

Arthritis in Teenagers



an information booklet for 13-20 year olds

Committed to curing arthritis

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About this booklet

If you are a young person – that is aged between 13 and 20 – who has arthritis, then this booklet is for you. It is based on discussions with young people who have arthritis about their specific needs and questions. It was written by a group of people, including doctors, physical therapists, occupational therapists and nurses, who regularly look after young people with arthritis.

The booklet is divided into three parts. **Part 1** explains what arthritis means for young people, including the main types and treatments. **Part 2** discusses how arthritis can affect the way you make the transition into adult life.

Arthritis in young people is known as JIA (juvenile idiopathic arthritis). We have tried to answer the main questions which young people ask if they develop arthritis. Of course, a small booklet like this cannot cover everything. It will give you basic advice and, as mentioned above, will also direct you to other sources of help, including other organisations and other useful **arc** booklets. A glossary at the back of the booklet explains technical and medical terms.

PART 1 – ABOUT JIA

This section explains what JIA means as an illness affecting young people. It describes the main symptoms, the main types of JIA and the different treatments.

What is juvenile idiopathic arthritis (JIA)?

JIA is the short term for juvenile idiopathic arthritis. **Juvenile** means that the arthritis began before you were 16 years old, **idiopathic** means that the cause is not known and **arthritis** means that one or more of your joints are inflamed – that is, they are swollen, painful, stiff and you may not be able to move them as far as normal. Even when you are over 16, doctors still use the term JIA as this type of arthritis is different from adult forms of arthritis.

The term JIA is relatively new and you may come across older terms, which mean essentially the same thing, such as juvenile chronic arthritis (JCA) and juvenile rheumatoid arthritis (JRA). The new term is now used by doctors worldwide to describe the different forms of arthritis in young people.

What causes JIA ?

We do not know the exact cause of JIA. There is no clear evidence that it is inherited (runs in families) but there are certain genetic markers which have been found more frequently in certain kinds of arthritis in children and adults.

There is no evidence either that an infection causes JIA. Sometimes children may have had a sore throat or other infection just before they become ill, but as yet no 'germs' have been identified.

We think that JIA is due to a combination of inherited (genetic) factors and factors from the environment, for example an infection that has not yet been identified.

Are all joint pains due to JIA?

No, not all joint pains are due to arthritis and not all forms of arthritis are JIA. Joint pains in young people are common and in most cases are short-lived (particularly after a viral illness) and cause no long-term problem. In fact, in children and young people, arthritis is an *uncommon* cause of joint pain.

How is JIA diagnosed?

There is no foolproof test for JIA. The diagnosis involves the doctor asking questions and examining you, and by this process ruling out other types of illness. Your doctor will want to rule out other conditions that can cause joint pain. You may have a number of tests including some of those listed below.

Blood tests

- **Haemoglobin** – a test for anaemia (lack of red blood cells)
- **Erythrocyte** sedimentation rate (ESR) – this is one test for inflammation

- **Autoantibodies** – these are proteins in the blood that are present with rheumatic conditions but can also be found in some healthy people. *Rheumatoid factor* is an autoantibody which is found in most adults with rheumatoid arthritis, but is rarely found in children. It may be found in some teenagers with polyarthritis (arthritis in many joints). *Antinuclear factor* is another autoantibody that may indicate the possibility of *uveitis*, which is inflammation of the eye (see [‘What effects can JIA have on your body?’](#)).

X-rays (radiographs)

X-rays of the affected joints are usually needed to allow the doctor to look for or assess any joint damage.

Ultrasound scans and magnetic resonance imaging

Ultrasound scans (similar to scans of babies in pregnant mums) and magnetic resonance imaging (MRI) are other ways to look at your joints.

Aspiration of a joint

Sometimes it is important to remove the fluid from an inflamed joint and test it, especially to check for possible infection. This can be uncomfortable and is usually done under sedation when you are younger (sedation is when drugs are given to make you sleepy).

Other tests

Sometimes, you may need to have other tests which may include a **chest x-ray**, a **heart scan** (called an Echo) to look for inflammation (**pericarditis**), a **bone scan** to check for inflammation in the bones, or even have a **bone marrow examination**.

Further reading: arc booklets ‘Blood Tests and X-Rays for Arthritis’, ‘When Your Child has Arthritis’.

What are the different types of JIA?

There are several different types of JIA, which are described below. It is important to know which type you have as some types are milder than others and this will help your doctor to plan your treatment and give you advice on the likely effects of your arthritis. Doctors describe different forms of JIA by the number of joints and the pattern of joints involved and whether there are other problems such as fever or rash.

