Living with arthritis

A guide for young adults

A practical guide to treatments, services and lifestyle choices
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 there are different types of arthritis some of which 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 people who were diagnosed with arthritis when they were young and 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, alcohol 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 . . . and live your life well!
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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 (long-term) illness such as arthritis. If you live with pain, fatigue, stress 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 everyday challenges of 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 connected with friends and 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.

One way to try and explain your arthritis to other people is to use words like, ‘My arthritis is an autoimmune condition like Crohn’s disease of the bowel, thyroid disease or diabetes in young people. My immune system is basically attacking the lining of my joints which become inflamed, swollen and painful. Sometimes this makes me feel generally tired and unwell. It is like having the flu all the time.’

You may also want to ask them to read this guide, so they can get a better understanding of arthritis and the challenges you may face.

**Overcoming challenges - 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 or bar stool. You may not see as much, but at least you will be there.

It is important not to give up on things you enjoy, but to find new ways to engage in them. 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.

Remember that you need to look after yourself especially well when you have a ‘flare’ of your arthritis. These periods of increased disease activity can happen to anyone – so just stay on your medications and build a little ‘pampering’ into your routine. From taking some time to start that great book you have been meaning to read, to taking a long bath and treating yourself to a little of your favourite indulgence. This is the time for break and an extra bit of tender, loving care.

**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 people 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
It is not uncommon for people with
arthritis to feel a sense of loss, grief or
feeling down as you may not be able to
do everything you used to do. If you are
experiencing feelings such as loneliness,
isoalt, stress, depression or anxiety,
it might be useful to talk to your GP or
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. Your GP
or a psychologist can assist you with your
emotional wellbeing and resilience, as
well as the management of anxiety and
depression, if present. They can also teach
you new skills to cope with pain.

You may be able to see a psychologist
funded by Medicare (e.g. a Mental
Health Plan) 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

Intimate relationships
Sometimes the physical and emotional
symptoms associated with arthritis can
have a negative effect on your or your
partner’s sex drive, sexual expression and
enjoyment. However, there are many
ways to overcome these challenges. Many
couples will become closer by discussing
things openly. Talk about your arthritis
and its impact and any challenges that
you face so you can arrive at a solution
that’s right for both of you. 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.
Physical activity is important for everybody and we all should be regularly exercising. Research has shown that regular exercise is one of the most effective treatments for arthritis. It can strengthen the muscles around your affected joints, improve mobility and flexibility as well as help reduce pain and fatigue.

The key is to find out which exercises are best for you. Your GP or rheumatologist will also be able to help you with this. They may even suggest seeing a physiotherapist, or an appropriately experienced personal trainer or an exercise physiologist, to help design an exercise program tailored to your specific needs. With a doctor’s referral you may be able to see a physiotherapist funded by Medicare. Or if you want to contact a physiotherapist directly, call the Australian Physiotherapy Association on 1300 306 622, or visit www.physiotherapy.asn.au

In general, low impact exercises such as walking, swimming, cycling, yoga or pilates are suitable. And remember to mix it up and do things that you enjoy, like bush walking or dancing. Also pace yourself. You want to find a level of activity that is not going to aggravate your pain. This may mean that you aim to walk for 30 minutes per day, but this is divided into two or three shorter walks.

Remaining physically active is important as extended periods of inactivity can make your arthritis worse, lead to deconditioning and make exercise more challenging when you decide to restart. Keep active and for more information see Arthritis Australia’s Physical activity information sheet.

Do some mental exercises also. Meditation and relaxation techniques, such as mindfulness, are also helpful for people living with a chronic condition like arthritis, and ongoing pain. These techniques can be taught to you by a psychologist, but there are also some good apps that are readily available.
The best diet for people living with arthritis is a healthy, balanced diet, one that helps maintain your general health and wellbeing. No diet has been shown to cure arthritis, but the good news is researchers have identified certain foods that can help control inflammation. Many of them are found in the so-called Mediterranean diet, which is rich in fish, vegetables and olive oil.

