk, or only in very low levels. Others can pass into your breast milk and will not be safe for your baby. Talk to your care team about your plans for breastfeeding, so the best choices can be made for you and your baby.

Menopause

RA symptoms

The effects of menopause on RA are unpredictable. Some women may notice an increase in symptoms at menopause while others may have some relief. For some women, treatment with hormone replacement therapy (HRT) may ease menopausal symptoms as well as help prevent osteoporosis. However, HRT is not suitable for everyone. Topical oestrogen creams can relieve vaginal dryness, which can occur with both menopause and RA.

Heart health

RA may increase the risk of developing conditions of the heart and blood vessels. For women, this risk increases after menopause due to a change in hormone levels. Talk to your healthcare team about ways to protect your heart. Regular checks of your blood pressure and cholesterol are recommended.

Bone health

The risk of osteoporosis rises after menopause. You will need to take extra care of your bones after this time, through healthy sun exposure or vitamin D supplements, regular weight-bearing exercise and making sure you have enough calcium in your diet. If you have not yet had a bone density scan, your care team may recommend one now. People with RA are eligible for a Medicare rebate for these scans, regardless of age.

Lifestyle factors

Many of the lifestyle measures we recommend for RA, such as not smoking, healthy eating and regular exercise, should help relieve menopause symptoms and look after your bone and heart health too. Stick closely to your RA treatment plan and work with your rheumatologist or GP to help manage menopause symptoms and improve your general health and wellbeing. You should also keep up to date with your health checks. It's recommended women over 50 have a breast screen (mammogram) every 2 years.





Senior years

Late-onset RA

RA can develop spontaneously in the senior years, with about 1 in 10 people first diagnosed with RA over the age of sixty-five. But most older people with RA will have been living with the condition for many years. RA that occurs later in life can be different to RA that begins earlier. In late-onset RA, symptoms can come on more quickly and may affect larger joints, like the shoulders. Late-onset RA can affect both men and women equally, while in younger people, women are more likely to have RA.

Managing medicines

Managing medicines can become harder in the senior years. Many people will also need to take medicines for other health conditions, such as heart and lung disease, and side effects can be more common as we age. Let your care team know about any new medicines you are taking. If you are worried, your care team can organise a medication review with a pharmacist.

Preventing falls

With increasing age comes the risk of falls and fractures (broken bones), so it's important to still look after your bone health. Your doctor may recommend you take an osteoporosis medicine at this stage to help prevent future bone loss. One fall and fracture may leave you unable to walk for weeks and risks you losing muscle strength, increasing your chance of another fall. While the pain of RA can discourage us from exercising, keeping active is our best safeguard against future falls.

Managing at home

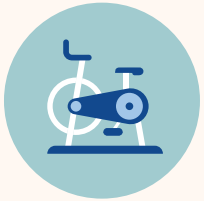
As you get older, you may find everyday tasks around the home become harder to do. Tasks can be made even harder when you have stiff, painful, or swollen joints. You may find that changing things around your home can make daily tasks easier and help keep you living independently. For example, putting handrails in your bathroom or near stairs can give you extra support. An OT can look at your home and recommend special equipment to make daily tasks easier and protect your joints.

Living with RA

This section offers tips for day-to-day life with RA, including: movement, healthy eating, how to manage pain, travelling, keeping a check on your mental health and how to access financial support if you need it.

Healthy movement
Healthy eating
Lifestyle choices
Mental health
Pain
Travel
Financial support
Surgery

Healthy movement



How staying active can help

Keeping active is one of the best things you can do for your RA. It helps to reduce your pain, strengthens your bones and muscles, supports joint function and improves your sleep and general health, including your heart health.

Good activities for RA

Activities that are likely to be good for your fitness include walking, swimming, water exercise, aerobics, and riding an exercise bike. Strength training with weights or resistance bands has also been shown to help. Yoga and Tai Chi are also recommended.

Getting started

It can be hard to begin on your own, so talk to your care team. They can refer you to an exercise professional (physiotherapist or exercise physiologist) who can help get you started. You may be able to get 5 visits with an exercise professional (EP) under Medicare. Your GP can arrange this.

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

Try not to let pain hold you back

Many people are fearful that exercising might make their pain and stiffness worse. The key is always to start slowly. Begin with very light activity, such as walking or water exercises. Then slowly, you can increase how hard you work and for how long. Don't try to rush or overdo it. If pain is still holding you back, an EP can help you work through some of your fears and worries and create a program that's suited to you.