Oligo-articular-onset JIA (sometimes called pauci-articular-onset JIA)

This is the most common form and is the name given when only a few joints are swollen ('oligo' or 'pauci' meaning 'few' and 'articular' meaning 'relating to the joints'). It affects about two-thirds of children with arthritis and most commonly affects one or both knees.

Oligo-articular-onset arthritis is most common in the pre-school-age group (under 5) with girls affected more than boys. This form of arthritis is often mild and has the best long-term outcome. That is, it is the most likely to go away and to leave little or no damage to the joints. It is always worth remembering, though, that this type of arthritis has the highest chance of developing **uveitis (inflammation of the eye)**, as explained in the section [‘Eye inflammation’](#), and so regular eye checks with an **ophthalmologist** (eye specialist) will be an important part of your treatment plan.

In older children (for example age 8 and above), oligo-articular-onset arthritis is more likely to affect boys and may go on to cause stiffness in your neck and lower back in your teens, or as a young adult (called **juvenile spondylitis** or **enthesitis-related arthritis**). You may also develop **uveitis** (see the section [‘Eye inflammation’](#)) which tends to produce a painful red eye. A blood test may show that you have a genetic marker for this sort of arthritis (a marker called HLA-B27).

Polyarticular-onset JIA

This is the next most common type. Polyarticular JIA (or polyarthritis) means that many joints are inflamed ('poly' meaning 'many' and, as mentioned above, 'articular' meaning 'relating to the joints'). Polyarthritis can begin in teenage years, particularly for girls, and may be very similar to adult-type rheumatoid arthritis. You may have a blood marker called rheumatoid factor which can be found by a blood test and you may have small painless lumps called **nodules** which are often found on the elbows.

This type of JIA tends to affect fingers, toes, wrists, ankles, hips, knees, and the neck and jaw. It may come on suddenly or can progressively involve more joints over a period of months. Generally speaking this kind of arthritis

may grumble on into adult life but it can go into a state where all the symptoms disappear. This is called remission – a state which can sometimes last for ever.

Extended oligo-articular JIA (sometimes called extended pauci-articular JIA)

With this form of JIA, you have oligo-articular JIA in the first 6 months and then develop problems with many joints after that (that is, it becomes polyarticular). This type of JIA can cause damage to your joints and your doctor may suggest early treatment with drugs like methotrexate to minimise this.

Psoriatic arthritis

Psoriasis is a scaling skin rash and with this you can also get arthritis. The joints may be affected before the skin rash appears – your doctor may look closely at your fingernails and toenails for early signs of psoriasis and may ask if any members of your family have psoriasis.

Systemic-onset JIA

This is the rarest type of JIA. It can affect children and young people at any age, with boys affected as much as girls. In this form of arthritis, joint pain is part of a general illness involving fever, rash, loss of appetite and weight loss. You may have enlarged glands in the neck, under the arms and around the groin area. Your spleen and liver may be enlarged, and the doctor will feel for this when examining your tummy, although you may not have noticed it yourself. Very occasionally, the covering of the heart is inflamed (**pericarditis**). In the first few weeks, there may be no sign of swollen joints, and the diagnosis may be uncertain. Lots of tests may be needed to confirm the diagnosis and this can be a worrying time. The long-term development of this form of JIA can be difficult to predict but usually the fever and rash will settle and the arthritis may sometimes grumble on for several years before settling.

What effects can JIA have on your body?

Many young people with JIA feel well, fully active and have normal growth and puberty (the process of reaching sexual maturity). Sometimes, though, having arthritis can cause problems with everyday activities like walking, bending, getting dressed or washing yourself, and can have an effect on your general health and development.

Varying symptoms

Your symptoms of arthritis can vary from day to day. Inflamed joints (when the arthritis is 'active') can be warm to the touch – they may look red and swollen and are painful to move. Typically you will feel stiffer in the mornings and after periods of resting. *Flare-ups* (where the arthritis gets worse) can happen after viral infections, stress, changes in medication or sometimes for no apparent reason. Sometimes arthritis stops being active, that is, the joints no longer feel warm, look red or are swollen, but they may still be painful and limit your ability to do things.

Eye inflammation

Uveitis is inflammation of the eye and this can happen with JIA. This risk is less in teenagers and young adults than in children but if it does develop and persists it can cause blurred vision or even loss of vision. Uveitis **does not always cause pain or a red eye** and may only be picked up by frequent checks by an **ophthalmologist** (a doctor specialising in eye problems), who will check your eyes with a **slit lamp** (a special type of torch with a bright light) to see if you have uveitis or not. It is important to tell your doctor about any changes you notice in your eyes.

General health

Having arthritis can affect your general health. Flare-ups can reduce your **appetite**, may cause **anaemia**, and make you feel 'run down' and tired. You should take care to clean your teeth regularly and properly to prevent **tooth decay** (caries) and gum disease.