Studies have shown that eating foods rich in omega-3 fats can help reduce inflammation. Foods rich in omega-3 include oily fish such as sardines and salmon, ground linseeds and walnuts. Also mono-unsaturated fats such as those found in vegetable oils, avocados and many nuts may help reduce disease activity. Limiting your intake of saturated fats, which are found in red meat, poultry and full-fat dairy products may also be helpful.

Maintaining a healthy weight is also important. Extra bodyweight increases the stresses on joints, especially the hips and knees. So losing a few kilograms, if you are overweight, can be helpful.

Remember, eating well is one way you can help manage your arthritis, but a healthy diet is not a replacement for taking medicines to manage your arthritis. For more information see Arthritis Australia’s Healthy eating and arthritis information sheet.
You may find it confronting to see the word ‘disability’ used throughout this guide as you may not think of yourself as having a disability. However, arthritis is a recognised disability and you may qualify for additional support if you need it.

If your condition does not have any impact on your ability to engage in study, work or do normal day-to-day activities then that is great. For many people this is not the case and obtaining help from disability services can help them live life to the fullest. More information about your rights will be covered in other sections of this guide such as at University, TAFE and in the workplace.

“When I was a teenager I did not see myself as being ‘disabled’ even though my arthritis was associated with a loss of movement. Some mornings I wished that my disease was more visible so that someone would offer me a seat on the tram. It was so painful to lift my arm to hold onto the hand-straps that I would almost be to the point of tears, but I never felt comfortable to go up to someone to ask if I could have their seat.

Now that I am older, I do consider myself as having a disability. There is no hiding that I can’t go about my daily life in the same way able bodied people can. However, I also recognise that this is a personal decision. My cousin who also has arthritis prefers not to tell her friends about her arthritis and has never used any disability services.

D, diagnosed with rheumatoid arthritis at age 16
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 approach 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 situation 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 online courses and other options to study without having to always go to the 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...
and/or 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 services (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.

You may not need or choose to use these services all the time, but if you have them in place you can access extra support when needed such as if your arthritis flares.

**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. Usually this will be the only person you will need to explain your condition and its impacts to. He or she will advise the faculty or department what recommendations are needed and the information will then be passed on to the lecturers and tutors, etc. You will not have to explain each time, but refer the asker to the Faculty office or your disability officer. 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 overcame challenges. 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)
- modified 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.
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% 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**

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 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 illegal 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 page 14).

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 or type for a long period of time due to painful fingers, you may be able to record the information and then transcribe it. Therefore being able to write or type for a long period, 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 ‘Your rights and responsibilities’ page on the JobAccess website, www.jobaccess.gov.au
**Employment**

**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. In many cases, the cost of workplace modifications may be (partially or fully) reimbursed by the Government. Employers can get more information about this from the ‘Access for Employers’ page on the JobAccess website, [www.jobaccess.gov.au](http://www.jobaccess.gov.au)

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.
- Allowing you to work from home on some days.
- Providing a parking space 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 the policy was in place prior to your arthritis being diagnosed. 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.

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 or call 1800 464 800.

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

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 or contact your superannuation fund or relevant insurance agency.
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, studying 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.

- **Employment Services Assessments** – this assessment helps work out the type of employment service or other assistance that can best help you to prepare for, find and maintain work.
  - Jobactive: Can assist you to find paid work. They can match your skills to vacancies and help with general job search assistance.
  - Disability Employment Services: This service has two parts:
    - Disability Management Service is for job seekers with disability, injury or health condition who need assistance to find a job and occasional support to keep a job.
    - Employment Support Service provides assistance to people with permanent disability and who need regular, ongoing support to keep a job.
  - In addition there is a network of specialist employment providers that help people with disabilities to find and keep a job. They provide training and ongoing support during job placements.

For more information about Centrelink services that may be helpful to you, visit [www.humanservices.gov.au/customer/dhs/centrelink](http://www.humanservices.gov.au/customer/dhs/centrelink) or call 13 27 17, or ask at your local Centrelink Service Centre.

**National Disability Insurance Scheme (NDIS)**

The NDIS aims to provide all Australians under the age of 65 who have a permanent and significant disability with the supports they need to enjoy an ordinary life, including assistance with employment. As an insurance scheme, the NDIS takes a lifetime approach, investing in people with a disability, with the aim of improving their condition in later life.

