





## How can this booklet help?

Finding out you have arthritis when you are young can be confusing and frightening. You may have thought that only older people were affected by arthritis. Possibly, the only people you have known with arthritis are your grandparents and their friends, but arthritis can affect people of any age, even children and teenagers.

It can be difficult to find information about how arthritis affects your life when you are a young adult. That is why Arthritis Australia has produced this booklet. It has been specifically designed to contain input from young people with arthritis who have overcome many of the same challenges you may be facing today. This booklet:

- has been written for young adults living with arthritis
- includes information about how arthritis impacts on daily living and what you can do to overcome some of the challenges you might face (for example, relationships, work, study and pregnancy)
- does not include information about medical treatments, other therapies, or the various types of arthritis.

The information in this booklet has been reviewed by a panel of young people with arthritis and medical experts to make sure it is current and relevant to your needs.

### So go ahead...step out and live your life!

The information in this booklet has been obtained from various sources and has been reviewed by Arthritis Australia. It is intended as an educational aid and should not be used in place of medical advice. It can be reproduced in its entirety but cannot be altered without permission from Arthritis Australia.

The National Health and Medical Research Council (NHMRC) publication *How to present the evidence for consumers: preparation of consumer publications (2000)* was used as a guide in developing this booklet.

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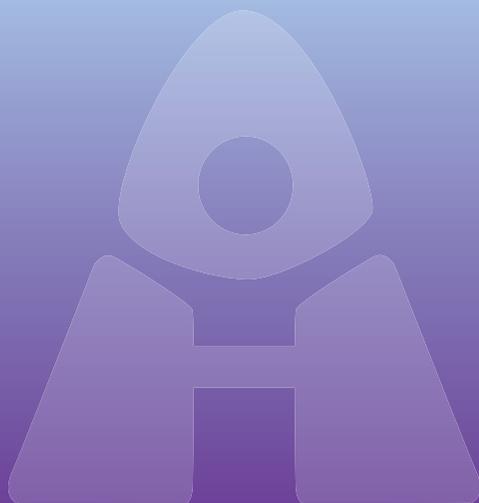
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## Contents

How can this booklet help?	1
Staying in touch	3
Hitting the books	5
Making it work	7
Bumps, births, babies and beyond	11
On the road	15
Navigating the web	19
Want to know more?	25



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## Staying in touch

*'Being a young adult who has had arthritis for more than half my life, it is easy to list the negative effects of the disease, and the problems of attempting to have a social life with a partner and friends. For one thing, I cannot attend all the social events I want to, nor can I stay as long as I would like. Also, my arthritis causes me to be grumpy at times, maybe due to pain or frustration, and this then affects the people around me. Other times I am sad and feel down, and my friends and family say that they "just don't know what to do". Sometimes my friends and family express frustration with me or, in particular, my arthritis. I worry about being a burden and asking for too much; other times I worry about how I can return their kindness.*

*However, arthritis has taught me how to acknowledge my feelings (both positive and negative) and be able to open up to my friends and family. I am better at understanding other people and arthritis has increased my sense of empathy. I am fantastic at saying "Thank-you", which never fails to put a smile on their faces. Finally, through the young adults' social support group, I have made some lifelong, understanding and marvellous friends.'*

**S, age 29, rheumatoid arthritis**

Having friends, an active social life and fulfilling intimate relationships is an important part of life. However, starting and maintaining these connections can be challenging, especially as a young adult with a chronic illness such as arthritis. If you live with pain, fatigue, depression and anxiety about the future, it can make it difficult to want to socialise and have the confidence and energy to start and sustain intimate relationships – but it is possible. And, in fact, research has shown that having secure, good-quality relationships can help you cope with the negative aspects of having arthritis.

### FRIENDS, FAMILIES AND PARTNERS

You might be the only person that you, or your friends, family or partner, know with arthritis. You may feel embarrassed to talk about your condition as you are worried people will not understand. This is a normal reaction, but do try to talk openly and honestly – others will have a better understanding of when you want to be left alone, and when you need them around. If you don't tell people what arthritis means for you – how it makes you feel and how they can help you cope – it is difficult for them to second-guess.

If you are finding it hard to leave the house, pick up the phone and call a friend, or suggest a movie night at your place. It is important to stay in touch with loved ones and, more than likely, you'll feel better after a chat. And, by sharing your feelings with your family, partner and friends, you may be pleasantly surprised by the support and understanding they give you in return.



## Get creative

Are there some activities that you and your friends, family or children enjoy that are now difficult for you to do? Be sure to explain to them why you can't always join in and try, where possible, to plan other activities and outings that you can cope with more easily. For example, if your friends are planning a full day of shopping and you know you will find this difficult, arrange to meet them halfway through the day for a coffee. Or if you really want to see a band but your feet or hips are too sore to stand all night, find a seat. You may not see as much, but at least you will be there.

Be positive and enjoy activities with friends in ways that are gentle to your body. With some planning (and sometimes a little help) you are likely to be able to do whatever you want.

## Someone like you

Do you sometimes feel you are the only young person struggling to cope with arthritis? If the answer is 'yes', consider making contact with other young adults with arthritis. Talking to others about how they cope will not only help you come up with practical solutions to many of the

challenges you face, it will remind you that you are not alone. Other people with the same or similar problems may understand better what you are dealing with than your family, friends, doctor or medical team.