Osteoporosis

Osteoporosis (thinning of the bones) usually causes problems in older people but we know that diet, exercise and general health in childhood and adolescence are very important in strengthening your bones. It is important to take steps when you are young to help prevent osteoporosis. You should try and exercise every day (walking is great) and eat dairy products (for example milk, cheese, yoghurt).

Puberty (reaching sexual maturity) and growth problems

Most people with arthritis grow normally and have normal puberty. Sometimes, though, having arthritis and being on steroids can slow your growth and make the changes of puberty happen later. In girls, the start of your periods can

be late and, once they start, they may not be regular, especially if you are taking methotrexate. The effect on growth and puberty may be seen in all types of JIA. This can be upsetting and make you feel different from your friends or classmates. It is important to remember that your growth can catch up and puberty usually happens normally, especially when arthritis is well controlled by your medication.

Parenthood

Most young people with arthritis can have healthy babies and enjoy parenthood normally. It is worth remembering that:

- The risk of your baby having JIA is extremely small.
- You will be advised by your doctor not to become pregnant while you are on methotrexate. However we know that if you have been on methotrexate in the past, then there is no known reason why you should not be able to become pregnant and have a healthy baby after you have been off methotrexate for a suitable period of time (see below).
- If you are planning to become pregnant or planning to father a child then it is important that you stop taking methotrexate because this drug can damage sperm and eggs and can harm the baby. Your doctor will advise you to be without methotrexate for at least 6 months before you try to become pregnant or try to father a child.
- You should discuss parenthood with your rheumatology nurse or doctor.

Further reading - see the sections 'How is JIA treated?' and 'A healthy lifestyle'.



How is JIA treated?

The aim of your treatment is to:

- control the symptoms of arthritis (pain, stiffness, and swelling)
- enable you to lead an active life at school or college
- enable you to enjoy an active family and social life
- enable you to do as well as you can at school
- help you become an independent adult.

It is important to do all of these things but at the same time try to reduce any side-effects caused by medicines.

There is a great deal of research into the treatment of arthritis and several new medicines are now being developed. You need to be aware of the main types of treatment and what you can do to help yourself in the following areas:

- Medicines
- Physiotherapy and occupational therapy
- Joint surgery (orthopaedic surgery)
- General health and healthy lifestyle (e.g. diet, sleep and exercise)
- 'Natural' and 'complementary' treatments.

MEDICINES

Medicines cannot 'cure' arthritis, but they can control the symptoms and help to reduce the possibility of joint damage. An increasing number of medicines are now available:

Non-steroidal anti-inflammatory drugs (NSAIDs)

These often help to reduce the pain, stiffness and swelling of arthritis. There are many different NSAIDs, for example naproxen, ibuprofen and diclofenac. You have to take them regularly to get maximum effect and their effect lasts hours not days. Side-effects can include indigestion, but you can lessen this by taking them along with food. If you get indigestion you should report this to your doctor.

Painkillers (analgesics)

These help to control the pain of arthritis. Common drugs include paracetamol, codeine, or combinations e.g. co-codamol. They have to be taken regularly to get maximum effect and their effect lasts for hours not days. Side-effects include constipation, drowsiness, or feeling 'a bit spaced out'.

Corticosteroids (prednisolone)

- These control inflammation and the pain, stiffness, and swelling of arthritis very well. They work quickly over a few days. Short courses (a few days) or low doses tend to have no side-effects.
- **Side-effects** with large doses can include weight gain, slowing of growth, high blood pressure, easy bruising and osteoporosis (thinning of the bones), and they can increase the risk of infection. Your doctor will aim to limit these side-effects by prescribing low doses and only for a short time, and if you are still growing then may suggest that you take prednisolone in the mornings every other day to give you a greater chance of being as tall as you should be. There is a risk of infection (probably very small) if you have **body piercing** (e.g. belly button) and are on steroids with or without other medicines for your arthritis, so please check with your nurse or doctor.



- Corticosteroids can be given by tablets, injection into the joint or into the muscle, or by a drip into a vein. **Joint injections** of steroid are very effective for many months, are very safe, and cause very few side-effects.
- If you are prescribed steroids, then your doctor should give you a **steroid card** (which tells people that you are on steroids). Always carry this with you.
- **Steroids should NEVER be stopped suddenly** (except if you have only been on them for a short time - under 2 weeks) as you can become very ill.
- To help reduce the risk of **osteoporosis** you should eat more calcium-rich foods (e.g. semi-skimmed milk, cheese, tinned fish such as sardines including the bones) and take regular weight-bearing exercise such as walking. Your doctor may suggest that you take calcium supplements.

If you are on corticosteroids you should not have certain vaccines, and you should also take care in relation to chickenpox. Please see the sections 'The risk of chickenpox' and 'Avoiding certain vaccines' below.