Healthy eating



There are no miracle diets

No diet has been proven by research to cure arthritis, so be cautious of special diets or supplements that claim they do. The best diet for RA is a healthy, balanced one to support your general health and prevent other medical problems. There is also no research that certain foods, such as acidic foods or dairy products are 'bad' for people with RA.

Try to eat 'Mediterranean'

Experts recommend a Mediterranean diet for its anti-inflammatory benefits in RA as well as its role in preventing heart disease and diabetes. This diet includes lots of fruit, vegetables, whole grains, seeds and nuts along with low-fat dairy and fish. It uses olive oil as the main source of fat and limits highly processed foods, sugary foods and drinks, and red and processed meats, like ham. If you don't like fish, fish oil supplements, when taken at the right dose, can help. Your care team can advise.

The benefits of staying a healthy weight

If you can, try to stay a healthy weight, as people living with RA and obesity appear to have higher disease activity and respond less well to treatment. Being overweight also raises your risk of other health conditions, such as diabetes. Losing weight is never easy, so ask your care team for help. Even a small amount of weight loss has health benefits.

Where to get help

For help with weight loss or simply working out the best things to eat, you can ask your GP or care team to refer you to a dietitian. You can also find one via Dietitians Australia at www.dietitiansaustralia.org.au. The Australian Government provides advice about the amount and kinds of foods that we need to eat for good health at www.eatforhealth.gov.au

Lifestyle choices



Avoid smoking

The harmful effects of smoking, such as heart disease and cancer, are well known, but smoking can also increase your risk of developing RA. For people with RA who continue to smoke, it can worsen symptoms and reduce the effectiveness of some medicines.

If you smoke, you can ask your care team for help with quitting. Or you can call the Quitline on 13 7848 or visit www.quitnow.gov.au

Vaping

We know less about the health effects of vaping but early research suggests e-cigarette use may also increase the risk of inflammatory types of arthritis, such as RA. For help to quit vaping, talk to a member of your care team or call the Quitline on 13 7848.

Drink in moderation

If you drink alcohol, try to keep this in moderation. Some arthritis medicines don't mix well with alcohol. This includes NSAIDs, paracetamol and methotrexate. Heavy alcohol use can have a negative effect on bone health, increasing the risk of osteoporosis.

Get a good night's sleep

A good night's sleep can help with pain and fatigue. Introducing good sleep habits can help. Examples include: reducing screen time (computers, TV and smartphones) directly before bed, avoiding caffeine late in the day and waking up and going to bed at the same time each day. For more serious sleep problems, talk to your care team who may be able to refer you to specialist support.

Mental health



You are not alone

Many people struggle with the mental health aspects of living with RA. Sometimes it can get you down, especially if pain and stiffness are stopping you doing many of the things you used to do. It may sometimes feel as though people around you don't really understand what you're going through.

Don't ignore your feelings

While many of these feelings are natural, with time they can overwhelm us if we don't address them. It's worth talking to your family and friends about how you're feeling and how they can help. Your care team should be aware of the challenges of living with RA and check on your emotional and mental wellbeing at least once a year. But don't be afraid to speak up at any time, especially if your feelings are intense and you can't seem to shake them.

Talk to your GP

Your GP may be able to suggest ways of reducing stress in your life or may prescribe medicines if you are very worried or depressed. They may also refer you to a psychologist or counsellor. These professionals will have more time to ask you about your worries, troubling feelings and moods and be able to suggest practical ways to work through them. There are Medicare rebates for some mental health services, which your GP can advise on.

Other support options

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

Pain



Pain relievers are not always the answer

Pain relievers are useful for short-term pain, such as early in treatment or during a flare. Unfortunately they can become less effective or cause side effects if taken for chronic (long-term) pain. Long-term use of strong opioid pain relievers may lead to dependence and sometimes even worsen the pain. There are other medicines that may help with some types of chronic pain, such as nerve pain, but no tablet is likely to be the complete answer to your pain.

Team-based support

Many health professionals can work with you to manage chronic pain. Physiotherapists can give you advice on exercise, hot and cold packs, and stretches. An occupational therapist (OT) can help you adapt everyday tasks, plan your activities to save energy, recommend home equipment such as lever taps or jar openers and help you learn practical ways to manage the thoughts and emotions that can come with long-term pain.

Enlist your mind power

Learning some simple mind techniques, such as relaxation and distraction, can help you to cope with your pain better. A trained professional, such as a psychologist, will be able to help and guide you. Some GPs, nurses, occupational therapists and physiotherapists can teach you these techniques too. There are also websites and apps you can use.

Medicinal cannabis

Many people are interested in trying medicinal cannabis for their pain, but more research is needed before doctors can widely recommend its use. The ARA has a useful factsheet on medicinal cannabis at www.rheumatology.org.au.