Call your **State/Territory Arthritis Office** on **1800 011 041** to find out about their young adult support services.

## Seek help

If you are experiencing feelings such as loneliness, isolation, depression and anxiety, it might be useful to talk to a psychologist. These types of feelings are normal aspects of the challenges of having arthritis, but you can learn practical skills to help you cope with the feelings and stay connected to the important people and things in your life. A psychologist can assist you with effective communication and how to help you manage anxiety and depression, and also teach pain management techniques.

You may be able to see a psychologist through Medicare if you get a referral from your GP. Or 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)**

## INTIMATE RELATIONSHIPS

Sometimes the physical and emotional symptoms associated with arthritis can have a negative effect on sexual expression and enjoyment. However, there are many ways to overcome these challenges. For more information see Arthritis Australia's *Sex and Arthritis* information sheet. Remember, emotional intimacy is equally important for a romantic relationship – trust, honesty and openness help to build a secure intimate relationship.



## Hitting the books

*"I was petrified about coming back to university with a walking stick, and paranoid that people would be asking stupid questions and staring at me. But no-one has said anything and my lecturers have been above and beyond helpful. I've found going part-time has helped me not get so tired and I use peer note-takers to help me keep up during lectures. If it's something you want to do, don't let arthritis hold you back. Know your limits and use the resources that are available as they're there to help you."*

**J, age 26, rheumatoid arthritis**

After you finish school, or if you are thinking about a career change, you might consider some further study or training. Trying to fit in studies while managing your arthritis and the rest of your life may be a daunting prospect, but with the right support and strategies you can successfully 'hit the books'.



## YOUR RIGHTS

Universities, TAFE and other educational organisations are not allowed to discriminate against students with a disability. In fact, there are national standards that require these organisations to take steps to help students with a disability to study and use facilities on the same basis as a student without a disability. This may include making 'reasonable adjustments' to teaching or assessment practices. This means that organisations take into account your disability and make appropriate changes to help you overcome barriers to studying successfully. For example, your arthritis may make it difficult to write for long periods, so a 'reasonable adjustment' could be to provide you with an extended period of time to finish an exam, to allow regular rest periods while you write.

## SOME THINGS TO CONSIDER

Depending on what you choose to study, there may be some options that make it easier for you to manage:

- **Workload** – If you find fatigue or tiredness a problem, you could consider studying part-time. Although it will take you longer to finish your course, it may be a wiser option than taking on too much and not making it to the finish line.
- **Mode of study** – Many universities and educational organisations offer options to study externally. This usually involves accessing lecture notes and study material online, without attending a campus. This mode of studying is not

available or suitable for all types of courses, but it may be a good option if you find it easier to study from home.

- **On-campus accommodation** – If you are facing long days of classes plus a lengthy commute, you may want to consider the option of living on campus. Most larger campuses have some form of accommodation available onsite which may make things easier for you.

## ASK FOR HELP

When you enrol, your first step should be to contact the disability (liaison) unit at your university or TAFE – all Australian universities and TAFE have staff responsible for disability services, although they may have different titles. Perhaps you do not think of yourself as 'disabled', so it may not have crossed your mind to seek out help from this type of service. However, these services aim to ensure that people with any chronic medical condition, like arthritis, are able to actively participate in all aspects of university or TAFE life.

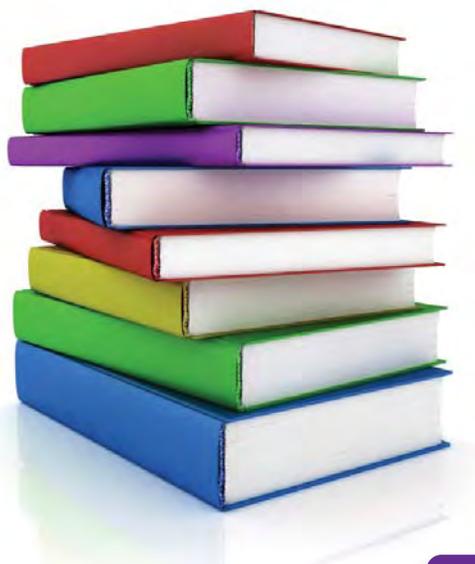
### How can they help?

You should talk to a disability officer at the university or TAFE you are attending about the services you are likely to need. If possible, contact the officer before you begin your course; preferably even in the year before you start. This will give you and your disability officer plenty of time to make any necessary arrangements. If you have concerns about managing study, you can discuss them with the officer – he or she may be able to tell you about the experiences of other students with your condition, and how they resolved difficulties. The disability

officer will also be able to refer you to academic staff who can advise you about your particular course.

Support services at universities and TAFE usually include:

- educational support (such as peer note-takers, whereby a colleague in your class provides copies of their notes if you find it difficult to take notes during lectures)
- alternative assessments (such as longer periods for exams)
- assistive equipment
- improved access to buildings (for example, relocating your class to a room without stairs)
- parking arrangements
- library assistance
- personal orientation to help you get to know the campus before you start.