Disease-modifying anti-rheumatic drugs (DMARDs)

These drugs dampen down inflammation and they can reduce the joint damage caused by arthritis. Also important is that, by helping to control your arthritis, they may enable your doctor to reduce the amount of steroids that you need to keep well (and that means less risk of steroid side-effects).

Methotrexate and, to a lesser extent, **sulphasalazine**, are the most commonly used DMARDs in JIA. They appear to be very effective, with many patients going into remission (with no active arthritis) and feeling very well. These drugs are slow to become effective and you may notice no benefit for several months. Side-effects of methotrexate and sulphasalazine are rare but regular blood tests are required.

- **Methotrexate** is usually given as a tablet just once a week, although some patients are given methotrexate as an injection into the skin or muscle. Folic acid is sometimes given once a week, 3 days after the methotrexate to help reduce the possibility of side-effects.
- **Sulphasalazine** is given in tablets taken every day.

If you are on **methotrexate** then a few points are worth stressing:

- **Avoid drinking alcohol**

Alcohol makes your liver more sensitive to the effect of methotrexate and there is a danger of damaging your liver if you drink too much alcohol while on methotrexate. Your doctor or nurse may advise no alcohol at all, but being honest, many young people do drink alcohol without apparent side-effects with their liver. A sensible compromise is a maximum of 5 units a week. Ask your nurse or doctor for advice.



- **Don't become pregnant**

If you are sexually active, reliable **contraception** is a must when you are on methotrexate (whether you are male or female). This is because, as mentioned above, methotrexate can cause damage to an unborn baby. If in the future you want to become pregnant or father a child then methotrexate should be stopped for at least 6 months beforehand. Discuss this with your doctor or nurse.

If you do have sex without adequate contraception (i.e. **unprotected sex**), then you should seek advice urgently from either your nurse or your GP. Remember the 'morning-after pill' is available.



- **The risk of chickenpox**

Chickenpox can be more severe if you are taking corticosteroids, either with or without methotrexate. If you have not had **chickenpox** (or are not sure) then it is important to discuss this with your doctor or nurse. They will give you advice about what to do if you are exposed to chickenpox or get chickenpox. You may also be able to have a **vaccine** against chickenpox. If you have had chickenpox, then you can get **shingles**. Again you should talk to your doctor or nurse about what you should do.

- **Avoiding certain vaccines**

All young adults are offered vaccines to protect against certain infections and these are very important. However, you must *not* have certain vaccines if you are taking methotrexate (or corticosteroids) – these include vaccines against rubella (German measles), BCG for tuberculosis (TB) and oral (taken by mouth) polio vaccines. However, other vaccines are safe and very effective in protecting you against serious diseases, and you can have them – for example meningitis and influenza vaccines. Check with your nurse or doctor.

New medicines in rheumatology

Through ongoing research there are several new and exciting medicines becoming available and their use in JIA is increasing and so far encouraging. Much information is available on the internet, but don't believe everything you read! Ask your nurse for information or bring the information to the clinic to discuss it.

Does it matter if I miss a dose of my medicines?

It depends on what medicine you miss.

- **NSAIDs and analgesics** – missing the odd dose will make little difference but you may feel a little more stiff and sore.
- **Methotrexate or sulphasalazine** – missing the occasional dose will make little difference. But after several missed doses, you risk a serious flare-up in your arthritis.
- **Steroids** – ***these should NEVER be missed*** as you can become ill very quickly. If you do forget to take a tablet or if you are sick (vomit) within an hour of taking your regular dose, then repeat the dose as soon as you remember. If you forget to take steroids over several days you may feel dizzy and have headaches and abdominal pain, and you must tell your doctor immediately. **Carry your steroid card with you at all times** (e.g. in a wallet or purse) – this will help to remind you and, importantly, others if you are too unwell to tell someone else (for example, if you were in an accident and needed to be treated by a doctor who does not know you).

PHYSIOTHERAPY AND OCCUPATIONAL THERAPY

When you have arthritis you may experience pain, swelling, stiffness, restriction of movement or weakness of your muscles. These problems may cause difficulties with everyday activities with your family and friends at home, at school, college or work.

Physiotherapy and occupational therapy can help your arthritis and can give pain relief, improve your ability to get on with life, and give exercises to stretch soft tissues and build up muscles and improve your heart and lung fitness.

Your therapists (physiotherapist and occupational therapist) will assess you and will develop a programme for your individual needs and give you advice about equipment, joint protection and gadgets and adaptations available to help you.

Pain relief

There are various ways to relieve pain, such as heat, cold, TENS, acupuncture, massage, hydrotherapy and relaxation.

Exercise

As a general rule you should try to exercise each day.