Travel



Plan ahead

There is no reason why a person with RA cannot travel or study abroad. However, it is important to plan ahead, confirming the travel dates with your rheumatology team beforehand to make sure the timing will not impact treatment.

Manage your medicines

You will need to make sure you have all the medicines you need for your trip prior to leaving. Laws and customs vary, so carry a letter that explains what the medicine is and why you need to take it.

Check the storage conditions and expiry dates on your medicines. If you are carrying biologics, many injections can only be stored out of the fridge for short periods. The TGA www.tga.gov.au has more information on travelling with medicines.

Get vaccinated

To help avoid illness, make sure you're up to date with both your annual vaccinations and any travel vaccinations you need for the countries you are visiting. However, check if there are some 'live' vaccines, such as yellow fever, that you should avoid.

Remember travel insurance

It's a good idea to take out travel insurance and declare RA as a pre-existing condition. While none of us hope to fall sick while we're travelling, it does happen and you don't want to find yourself in hospital without any coverage. For more information go to www.smartraveller.gov.au.

Financial support



Get advice

There is help available for people with RA. Your care team may be able to refer you to a social worker, who can help explain the financial and health services that are available to you.

Pensions and other benefits

Services Australia will be able to decide whether you are eligible for the Disability Support Pension, as well as other concessions such as a Health Care Card, which allows you access to cheaper PBS medicines and other benefits.

The Mobility Allowance can help with travel costs for work and study if you have a disability or illness that means you can't use public transport. Visit www.servicesaustralia.gov.au.

Support for carers

Services Australia also administers the Carer Payment and Carer Allowance, which provide financial support to carers. Different rules apply for these payments. More information is available on the Services Australia website.

NDIS

RA is covered under the National Disability Insurance Scheme (NDIS) and some people may qualify for funding under the scheme. You must be aged 65 years or under and your eligibility and level of funding will depend on the effect of your disability on your life. A member of your care team can complete a form in support of your application. For more information about eligibility and how to apply to join the scheme visit www.ndis.gov.au.

State services

The state or territory governments may offer their own payments and benefits. You can learn more about these by visiting the state or territory government website for the region you live in.

Surgery



Assessing the need for surgery

Improvements in the treatment of RA mean people are less likely to need surgery for their arthritis. However, if your joints have suffered major damage, your rheumatologist may refer you to an orthopaedic surgeon to assess your need for surgery. The main aims of surgery are to relieve pain and improve a joint's movement or alignment (e.g. straighten a finger).

Types of joint surgery

Operations for RA include arthroscopy. This is a 'keyhole' surgery, where the surgeon uses a camera to examine a joint. In a synovectomy the lining of the joint is removed to help relieve pain and swelling. Total joint replacement (arthroplasty) is for badly damaged joints. Frequent targets include knee or hip joints, but other joints can be replaced.

Medicines and surgery

Whatever type of surgery you are having, changes to your medicines may be needed. Some DMARDs can cause immunosuppression which may increase your risk of infection after surgery. While many DMARDs can be safely continued others may need to be stopped before your operation. The timing of this needs to be carefully managed, however, as stopping them too early may increase the risk of a flare. Your care team can advise.

Non-surgical alternatives

There are many alternatives to surgery that can help manage damaged joints. Your care team may recommend you try these before surgery. These include managing your weight to reduce the stress on joints, exercise to improve strength and flexibility, and steroid injections.

What you can do

This section covers all of the next steps you can take after reading this guide. It includes questions to help you decide if you are receiving high quality care, ways that you can advocate for improved care, support communities that can connect you to other people with RA, and extra resources to support you as you continue to learn more.

Am I getting quality care?
Advocating for your care
Support communities
Extra resources

Am I getting quality care?

The Clinical Care Standard for RA includes statements and principles that describe high quality RA care. Everyone with RA in Australia should have access to healthcare services that work well, are safe, available when they need them, affordable and fair. We know that this is not yet the reality in Australia, but developing the Clinical Care Standard is a first step towards that happening.

Here are some questions you can ask about the care you're receiving to decide if it meets the Australian standard.

If you answer "no" to one or more of these questions, see page 36 for ways that you can speak up for better care.



Questions to ask about your care

Was I able to see a rheumatologist for diagnosis within 4 weeks of being referred?

Was I offered pretreatment tests (e.g. blood tests) and do I still receive ongoing testing to ensure the safe use of my DMARDs?

Was I able to start treatment with DMARDs within 4 weeks of diagnosis?

Is my disease activity monitored regularly by my care team – every 1 to 3 months, or once every 6 to 12 months if my disease is well-controlled?