The National Disability Insurance Agency (NDIA) manages the NDIS in partnership with State and Territory Governments and established disability providers. For more information about the NDIS visit [www.ndis.gov.au](http://www.ndis.gov.au) or call 1800 800 110.
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 also develop arthritis. It is important for both partners to be fully aware of the risks and challenges 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, even if you are a male**

If you are thinking about having a baby, it’s a good idea to talk to your rheumatologist, obstetrician or GP before you or your partner become 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.

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**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, diagnosed with rheumatoid arthritis at age 28 years.*
You should discuss each medicine you take with your GP 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 while trying to conceive and during pregnancy.

**Should I stop taking all my medicines before becoming pregnant?**
You should never stop taking prescribed medicines without talking to your rheumatologist or GP first. Your doctor can recommend the safest combination of medication at the lowest effective dose to reduce the risk of the medicine causing problems for the developing baby.

**I’m male. 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. Your rheumatologist will give you advice about the safest medicines to use when you are trying to conceive.

**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, which are at worst one of several risk factors.

It is important to avoid smoking, both by the mother but also by all members of the family, during pregnancy. Not only has this been shown to be associated with additional risks to the baby, new research suggests that it may also increase the risk of the child developing some forms of early onset arthritis and other auto-immune diseases.

For reassurance, it’s a good idea to talk to your rheumatologist or GP 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, for about 50 to 70% of women with rheumatoid arthritis their symptoms will improve during pregnancy usually starting during the first trimester, although they usually return after the baby is born with many women experiencing a flare in their arthritis in the first few months after childbirth. 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.

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, weeks or first few months 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.

The most important aspect for your baby is to have a mother who can bond and enjoy having a baby. If that requires the mother to take medication and to stop,
or not start breastfeeding, that may be in the best interest of both the baby and the mother, as well as other members of the family. Your doctors can help you with what can be a difficult decision.

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?**

Your doctors will recommend medicines that are safe for your baby while you are breastfeeding. 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 with baby/infant formula. 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 may give the impression that you’re ashamed, it can also create 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 that you may find useful:

- 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.

- Pace yourself. When playing with your children consider planning a number of different games with different levels of physical activity. This way you can take short breaks and extend your play time with them.

- 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, get outside help to lighten the load.
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.
If you are making your own bookings online, you may wish to call the place you are planning to stay at to discuss your needs and to confirm that accommodation meets your needs. Don’t simply rely on making any special requests online. If additional arrangements are made, get these confirmed by email and record the name of the person who you spoke with.

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 take all the important items that make your arthritis more manageable on a daily basis. Remember to take any special equipment or aids that you use regularly, such as:
- special pillows
- hot packs
- orthotics (shoe inserts), splints or braces.

Just before a trip is not the time to break-in brand-new shoes. Instead, wear a trusty pair of shoes with good support and traction.

Make sure you have an adequate supply of your medications for the whole trip plus an allowance for a few extra days. (For more advice see the Medicines section). Ensure your medication is in your hand luggage, with a letter from your doctor. Checked-in luggage can get lost, even if only for a day or two, and you won’t find it easy to replace your medication when away from home. Customs will be reassured by a letter from your doctor.

Use lightweight luggage with wheels (although this is not suitable for all surfaces, such as cobblestones, although bigger wheels can help) and/or shoulder straps to make it easier to transport. Another way to lighten your load is to take clothes you can wash and dry easily overnight.

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 (remember that
many older hotels and youth hostels across Europe and Asia do not have lifts)