- Your general fitness will be helped through regular exercise, especially swimming. Weight-bearing exercise (such as walking) will help prevent osteoporosis.
- Your therapist may advise other exercises to increase flexibility and strength of muscles which may help prevent damage to the joints and maintain and increase the range of movement.

- Try to set aside 15–20 minutes each day to 'work out'. This does not need to be too energetic but you should check that each joint in your neck, spine, arms and legs moves fully. As your arthritis becomes controlled and your general fitness improves you can make the exercises a bit harder (for example by using weights – but see below).
- It is best not to use free weights without first getting advice from your physiotherapist, but instead to use equipment such as a multigym where the weights are controlled.
- If you have a 'flare' or a specific joint problem your physiotherapist will help you to improve or regain your strength.

Posture

For the body to work efficiently, a good upright posture is important. This means keeping the muscles strong enough to keep the back straight, with the shoulders relaxed but held back and the head up. This is particularly important when you are sitting using a computer.

Splints and insoles

The use of splints to rest or protect a joint may be needed. The wrist joints are often a problem as your written and computer work at school increases. Splints for the wrist will help to stabilise the joint and give support to allow you to keep going for longer periods. Combined ankle and foot splints will assist weak ankles and hold the heel in a good position. Insoles will give added support to the foot and ankle and can often help to relieve pain in the knees and hips.

Joint protection (avoiding certain types of strain on the joints)

It is important to be aware of joint protection even if your arthritis is well controlled. The muscles and soft tissues which hold your joints in place can be put under strain as you use them. Use support for the joints if necessary and ensure that your muscles are as strong as possible. (See **arc** booklet '[Looking After Your Joints When You Have Rheumatoid Arthritis](#)'.)

Personal hygiene and grooming

Due to stiffness and pain in your joints or weakness of your muscles you may have difficulty in reaching some parts of your body. Equipment can be bought to help with this so that you can manage your daily routine of toilet and grooming. For example, a hairbrush can be adapted by adding longer handles or larger grips. The occupational therapist can give advice and provide equipment to help you be independent – for example, an aid to get in and out of the bath.

Clothes

It is important that you can wear the clothes and shoes that you like. Sometimes difficulties with dressing can be overcome by using Velcro fastenings and elastic.

Mobility

Walking is a good exercise and is an important part of life, allowing you to join in with everyday activities such as shopping with family and friends. Most young people with JIA have normal mobility. However, it is important to allow extra time to get from place to place especially if you have to use stairs. There are times when **crutches** may be needed to help with walking, allowing you to maintain your independence. If you find walking distances becomes a problem then a **wheelchair** may be used. To ensure you get the right wheelchair for your needs then an assessment will be necessary. A wheelchair is to aid your mobility and not to replace it.

CAN JOINT REPLACEMENT SURGERY HELP TREAT JIA?

Occasionally JIA can result in joint damage that can cause pain and difficulties with daily activities, for example walking. Joint replacements are now a very successful treatment in adults with arthritis. They are very effective in relieving pain and improving mobility and can last many years. In a young adult, joint replacement surgery is very effective but is much less common, so you may be referred to a specialist centre if joint replacement surgery is needed.

Further reading: arc booklets '[A New Hip Joint](#)', '[A New Knee Joint](#)'.

A HEALTHY LIFESTYLE

Everyone can improve their general health through healthy eating, regular exercise, adequate sleep and avoiding smoking, illegal drugs and too much alcohol.

- **Does exercise help my arthritis?**

Everyone should work their muscles and joints to maintain the flexibility of the body and improve strength and stamina. Exercise is important for the general fitness of your heart and lungs, and it protects against osteoporosis and helps you to relax. Regular exercise and sports should be enjoyable and are a great way to meet new friends. Most sports are suitable for you to join in (especially swimming) but you can ask for advice from your doctor, nurse or therapist.

- **Can changing my diet help my arthritis?**

Generally speaking you should aim for a well-balanced diet with plenty of fruit and vegetables and a high fibre content, avoiding too much fat. You should also have lots of calcium-rich foods (for example milk, cheese) to help prevent osteoporosis. There are lots of 'old wives' tales' about diet and arthritis – these are often unproven. Be careful not to have a diet which doesn't contain enough vital foodstuffs – this can cause problems in itself (such as anaemia).

*Further reading in this booklet: **Part 2 – About Transition**.*

*Further reading elsewhere: **arc** booklet '**Diet and Arthritis**', NOS booklet '**Osteoporosis and Diet**'.*

WHAT ABOUT 'NATURAL' OR 'COMPLEMENTARY' THERAPIES?

There are many people who make claims for certain treatments that are not 'conventional' medicines. Some of these may be helpful, but there is little evidence to support their use in everyone with JIA. The internet has lots of information on many products. Be cautious – many products are advertised heavily and can be very expensive – and may well not work. Discuss your queries with your doctor or nurse.