Do I have a means of contacting someone from my care team for advice if my symptoms worsen between appointments, or I develop side effects?

Are my vaccination records checked every year and am I given advice on any vaccines I need to get to remain protected?

Does my care team ask me questions about my emotional and mental wellbeing at least once a year? Have I been offered a referral to support services if needed?

Does my care team regularly ask me about my pain and how this impacts on my health and social aspects of my life? Have I been offered a range of pain management options?

Have I been given help to access services to help me become more physically active, in a way that suits me and my condition?

Has my care team helped me to access information, educational resources, and support services for RA?

Was my risk of heart disease assessed at the time of my diagnosis? Has my heart disease risk been assessed every 2 to 5 years since then?

Was my risk of a fracture assessed at the time of my diagnosis? Has it been assessed since then?

Advocating for your care

Advocating means speaking up for something or someone.

When you advocate for your care, you are asking for your rights and opinions to be respected by your care team.

We know that this is not always easy but the RA Clinical Care Standard makes it clear what your rights are.



What do I do if my care is not meeting the Quality Standards?

Even when health professionals are trying their hardest to deliver good care, there may be times where the care described in the Clinical Care Standard is not fully met. If you have questions or concerns about your care, here are some things you can do:

In the first instance, it is best to raise any questions or worries with a member of your healthcare team

If you see a private rheumatologist, talk first to your GP. They can advocate on your behalf, or refer you to another rheumatologist for a second opinion.

If your concerns haven't been resolved, there are other paths you can take. If your care is through a public clinic, the hospital should have a process in place. You can usually find this on their website.

How can I advocate for my care?

People with RA, their support people, health professionals and advocacy groups all want to see better care for people with RA. There are ways that you can get involved in advocacy, including:

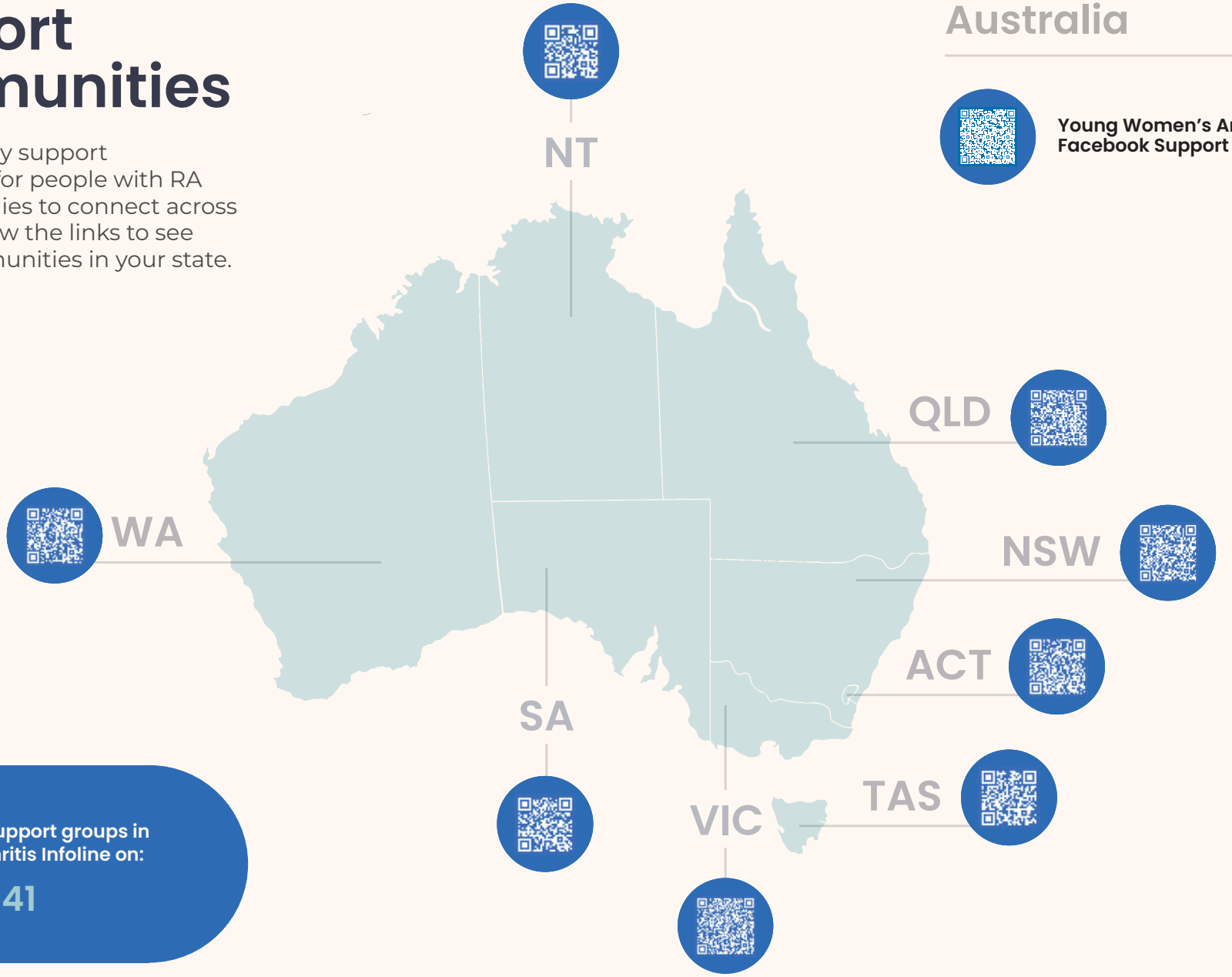
Get involved with consumer advocacy groups such as Arthritis Australia