## Making it work

*'I have found that honesty is the best policy when dealing with my arthritis at work. If you don't tell your employer that you are living with arthritis, this can lead to more problems in the future. I was very lucky to have forward-thinking parents who put me in control by making me communicate with my medical team and support network. This enabled me to be confident in discussing my personal situation, thus making it easier to handle such things as job interviews.'*

*Many professions don't need any physical labour and many can be done from the comfort of your own home. It is important to find a profession that you can handle, and one with understanding employers. It is even more important to find a job that you really enjoy. Work can be a fantastic distraction from the day-to-day struggle of living with arthritis.'*

### **B, age 39, juvenile onset rheumatoid arthritis**

When you have arthritis, work can sometimes feel a lot like hard work – especially if your physical symptoms are affecting your ability to get your job done. You might be finding it challenging to stay in your current job, or are worried about finding new work because of your condition.

The good news is that treatments for arthritis have significantly improved and, nowadays, many more people with arthritis can keep working despite their condition. In fact, more than 50 per cent of people with rheumatoid arthritis continue to work for

twenty years after their diagnosis. Staying in the workforce may require anything from a little support to a complete change of roles, but there are many services available to help you.

## YOUR RIGHTS AT WORK

### A quick word about the term 'disability'

You may find it confronting to see the word 'disability' used throughout this section. Perhaps you have just found out you have arthritis and are hardly what you would consider 'disabled'. If your condition does not impact on your ability to carry out your tasks at work, then feel free to skip this chapter! But if your condition is making it difficult for you to perform your usual work, or find new work, it is important to understand that arthritis is a recognised disability. This means it attracts certain rights outlined in the Disability Discrimination Act and, in addition, you may be eligible for additional support to help you stay in the workforce.

### Disability Discrimination Act 1992

A person with a disability has the same rights as other people to a safe workplace that is free of discrimination. These rights are defined under the Australia-wide Disability Discrimination Act, and there are also State-based anti-discrimination laws that protect you from being treated unfairly at work. The Disability Discrimination Act makes it against the law to discriminate against people with a disability in employment. This includes during recruitment, with employment benefits and conditions, termination or dismissal. Simply, this means

that if you can do the essential activities or 'inherent requirements' of a job, you should have just as much chance to do that job as anyone else. You also have the right to workplace modifications or 'reasonable adjustments' that minimise the impact of your disability in the workplace (see 'Reasonable adjustments' section on p. 9).

## DO I HAVE TO TELL MY EMPLOYER I HAVE ARTHRITIS?

Whether to tell your employer about your condition or not is up to you. There is no legal obligation for you inform him or her about your disability unless:

- it may affect your ability to work safely and/or put the safety of co-workers at risk, or
- it is likely to affect your performance or ability to meet the inherent requirements of the job.

The 'inherent requirements of the job' are tasks that must be carried out in order to get the work done. For example, an inherent requirement for an administrative job might be to record minutes from meetings. If you are unable to write shorthand for a long period of time due to painful fingers, you may be able to record the information on a dictaphone and then transcribe it. Taking shorthand, therefore, is not an inherent requirement of the job because you are able to perform the work in another way.

In many cases it can be helpful to talk to your employer about your arthritis. For example, you may need to request reasonable adjustments such as modified equipment or flexible working arrangements (see next section). You may also find it helpful to tell your employer and co-workers something about your condition so they will be more understanding if you have frequent days off work due to your arthritis. They may also be more likely to help out with tasks that you find challenging, such as moving heavy deliveries or rearranging conference room facilities. However, the decision is entirely up to you.

For more information about telling your employer about your condition, go to the 'Disclosure and privacy' page on the **JobAccess** website, [www.jobaccess.gov.au](http://www.jobaccess.gov.au)





## REASONABLE ADJUSTMENTS

Depending on how your arthritis affects you, you may need modifications to your workplace to be able to do your job. If so, your employer should be able to make reasonable and appropriate changes to the work environment to minimise the impact of your condition on your work. These changes are called 'reasonable adjustments'. This should enable you to have an equal chance to be considered for selection, promotion, transfer, training or other employment opportunities. Reasonable adjustments also aim to ensure safety for you and your co-workers in the workplace.

In most cases you will be able to tell the employer what is needed to help you continue in your role. If necessary, employers should also seek advice from government agencies or organisations that represent or provide services to people with a disability.

Examples of reasonable adjustments employers may make include:

- Modifying work premises. For example, providing ramps, modifying toilets, and replacing doorknobs to your office or the nearest toilet with lever handles.
- Changes to job design, work schedules or other work practices. For example, swapping some duties among staff, allowing regular stretch breaks, and flexible working hours to allow you to attend medical appointments.
- Modifying equipment – such as lowering a workbench to allow you to sit on a stool rather than having to stand and cause strain to your back and legs.

- Adjusting your regular start time if morning stiffness makes it difficult for an early start. You may be able to work the hours at the end of the day instead.
- Providing a car park close to the work entrance to minimise your walking distance.