*Further reading: **arc** booklet '**Complementary Therapies and Arthritis**', Arthritis Care booklet '**Alternative Remedies**'.*

Why do I need to be seen regularly in clinic?

The rheumatology team will want to see you regularly to ask how you are, examine your joints (you may want to wear shorts and t-shirt to be examined in) and may want to do tests to make sure that the medicines are working for you and monitor for any side-effects of these or any problems associated with the arthritis itself. It is important for the doctor to check on your general health including growth (height and weight) and changes of puberty. Your clinic visit is also an opportunity for you to ask questions. The rheumatology team may well be able to help with concerns about school or college work and will be keen to discuss your plans for the future.

What happens to JIA in the long term?

In most cases, children's arthritis has a good outcome, with 70% of people having no problems as adults. You should look forward to a future that is no different from your friends' and classmates'. Many young people with JIA have achieved highly, with good jobs and satisfying, fulfilling lives.

In about 30% of cases, arthritis can remain active into adult life. Some young adults with JIA have joint damage that limits their daily activities to some extent and a few may need **joint replacements**. Other problems can sometimes occur. Some people are physically smaller than average or have **osteoporosis** as a result of their arthritis and/or treatment with steroids.

A successful outcome in JIA requires many things. How you approach it can make a big difference. You need to be looked after by a team experienced in dealing with JIA working with your family doctor. Just as important, though, you need a caring, helpful environment with family, friends and teachers, as well as health professionals. You also need to know how to get help that you can understand, know who to approach and be confident enough to ask for support and advice.

*Further reading: '**CHAT 2 Parents – Arthritis in Teenagers**', a booklet for parents of young people with JIA, available from Arthritis Care (see **Useful books** below).*

PART 2 – ABOUT TRANSITION

This section discusses how JIA can affect the way you make the transition into adult life. You need to think about a range of issues, including your general health and lifestyle, your plans for adult life and your relationship with your doctor.

About your general health

Adolescence is an exciting time when you go through many changes – in the way your body looks, what is happening at school and in your social life. Arthritis can affect many of these changes and these changes can affect your arthritis. Your rheumatology team will be interested in any concerns or worries you may have in these areas. One way the rheumatology team remembers to ask about these things is to use the term 'HEADS' as a simple checklist, as in the headings below.

Home

As you grow up, your relationship with your family changes. Sometimes this happens without any problem but sometimes there may be tension and disagreement – the 'storm and stress' of adolescence. Your family can be valuable allies and it is important to keep talking to them, even if you don't agree all the time!

Most young people will want to leave home and set up their own home. In order to do this, it is important for you to learn how to become independent and confident in looking after yourself. You may need help from others to achieve these goals, as may your parents who can find it difficult to 'let go'. Sometimes they too need some patience and understanding!

Education (and beyond)

'What do you want to do when you grow up – and how are you going to make it happen?' This is a very important question and a good education is a very important part of the answer. Teachers, Careers Counsellors, occupational therapists or Disability Employment Advisers are key people for advice in this area. However, education is not the only factor to be considered – there are other important aspects to preparing for the world of work:

- learning to speak up for yourself
- being aware and knowledgeable about arthritis and how it affects your life
- gaining work experience
- becoming independent at home, at school and in your health care.



Activities

Friends outside your family circle become increasingly important the older you get – a happy social life is important for your self-esteem and well-being. Learning to drive may help you to be less dependent on your family (e.g. for lifts) and will also help when you become an independent working adult.

Keeping as physically fit as possible is also important – doing some form of exercise 2–3 times a week is important for all young people whether they have arthritis or not. Weight-bearing exercise, for example walking, running, dancing or racket sports, is particularly important to protect against thin bones (osteoporosis) later in life.

Drugs

Adolescence is the time when many people first meet alcohol, cigarettes and illegal drugs. You may feel tempted or pressurised to try them out. It is important for you to understand the risks and the side-effects of these on your health before you decide to try them. Illegal drugs and/or alcohol can interact with medication used for arthritis. For example, you should not drink more than 5 units of alcohol per week when you are taking methotrexate (see section '[Avoid drinking alcohol](#)').

If you have any questions or concerns in this area there are many sources of information and people who will listen in confidence, including your rheumatology team – so please ask.

Sex

As you grow up, you become aware of your own sexuality. Sometimes this causes worries for you and may be difficult to talk about. You may be concerned about looking different from your friends and worry about forming relationships and being attractive. You may worry whether joint pain or affected joints will cause problems physically with having sex. Concerns like these are often helped by talking to someone in confidence. From a practical point of view, for example, comfortable positions to use during sex can be suggested which are good for both partners, with and without arthritis.