• the location of elevators in relation to the room
• is the bathroom shared or en-suite? Some are tiny so check it will be big enough for you
• 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).
- Don’t schedule a flight that will require you to wake up extremely early, especially if your joints tend to be stiff or achy in the mornings.
- Allow extra time to get through terminals.
- Visit the bathroom before boarding to avoid having to use cramped on-board facilities.
- Ask for an airport wheelchair/transport if you will have difficulty walking through terminals or have to change aircraft. This can often be arranged before you travel rather than on the day.
- 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.
- Get to your departure gate early as you may be able to board early, to give you extra time to get to your seat and settle in before other people board.
- Get up and walk around during long flights. Research has shown that people with arthritis have a higher risk of deep vein thrombosis than the general population. Deep vein thrombosis occurs when a blood clot forms in the veins of your legs due to inactivity. You can help prevent deep vein thrombosis by getting up to walk around at least every 2 to 3 hours. You may also want to discuss the use of compression stockings with your GP before you travel.
- Do seat exercises. This will help prevent stiffness in your joints while sitting during the flight and decrease your risk for deep vein thrombosis. For example:
  - Raise and lower your toes while keeping your heels on the ground.
  - Raise and lower your heels while your toes stay on the ground.
Travel and holidays

- Tighten and relax the muscles in your legs.

Also check out the information from the airline you are travelling with for their tips on preventing deep vein thrombosis.

- Use heat or ice therapy. If either heat or ice helps ease your joint pain, use it on the plane or train too. Bring along and use heat wraps or have a resealable plastic bag on hand and ask the attendant to fill it with ice.

Tips for car travel

- Take 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).

Be sunwise

If you’re heading on a summer vacation, use sunscreen, wear a hat and sun-protective clothing to protect you against the sun’s rays. This is especially important as some medicines used to manage arthritis make you more prone to getting sunburn.

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. Also plan your activities with an awareness of your arthritis. If it takes you time to get moving in the morning avoid early starts. 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
Travel and holidays

Make sure you understand exactly what your cover provides, and whether it is adequate for your needs. It is very important to look at the definition of pre-existing conditions in the policy you are considering. Different types of travel insurance will have different limitations on what is covered, so do your research, read the fine print and shop around. Also consider asking your travel agent or an insurance broker if they can get you cover you need.

For more information, see the Chronic Illness Alliance’s ‘WorkWelfareWills’ page for more information about travel insurance policies at www.chronicillness.org.au

Medicines

It is important to make sure you pack enough medications to last the entire trip, including a few extra days for safety. You should also consider taking extra prescriptions from your doctor, in case you are gone longer than expected. Since luggage can be lost, keep some, if not all, of your medications in your carry-on luggage. 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). This is especially important if you are taking an opioid analgesic (such as codeine or morphine) even if some of these are available in Australia without a prescription. 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 (ask your doctor about these limits).

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. Scan these documents so you also have an electronic record. You may wish to leave a copy of this letter and your prescriptions with friends or family who are staying at home, so they can fax or email this to you in an emergency. 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. Be mindful that not all countries have the same levels of quality control for medicines as Australia has. Sometimes medications obtained overseas may not contain the same ingredients as they do in Australia.

- If your medications need to be refrigerated, plan for this and let your airline know in advance about your need to use ice packs. Ideally the letter from your doctor should also make reference to this.

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 before you travel.

More information on travelling with medicines is available from Department of Human Services website, www.humanservices.gov.au/customer/services/medicare/travelling-overseas-pbs-medicine or by phoning the Travelling with PBS Medicine enquiry line, 1800 500 147.
Alcohol, cigarettes and drugs

Drinking alcohol is part of some people’s everyday life. However, alcohol can interact with some of the medications routinely used to manage arthritis and can make unwanted or side effects worse, including increasing the risk of liver damage. For people with gout drinking beer, which is rich in purines, may make your gout worse. For some it will mean the need to avoid alcohol altogether, while for others it will mean having to limit alcohol consumption to a small number of drinks per week. Please check with your rheumatologist, GP or pharmacist about whether you need to avoid or limit your alcohol consumption.

Smoking is known to cause many health problems including heart disease and lung cancer. Arthritis e.g. rheumatoid arthritis has also been shown to be more common and more severe in smokers, including passive smokers.

People with arthritis may have additional problems related to smoking. For example, people with ankylosing spondylitis may have reduced ribcage movement when they breathe which can make smoking related problems such as cough and recurrent chest infections more troublesome. In addition, there is some evidence that passive smoking, that is exposure to other people’s cigarette smoke, can make some conditions such as lupus worse. The good news is quitting smoking can reverse some of the damage caused by smoking. The best way to quit, is to never start smoking, but if you are a smoker you may want to talk to your doctor or pharmacist about getting help to quit smoking.