## SUPERANNUATION AND INSURANCE

Most superannuation policies include disability benefits – but not all. If you can't do your usual job because of disability or illness, you may qualify for a superannuation disability benefit. These benefits 'top up' the contributions in your superannuation fund if you have to stop work. You may also be able to claim disability benefits under various insurance policies that you may have previously taken out, such as income protection insurance or mortgage protection insurance. If your illness has progressed and you are thinking it is time to either reduce your hours or leave completely, it is wise to get good advice before telling your employer.

For more detailed information about accessing superannuation or insurance policies, see the 'WorkWelfareWills' section of the **Chronic Illness Alliance's** website [www.chronicillness.org.au](http://www.chronicillness.org.au) or contact your superannuation fund or relevant insurance agency.

## HOW DO I GET HELP?

Understanding your rights and options at work can be confusing and overwhelming, so here are some services and organisations that might be able to help and guide you.

## JobAccess

JobAccess is an information and advice service that offers practical workplace solutions for people with disabilities and their employers. JobAccess can assist you if you need additional support to help find or keep a job. It includes a comprehensive, easy-to-use website and a free phone information and advice service through which you can access confidential expert advice. JobAccess can arrange a free workplace assessment for eligible employees and will pay for the cost of workplace modifications and adjustments if required. For more information, visit [www.jobaccess.gov.au](http://www.jobaccess.gov.au) or call **1800 464 800**.

## Centrelink

Centrelink is an Australian Government agency that delivers payments and services for a number of government departments. You can get advice about options to improve your chances of getting a job, how to access training, and ways in which to build your skills and confidence for work. Centrelink services include:

- **Income support payments and allowances** – such as a disability support pension and a mobility allowance, which assists you if you are unable to use public transport due to a disability and are working or looking for work.
- **Job capacity assessment** – you may be referred to a Job Capacity Assessor to assess your ability to work. This assessment will identify suitable services to help you re-train and overcome barriers to finding or keeping a job.
- **Referral to Australian Government employment services** – if your arthritis makes it hard for you to find or keep

work, these services may be able to help you (you may need to have a Job Capacity Assessment beforehand):

- **Job Network:** Can assist you to find paid work. They can match your skills to vacancies and help with general job search assistance.
- **Disability Employment Network:** A network of specialist employment services that helps people with disabilities to find and keep a job. They provide training and ongoing support during job placements.
- **Vocational Rehabilitation Services:** Can help you manage the effects of your arthritis and support you in returning to the workforce.

For more information about Centrelink services that may be helpful to you, visit [www.centrelink.gov.au](http://www.centrelink.gov.au) or call **13 2717**, or ask at your local Centrelink Customer Service Centre.





## Bumps, births, babies and beyond

*'I had feared that becoming a mother was selfish when at times my RA caused great limitation. I felt vulnerable as I ceased taking arthritis medications to fall pregnant; I could no longer pop a pill to dull pain or reduce fatigue and had to find new ways of coping. After a textbook pregnancy with three minor flares and a trouble-free birth, a post-birth flare hit me seven days after our beautiful son was born. With inflamed fingers and shoulders, I struggled for months with press-studs on baby clothes, nappy changing and carrying our baby. I breastfed for eight months, until I could no longer cope with the pain or threat of permanent damage.*

*This journey has been challenging for me and those close to me, but the rewards have been unimaginable. Our son gives me strength to keep going when pain tries to immobilise me. I hope that through my journey with arthritis, I inspire our children to follow their dreams and view challenges as opportunities to develop inner strength and determination.'*

### **S, age 32, rheumatoid arthritis**

Starting a family is a big step for any couple; perhaps even more so if you have arthritis. You may be worried about whether you can cope with children, how pregnancy might affect your arthritis, and if your children will develop the disease. It is important for both

partners to be fully aware of any risks and problems associated with pregnancy.

Coping with a newborn baby, a toddler or a child requires love, time and commitment from both partners, especially when one has arthritis.



## PREPARING FOR PREGNANCY

### **Talk to your doctor**

If you are thinking about having a baby, it's a good idea to talk to your rheumatologist, nurse or doctor before you get pregnant. Some medicines used for arthritis should not be taken during pregnancy as they can be harmful for the growing baby and, even if you are male, you may need to stop taking certain medications three to six months before trying to conceive.

You should discuss each medicine you take with your doctor or specialist several months before you try to become pregnant. Your rheumatologist can give you advice about which medicines should be stopped, the safest combination of medicines to take, or other treatments you could use.

## Should I stop taking all my medicines before becoming pregnant?

You should never stop taking prescribed medicines without talking to your rheumatologist or doctor. Your doctor can recommend the safest combination of medication at the lowest reasonable dose to reduce the risk of the medicine causing problems for the developing baby.

## I'm a guy, does it matter what medicines I'm taking?

It's not only women who should talk to their doctors about starting a family; the same advice applies to men with arthritis. Some medications should not be taken by the male partner for several months prior to conception. Your rheumatologist will give you advice about the safest medicines to use during this time.

## What are the chances of my baby having arthritis?

It is natural to feel concerned about the risk of 'passing on' arthritis to your child, but with most forms of the disease the chance of this is low. Even though some types of arthritis tend to run in families, there are many other factors involved beyond the genes inherited from parents.

For reassurance, it's a good idea to talk to your rheumatologist or doctor for more specific information about your particular type of arthritis.