If you do become sexually active, it is important to practise safe sex and use condoms. If you are on drugs like methotrexate, contraception is *vital* as these drugs can cause harm in an unborn baby. For all women who are sexually active regular cervical smears are important. The rheumatology team will be willing to listen to any concerns you have relating to your sexual health, and to give helpful advice. Don't be afraid to ask.



How can I get help?

It is important that you feel that the issues above are discussed with someone who will listen in confidence and not be judgemental in their advice. The person or people you choose to confide in will depend on your individual circumstances. However, think about talking to a member of your rheumatology team (doctor, nurse, or therapist) or your school/college nurse or tutor.

The school/college nurse and doctor should be told that you have arthritis; this will help the school to understand the illness and any problems you may face now or in the future. It is important that your views on who should tell your school are considered. This could be by you, your parents, your rheumatology team or your GP. The school nurse and doctor will also be able to give advice on general health issues such as diet, skin, hair, teeth, weight problems, sexual health, contraception, bullying, smoking. They can discuss issues with you in confidence, and should ask if your parents should be informed.

Remember you can register with a GP in your own right when you are 16 years old. The relationship with your GP is confidential and your parents will be informed only if you give permission to your GP.

There is a lot of information available – a list of books, booklets, web sites and postal addresses appears in the section below.

Further reading in this booklet – section '*How is JIA treated?*' (covering medicines, physiotherapy, occupational therapy, diet and exercise).

More about transition

Transition is the term used to describe the many changes which take place between being a child and developing into an independent adult. It is the broad term used to describe the process of 'growing up'. The so-called 'tasks of transition' are the same whether you have arthritis or not and include:

- developing your personal and sexual identity
- becoming independent from your parents or parent figures (this includes taking responsibility for health, education, managing money matters, being able to 'stand up for yourself', being independently mobile and running a home)
- developing relationships outside the family
- planning for the future, including finding a job or career.

These tasks of transition can be difficult for every young person whether they have arthritis or not. The process takes many years. Often much of it takes place in the so-called adolescent years between 12 and 19 years of age, but it varies from person to person. Some of the tasks may go on into your twenties.



How does having arthritis affect transition?

- For many young people with arthritis the transition will happen 'normally'. But for some young people, arthritis may persist into adult years from childhood, or arthritis may develop in the teenage years.
- Having arthritis when you are a teenager or young adult can seem especially tough. At this age, apart from having to cope with the arthritis and its treatment, you are also faced with a very important time at school or college with decisions to be made about career choices. Of course you are also facing many changes in your body, and developing new relationships with friends which may include sexual relationships.
- Having arthritis as a teenager or young adult may limit your lifestyle because of physical problems, for example not being able to walk far and having to rely on others such as parents for transport when friends are taking the bus or train independently.
- You may be anxious about developing relationships because you feel you look 'different'. Your social life may be affected because of the restrictions on drinking alcohol if you are taking methotrexate. You may feel singled out for 'special' attention by teachers, parents and doctors, which may mean that you miss time from school, college or work.
- Occasionally there are problems with bullying at school. If you are being bullied it is important to discuss such problems with friends, your parents and your teacher. This often stops the bullying quickly and with little fuss. Do not let the problem linger.
- Planning your future can be difficult because of uncertainty about how your arthritis affects you. Your education may be affected if you miss school or college through being unwell at times.
- Sometimes young people stop taking their medication, wearing their splints and doing their exercises. This can make your arthritis worse.

- Your doctor, nurse and therapists are often aware of many of the concerns you will have and will welcome you asking for advice; there is a lot of help available, much of which is mentioned in this and other booklets.
- It is very important that you discuss concerns with your rheumatology team, other health professionals or tutor/teacher – they may be able to help directly or point you in the direction of someone who can help.

Further reading: 'After 16 – What's New: Choices and Challenges for Young Disabled People'; 'Don't Pick on Me: How to Handle Bullying'; 'CHAT 2 Parents – Arthritis in Teenagers'.

The changing relationship with your doctor

As you grow older, your relationship with your doctor changes. As a child, your doctor would tend to talk *about* you to your parents. You probably did not have much say in deciding about your treatment, and your parents were responsible for your health care. As an adult you are expected to see a doctor on your own, explain your problems, understand the explanations and treatments given, and be responsible for your appointments and taking medication.

Transition involves this change-over of roles – you take on more responsibility for your own health care and your care is transferred from a Children's Department to an Adult rheumatology department. This may involve a change of doctor, physical therapists, nurse and even hospital. All this change can be difficult for you, your parents and your doctor.

You will probably need to discuss with your parents when you want to see the doctor on your own. Many parents have difficulty in 'letting go' and you may want to see the doctor with your parent(s) present for a few times, with your parents taking a 'back seat', before you see the doctor alone.