Write to your local MP, advocating for better RA services in your area

Use this guide as a conversation starter, working with your rheumatology team to align your care with your needs

Support communities

There are many support communities for people with RA and their families to connect across Australia. Follow the links to see support communities in your state.



Australia

Young Women's Arthritis Facebook Support Group

To learn more about support groups in your area, call the Arthritis Infoline on:

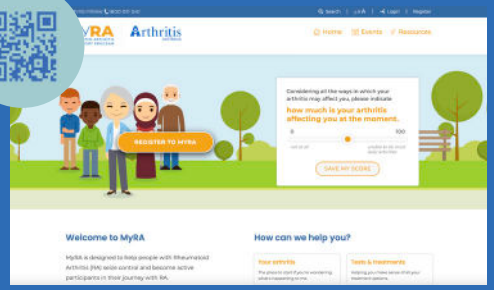
1800 011 041

Extra resources

We've compiled some of our favourite resources on a range of RA topics.

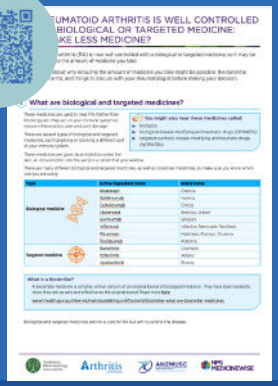
Visit the Arthritis Australia website for other RA resources.

Living with RA



MyRA

Well controlled RA



Can I take less medicine?

Flares



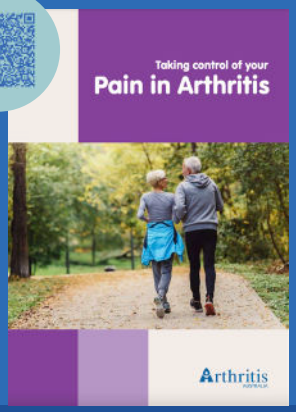
Managing your arthritis flare

Surgery



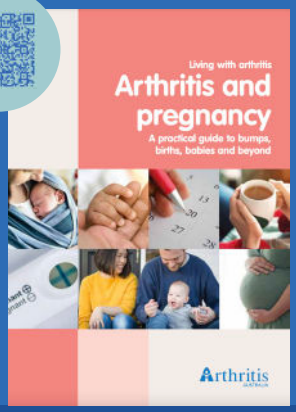
Joint replacement

Pain management



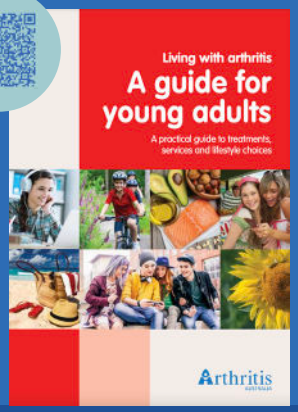
Taking control of your pain in arthritis

Pregnancy



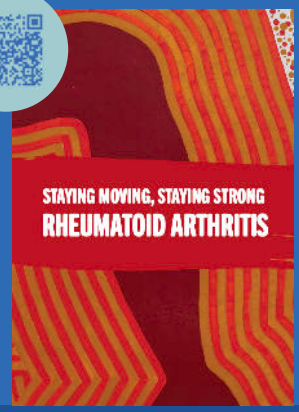
Arthritis and pregnancy

Young adults



A guide for young adults

Movement



Staying Moving Staying Strong

We would like to thank all of the people who made this guide possible.

Thank you to all of the people with RA who generously shared their time to co-design this guide.

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Arthritis AUSTRALIA