## DURING PREGNANCY

### Will my arthritis get better or worse when I'm pregnant?

The effect of pregnancy varies with different types of arthritis. Some medicines may have to be stopped before you become pregnant, which may cause your arthritis to get worse. However, pregnancy relieves the symptoms in about 80 per cent of women with rheumatoid arthritis, although they usually return after the baby is born. Other types of arthritis may either become worse or improve during pregnancy and, of course, the increasing weight of the baby may cause you aches, pains and other symptoms associated with pregnancy.

### Does having arthritis affect my chance of a normal pregnancy?

Most types of arthritis do not harm the baby, or increase the risks of any problems in pregnancy, but you must always be careful with the medicines you take while you are pregnant. Some women with lupus may have a higher risk of complications during pregnancy, although this is not the case for most. If you have lupus, talk to your specialist about possible problems before becoming pregnant.





## AFTER THE BIRTH

### How will I cope with a new baby?

A newborn baby is exhausting for any parent and the stresses can be much greater for a woman with arthritis. For example, women with rheumatoid arthritis often find that their condition flares up again in the days or weeks after the birth. This can obviously make caring for your baby and yourself much more difficult, so support from a partner, other family members or friends is crucial in sharing the care of a small baby.

Before the baby arrives, try to plan for this time by arranging extra help from family and friends once the baby is born. It might be useful to make a roster for your support people to help you with activities such as shopping, cleaning, washing and bathing the baby. You may also find it helpful to talk to a midwife, physiotherapist and/or occupational therapist about ways to make holding, dressing, washing and feeding (particularly night feeds) a baby manageable if you have pain and stiffness. Equipment such as baby slings or carriers and breastfeeding pillows can be great to help take pressure off sore joints.

You could also ask a social worker about community support services that are available to help you cope in the first few months after the birth, and you may find it helpful to talk to other parents with arthritis who have faced similar challenges. Contact your State/Territory Arthritis Office for details of support services that might be suitable for you. And don't forget to find out about local mothers' groups as these can be an excellent source of support, information and fun.

Each pregnancy can be different so you should consider all of these options every time you become pregnant, even if it has been easy before.

### Can I breastfeed?

If you need to treat your arthritis while you are breastfeeding, your doctors will recommend medicines that are safe for your baby. However, some medicines should not be used if you are breastfeeding as they may affect the baby through your milk. If these medicines are necessary, the baby should be bottle-fed. You and your rheumatologist will need to decide what's best for the wellbeing of both you and your child when treating your arthritis after the birth.

## PARENTING WITH ARTHRITIS

It can be very difficult to cope with the tough demands of parenting when you're experiencing pain, fatigue and other symptoms of arthritis. However, some simple changes in the way you approach parenting may help you cope.

The most important thing is to keep the lines of communication with your children open. Hiding your condition not only gives the impression that you're ashamed, it also creates an air of uncertainty that may cause children to feel more worried and anxious. Give them information that is appropriate for their age and understanding. For example, a four-year-old will understand that you have a condition that is painful and sometimes makes it hard for you to move and sit on the floor with them. An older child or teenager can probably handle more information, such as what happens during a flare.



## Here are a few more tips:

- Be active in short bursts. If playing soccer with your children for an hour or so is out of the question, ten or fifteen minutes can still be enough for that ever-important bonding time.
  - Be a cheerleader. If you're having a bad day or your arthritis is more severe, your children will be surprisingly understanding about you not being able to climb on the swings in the playground, or play physically-demanding games with them. Simply having you there, as an 'admiring audience', is usually what they really want and remember.
  - Focus on the activities that you *can* do comfortably together, like reading, playing board games, painting and doing other craft activities.
  - If you're a parent of school-age children, participate in school activities, but be selective with what you do and take on light tasks such as reading. Children love having a parent involved at their school and it makes them feel 'special', while also providing an opportunity for them to explain to their classmates why there are some things their parent doesn't do. It encourages discussion about 'difference', which is valuable to all.
- Plan around painful times. Whenever possible, schedule family outings, birthday parties or other activities for the time of the day when you're usually at your best.
  - Sit wherever possible. Whether you're helping your children to get dressed in the morning, playing with them, or combing their hair, find a comfortable chair to sit in.
  - Choose arthritis-friendly clothes for your child. When shopping for clothes for small children who still need your help to get dressed, look for items with zippers, Velcro fastenings and elastic waistbands.
  - Ask for help. When you're feeling overwhelmed or having a flare, it's important to let your children, partner and family know that you need them to pitch in more until you feel better. Where possible, hire outside help to lighten the load.





## On the road

*'I love to travel. I have been lucky enough to have had the opportunity to cruise to Alaska, Hawaii and around the Pacific, to travel from Darwin to Adelaide on The Ghan, and take a twenty-one-day bus tour around Europe. I rode a mule (a very large horse!!) to the bottom of the Grand Canyon for two days and rode an elephant in Thailand. On most occasions I have had to travel with a biological DMARD (a medicine that is given as an injection).*

*Travelling is about experiencing new things, meeting people and having fun. Just because you have a medical condition it does not mean that you cannot travel and experience all the joys it has to offer. All it takes is a little bit of thought and preparation, being realistic with itineraries (factor in more rest days) and maybe travelling with a buddy – to help carry your bags!!'*

**K, age 42, rheumatoid arthritis**

You may have always dreamed of hitting the open road ... but then you discovered you have arthritis. There is no need to throw the suitcase away just yet; with careful planning you can still have the trip of a lifetime.