Some people may be thinking about experimenting with illicit drugs. For example some may be tempted to use marijuana (cannabis) for pain relief. However, the evidence to date for marijuana and pharmaceutical cannabinoids does not support the use of these drugs for pain relief in people with arthritis. In addition, there is concern around the use of cannabis especially when you’re young and the brain is still developing (noting that brain maturity occurs at approximately 25 years of age).

If you are thinking about alcohol, smoking or illicit drugs, discuss it with your rheumatologist or GP. If you usually go with your parent or other family member to see the rheumatologist, you may want to call ahead and organise to have a part of the appointment by yourself so you can discuss these issues in private before being joined by your parent.
You have probably grown up with the internet, so some of the information in this section may not be news to you. However, different people have different levels of knowledge and our aim is help people to navigate through the vast amount of online information so that they can get information from reputable sources.

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, pharmaceutical companies 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 verify 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 or reviewed.

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 current.

**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 impact on quality of life
- other available treatments and lifestyle options
- the likely effect of not using the treatment
- the cost, availability and how to obtain 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 influenced by 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 a type of 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 Healthdirect you know the information will be of a high standard.

Social media

Social media is a good way to connect and share your experiences with people that may be facing similar issues that you are. People connect in groups on Facebook and Google+. A wide range of conversations can also be shared on Twitter and Instagram. These include personal experiences of people living with arthritis, friends or family members of people with arthritis as well as patient advocacy groups. Don’t forget
that whether it is a washing machine or medication for arthritis, negative comments are more likely to be shared than positive ones.

Just like everything you read on the internet cannot be taken at face value, the same applies to social media. It is important to understand that we are all individuals and for example how our body responds to a medicine will differ from person to person. So even though social media is a great way to connect with people like you, it should not replace the medical advice you get from your rheumatologist or GP.

**Chat rooms, blogs 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.

A blog is a personal online journal. Blogs generally represent the personality of the blogger or reflect the purpose of the web site that hosts the blog. Blogs can be a good way to share experiences, but remember the blogger’s journey may be different to yours.

**TIP: Looking to learn more about your condition and connect with others like you? Follow Arthritis Australia (facebook.com/arthritisaustralia and @ArthritisAust) for the latest in arthritis-related news, research, videos, and policy.**

**Other stuff**

Always talk to your doctor – Before you make a decision based on what you find on the internet, talk to your GP 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 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 side-tracked 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 or add them to a favourite’s folder and follow them up later.
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 you and 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. Your support team, may change over time as your needs change. Remember your GP can help you access some of these services through a Care plan.

If you are not satisfied with any member of 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)
- **General practitioner**: The Royal Australian College of General Practice  
  [www.racgp.org.au](http://www.racgp.org.au)
- **Physiotherapist**: Australian Physiotherapy Association  
  [www.physiotherapy.asn.au](http://www.physiotherapy.asn.au)
- **Occupational therapist**: Occupational Therapy Australia  
- **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  
- **Exercise physiologist**: Exercise and Sports Science Australia  
  [www.essa.org.au](http://www.essa.org.au)
Useful resources

**Australian resources**

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 more information about living with rheumatoid arthritis, ankylosing spondylitis or psoriatic arthritis visit Arthritis Australia’s empowered website at [empowered.org.au](http://empowered.org.au)

For links to quality online information about arthritis, start at the Australian Government’s Healthdirect website, [www.healthdirect.gov.au](http://www.healthdirect.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)

**International resources**

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

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:

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

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

**Arthritis New South Wales**  
Unit 1.15/32 Delhi Road  
North Ryde NSW 2113  
Locked Bag 2216 North Ryde NSW 1670

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

**Arthritis Queensland**  
1 Cartwright Street  
Windsor QLD 4030  
PO Box 2121 Windsor QLD 4030

**Arthritis South Australia**  
118-124 Richmond Road  
Marleston SA 5033

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

**Arthritis Western Australia**  
17 Lemnos Street  
Shenton Park WA 6008  
PO Box 34 Wembley WA 6913