### BEFORE YOU GO

#### Get advice

When planning a big trip, consider getting advice from a travel agent. They may be able to help you with planning, booking accommodation and recommending locations that suit you and your physical ability. Make sure your travel agent understands your needs and abilities so your trip can be as enjoyable as possible.

#### Get organised

Planning ahead is the key to successful travelling. Ensure regular blood tests and doctor visits are conducted before you leave. Research any vaccinations that may be required to visit the countries on your itinerary. Most vaccines can be given safely with the majority of medicines used for arthritis, however check with your rheumatologist before receiving any vaccines. Vaccinations may need to be done well in advance to ensure that you are fully protected. Seek advice at least six to eight weeks before travelling.

While it is best to pack light, make sure you bring all the important items that make your arthritis more manageable on a daily basis. Remember to bring any special equipment or aids that you use regularly, such as:

- special pillows
- hot packs
- orthotics (shoe inserts), splints or braces.

Use lightweight luggage with wheels (although this is not suitable for all surfaces, such as cobblestones) and/or shoulder straps to make it easier to transport.

### TRAVEL TIPS

#### Tips for choosing accommodation

Consider:

- walking distance from the room to other services (such as the restaurant and pool), major attractions and transport
- the number of stairs
- the location of elevators in relation to the room



- handrails in bathtubs/shower and near the toilet
- separate shower or shower over the bath
- wheelchair accessibility (if necessary)
- availability of room service
- the standard of accommodation (to ensure adequate rest).

## Tips for air, train or bus travel

- Reserve seats ahead of time and make requests for any special needs.
- Schedule trips when fewer people are travelling (for example, mid-week).
- Allow extra time to get through terminals.
- Visit the bathroom before boarding to avoid having to use cramped onboard facilities.
- Ask for an airport wheelchair/transport if you will have difficulty walking through terminals or have to change aircraft. Check before you board if you will be required to walk down steps to get off the plane at your destination, and ask about alternatives.

## Tips for car travel

- Bring pillows, lower back supports or hot packs.
- Push the seat back as far as possible to give yourself plenty of leg room.
- Stop and stretch every hour or two (or whenever you need to).

## Pace yourself

The most important tip for enjoying a holiday is to begin the trip well rested. When you arrive at your destination, allow time to rest before getting out and about. Prioritise activities and try not to do too much in one day; it is a good idea to alternate active and restful periods. If you are travelling with a group, plan how you will spend time by yourself in case you are unable to join or keep up with the activities (such as reading a book or enjoying a coffee at a cafe). Incorporate rest days wherever possible. For example, if doing a group tour, arrive a day early to give yourself time to prepare.

## TRAVEL INSURANCE

Travel insurance covers you for events such as lost luggage, cancelled flights and illness or injury that can occur while you are on a trip. You can get travel insurance if you have arthritis, although you need to make sure you understand exactly what your cover provides, and whether it is adequate for your needs. Different types of travel insurance will have different limitations on what is covered, so it is best to shop around. For more information, see the Chronic Illness Alliance's document entitled **'WorkWelfareWills'** at [www.chronicillness.org.au](http://www.chronicillness.org.au)



## MEDICINES

It is important to make sure you pack enough medications to last the entire trip, and you should also consider taking extra prescriptions from your doctor, in case you are gone longer than expected. Since luggage can be lost, it is not wise to pack all the medications in your suitcase; keep some in another bag. Along with your medications, take the name and contact details of your doctor and specialist in case you need their advice while you are away.

Before you leave, you should check that your medicines are legal in the country or countries you are visiting and/or travelling through. You can do this by contacting the country's mission (embassy, high commission or consulate). A list of missions is available at the Department of Foreign Affairs and Trade website, see

**<http://protocol.dfat.gov.au/Mission/list.rails>**

It is illegal to take or send Pharmaceutical Benefits Scheme (PBS) medicines overseas unless they are for your personal use, or the use of someone travelling with you, for example a child. There are also restrictions on the amount of PBS medicine you can take into another country.

When planning to travel overseas with any medicines, including PBS, over-the-counter or private prescription medicines, it is important that you:

- Talk to your doctor and pharmacist and discuss the medicine you will need to take.
- Carry a letter from your doctor detailing what the medicine is, how much you will be taking, and stating that it is for your own personal use. Make sure you have more than one copy of this – carry one

with your passport and one with your medicines. Check that the medicines have the same name on the label as in the letter.

- Leave the medicine in its original packaging so it is clearly labelled with your name and dosage instructions.

It is important to be aware that some medicines which are readily available in Australia may not be available in other countries, or if they are available they may be packaged under a different brand name. Keep an eye on the strength of the active ingredients of similar sounding medications overseas – they can vary.

Do not try to save luggage space by combining different medicines in one container. Keep all medicine in its original labelled container to avoid problems at Customs. And if you require your medicines to be refrigerated, discuss this with your airline.

More information on travelling with medicines is available from Medicare Australia's website, **[www.medicareaustralia.gov.au](http://www.medicareaustralia.gov.au)** or by phoning the **Travelling with PBS Medicine** enquiry line, **1800 500 147**.





## Navigating the web

*'The moment I got home after being diagnosed with rheumatoid arthritis, I hopped on to the internet to read as much as I could about it. I wasn't familiar with the internet and so was not aware that it can provide a lot of false information. Two websites in, and I came across a site that provided a distressing statistic. I cried after reading it, believing it to be completely true. It wasn't until I told my mum what I had read, that she decided to get on the webpage I had found to have a closer look.*

*It turns out that the site had provided a statistic on a completely different matter (as shown by the original source that the site had collected the information from), and so it was totally misleading. Now that I'm more used to the internet, and know not to believe unreliable sites, I can read about arthritis and expect not to come across incorrect information.'*

**K, age 18, rheumatoid arthritis**

The internet is full of health information: some of it is reliable, some is not. It is important to weigh up the information you find on the internet to make sure it is accurate and trustworthy. Here are some questions to ask yourself about a health website to help you decide whether it is reliable or not.

### What is the purpose of the site?

The purpose of the site should be clearly stated and this should help you evaluate its trustworthiness. If this is not the case, try to analyse the purpose by using the home page. Is the site designed to inform, persuade, sell, outrage or entertain? What can you tell about the target audience? And is it relevant to you and your circumstances?

The best places for sound health information on the web are consumer advocacy groups (such as Arthritis Australia), health professional groups (the Australian Rheumatology Association, for example), well-known hospitals, and government- and university-sponsored sites.

## Who wrote the information?

The website should list the details of the author or authors of the information. The information is more likely to be trustworthy if it comes from a reliable source, such as a reputable organisation or a qualified health professional. If the information is important and will influence your decision-making, don't just take credentials at face value. Anyone can claim to be a health professional – but are they really? If in doubt, try to establish verification of the claims from another reputable source.

## Who runs the website?

To help you decide whether to trust the website, you need to know who is involved and why they are providing the information – the organisation or agency responsible for the site should be shown. The website should also list contact details for you to get in touch with the publisher or make comments and ask questions.

By looking at the URL (Uniform Resource Locator) and the domain, you can determine ownership and/or sponsorship of the site.

A person's name in the URL may mean it is a personal site and probably less reputable for scientific or treatment information. The domain may indicate the type of organisation, such as:

- .gov = government
- .edu = educational
- .org = non-profit organisation
- .com = commercial.

However, this is only a rough guide. More and more organisations, including Arthritis Australia, have a .com in their URL. Look for an 'About us' section on the site and if they have one, read it carefully. If not, look around the home page for some other clues as to ownership. You shouldn't have to look too far if the site is reputable.

## Is the information current?

A good website will state, on each page, when the information or page was updated. Even if the text has not changed, you want to know whether the site owners have reviewed it recently to ensure that it is still valid.

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WWW.





### Is the information accurate?

It is important to decide if what you're reading is factual. Ask yourself if it is clear whether the information is based on scientific evidence. Is it clear where the information is sourced from? Does it use valid, reliable and up-to-date research that has been done by a reputable organisation such as a university or government-related institution? If the information sounds unbelievable and has no evidence for its claims, it probably is unbelievable.

Try to find out if:

- there is an editorial board
- whether people with relevant professional and scientific qualifications review the material before it is posted, or can just anyone add to the site
- whether the information is tied to sponsorship, advertising or products and therefore possibly biased?

### Is the information objective?

It is important to understand why the information is being made available and the purpose behind the site. Is it well-balanced and presented without bias? A website published by a commercial organisation or business may be trying to sell a product, and would be less likely to give any negative points relating to the product. For treatments, information should cover:

- how treatments work
- the benefits and harms
- the affects on quality of life
- other available treatments and lifestyle options
- the likely effect of not using the treatment
- the cost, availability and how to access them.



Companies that sponsor sites like to have their logo and/or links to their company's home page embedded in the sponsored site, so this gives you an idea about where some of the money for the website has been sourced. This is not necessarily a bad thing. Many excellent sites have sponsorship or advertising of some sort, and it is up to you to decide whether the information is tainted because of this sponsorship.

## Does the information meet your needs?

What you need to know will depend on your personal situation and your understanding of the topic. You may have to go to several websites until you find the level of information that is right for you. For example, if you have just been diagnosed with arthritis, you may want some basic facts and advice. As you understand more about your condition, you'll probably want to go to more technical websites, such as those involving medical research. Also, remember that there are well over a hundred different types of arthritis, so make sure the website clearly states the conditions it is describing.

## Is the site easy to use?

Good websites will make it easy for you to read the information and understand the language. Some other things to look for include:

- a search feature that is clearly visible on every page
- printer-friendly versions of the information
- a text enlargement option that is easy to use

- contact details so you can seek more information or support
- a medical dictionary or glossary.

## Does the site protect your privacy?

Some sites ask for personal details, including those about your health. Any credible health website asking for this type of information should tell you exactly what they will and will not do with it. You need to feel comfortable that your details are protected, and you can do this by checking whether the website has a privacy policy.

The policy should:

- be written in words you can understand – don't sign up for anything that you are not clear about
- respect the confidentiality of your information
- list the rights and responsibilities of the user (you) and provider (them)
- say how the information will be used
- say whether the website uses cookies, which enable websites to remember your visits in the same way that a shopkeeper remembers your face.

Websites routinely track the paths visitors take through their sites to determine which pages are being used. The website should also tell you how to unsubscribe or opt out if it does not meet your needs, and what then happens to your personal information.



## Other things to look for

Good websites will:

- have a disclaimer that says the information does not replace the advice of a health professional – remember, all information you find on the internet is general advice and it may not be relevant or safe for you and your condition
- clearly state any costs involved upfront
- meet the needs of visually and hearing-impaired users
- meet culturally and linguistically diverse needs, including using translations or links to translating services.



If the website is accredited by the Health On the Net Foundation (HON Code) and/or HealthInfoSite you know the information will be of a high standard.

## Chat rooms and forums

If the site hosts chat rooms or other online discussion areas, it should explain the terms for using this service. Is it moderated? If so, by whom and why? It is always a good idea to spend time reading the discussion without joining in so that you feel comfortable with the environment before becoming a participant.

## Other stuff

**Always talk to your doctor** – Before you make a decision based on what you find on the internet, talk to your doctor or specialist. Print off any website information and take it to your next appointment to discuss whether it is suitable and safe for you. Remember, if you are reading information from another country, there may be different access to medications and treatments, depending on their healthcare system. Some treatments may not be approved for use in Australia, or the cost may vary significantly.

**Be sceptical!** – Many health and medical sites are out of date and provide poor-quality information. Is what you have found available on only one website, or can you find supporting information on other reliable sites?

**Be ruthless** – Don't get sidetracked or be led off into a new direction. Try to stay focused; your time is precious. If you find other sites that interest you, but they aren't exactly what you are looking for this time, write down the addresses and follow them up later.





## Want to know more?

### ASSEMBLE YOUR TEAM

You will most likely have been diagnosed with arthritis by your GP or by a rheumatologist. Along with your family and friends, your healthcare team may very well become an important and longstanding part of your life. You will see them regularly, they will know a lot about your arthritis and its progression, and you will be working together to manage the impact of arthritis on your life. Your team is also a reliable and informed source of information about arthritis – learning as much as possible about the disease can help you deal with the anxiety of ‘what is going to happen to me?’.

It is very important, therefore, that you have the ‘right’ support team – that you feel comfortable with your GP, rheumatologist and other health professionals; can talk openly with them; and have trust in them. If you are not satisfied with your healthcare team, you should consider seeing someone else. For more information about finding a health professional to help you manage your arthritis, contact the following:

#### Rheumatologist

##### Australian Rheumatology Association

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

#### Physiotherapist

##### Australian Physiotherapy Association

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

#### Occupational therapist

##### Australian Association of Occupational Therapists

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

#### Psychologist

##### Australian Psychological Society

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

#### Dietitian

##### Dietitians Association of Australia

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

#### Podiatrist

##### Australian Podiatry Council

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

#### Exercise physiologist

##### Australian Association for Exercise and Sports Science

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

### USEFUL WEBSITES

Your **State/Territory Arthritis Office** can provide you with details of support services for young people with arthritis and other information resources that may be useful. Freecall anywhere in Australia: **1800 011 041** or visit **[www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au)**

For access to quality online information about arthritis, start at the Australian Government’s **HealthInsite** website, **[www.healthinsite.gov.au](http://www.healthinsite.gov.au)**

For advice on healthy eating and exercise, visit the Australian Government’s **A Healthy and Active Australia** website, **[www.healthyactive.gov.au](http://www.healthyactive.gov.au)**

The **Arthritis Research Campaign (UK)** provides a wide range of information about living with arthritis, including pregnancy, sexuality, work and using the internet. These resources are available online at **[www.arc.org.uk](http://www.arc.org.uk)**

**Arthritis Care (UK)** provides information about working and parenting with arthritis on their website, **[www.arthritiscare.org.uk](http://www.arthritiscare.org.uk)**

## ARTHRITIS AUSTRALIA

- Arthritis Australia is a not-for-profit organisation that provides support and information for all Australians affected by arthritis.
- Contact your State/Territory Arthritis Office on the Freecall number below for information, education and support for people with arthritis:

Freecall anywhere in Australia: 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 South Australia

118 Richmond Road  
Marleston SA 5033

### Arthritis New South Wales

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

### Arthritis Tasmania

127 Argyle Street  
Hobart TAS 7000  
GPO Box 1843 Hobart TAS 7001

### Arthritis Northern Territory

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

### Arthritis Victoria

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

### Arthritis Queensland

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

### Arthritis Western Australia

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



### Arthritis Australia

1st Floor 52 Parramatta Road, Forest Lodge NSW 2037

**Mail:** GPO Box 121 Sydney NSW 2001 **Phone:** (02) 9552 6085 **Fax:** (02) 9552 6078

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



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**Freecall: 1800 011 041**