It is important that you know as much as you can about your arthritis, the treatment options and the likely outcome of your arthritis. Patient education is a very important role of the rheumatology team and you should feel free to ask questions. This should help build the relationship between you and your doctor. This relationship needs to be open, frank and with both sides able to discuss issues in a friendly manner, and with you being involved in the decision-making process. You should expect the opportunity to ask questions and understand the replies. All this takes time – it may not always be possible in a busy clinic – but at least you should be told about how to get more information.

If you are better informed, you will feel more in control. This usually means you cope better with your arthritis and are able to plan your future with greater certainty.

When should planning for transition start?

Planning for transition needs to start early (ideally as soon as possible once arthritis has been diagnosed), and needs to be carefully co-ordinated between you, your family, school and the rheumatology team. Transition is a gradual process that occurs within the day-to-day activities of family life, and school life.

The plan for transition should include:

- Your Education Plan – This may include a **Statement of Special Educational Needs** (see below).
- Vocational planning – This should include **Careers Advice** from an agency experienced in the counselling of people with arthritis and should link with **Disability Employment Advisors**. The plan should encourage job experiences, e.g. babysitting, Saturday jobs, to promote responsibility and encourage your financial independence (see sections on [Benefits](#), [Learning and Training](#), and [Work](#)).
- Your future rheumatological care – This will include details of the adult rheumatology team, the hospital, plans for monitoring of medication and an approximate date for transfer to adult healthcare.

Your paediatric rheumatology team should be responsible for drawing up the Transition Plan and you and your family should be involved. Ideally you should have a written copy.

It is important that you and your doctor discuss your future. Your doctor may be able to give advice on how your arthritis may be in the future – information that is vital to planning your higher education, career and work.

If you have arthritis, the school – and your timetable and routine – may have to be adapted to allow you to get to and around school. Your physiotherapist and occupational therapist will often give advice.

Some young people with arthritis have a '**Statement of Special Educational Needs**' which is put together after a formal assessment of your difficulties. This document is produced by one of your teachers and may contain advice

from those health professionals involved in your care, including your therapists, rheumatologist and GP. The Statement will identify special educational and other needs you may have, and must be reviewed annually. From when you are 14 years of age, this annual review will include input from the Careers Advisory Service and Social Services. If you have such a Statement then it will be part of your Education Plan.

A **Special Needs Co-ordinator (SENCO)** is the teacher who:

- is responsible for registering that you have special education needs and helps to prepare your Statement of Special Educational Needs
- ensures that your education planning is agreed between you, your parent(s) and the school
- is responsible for the day-to-day running of the plan, ensuring that it is effective and that your needs are met.

SOME REAL LIFE STORIES

Here are some real life histories from young people who happen also to have arthritis. The words are written by the people themselves but we have changed their names. They make the point that despite having arthritis, many young people are happy and lead rewarding lives. We hope you find them encouraging.

Mandy (aged 14)

My arthritis started when I was 8 and it affected my knees. I remember them being really swollen and feeling very heavy but they didn't hurt much. I wasn't ill but I knew my mum and dad were really worried about me. I went to the hospital and saw the doctor who told me and my mum that I had arthritis. I didn't know what it meant but I knew it must be bad because I heard mum crying later on when we got home. I had to take some medicine every day and then go into hospital a few weeks later to have an anaesthetic and have my knees drained and some steroid medicine put inside them when I was asleep. It didn't hurt a bit and I didn't have to stay in hospital. After that I had loads of exercises to do which were a bit boring to do at home but my physiotherapist was fun and we had a laugh. She explained why I had to wear splints on my knees at night.

I don't think my friends really believed me when I told them I had arthritis and that upset me a lot at the time. But after I had my knees injected my knees have never been swollen again and I was able to be normal again at school and start doing swimming and PE. When I went to Middle school, I remember that my knees were fine, I had no medicines to take and no exercises to do. I was really pleased that I got picked for the school swimming team. I have to go to the hospital about once a year to see the doctor and also have my eyes checked. When I leave school I don't know what I want to do yet, but I want to work with children. Maybe I'll be a nurse.

Susan (aged 37)

I have been happily married for 18 years. I have two children.

My arthritis is the systemic type and I don't really remember the time before it all began. I do remember that between ages 10 and 13 it was not a problem and then at 13 I had a nasty flare-up. This was in 1976 and at that time children were often in hospital for weeks or months. I was in hospital for 7 months. This was like being at boarding school and although we were naughty we knew we couldn't be expelled! I cried when it was time to leave and go home!

Whilst I was in hospital my family had moved house and then I had to change schools. I was 14 and this was probably my most difficult time growing up and having arthritis. I took a long time to settle in school and I was bullied and had to try and ignore unkind remarks. I made a few very good friends, but left at 16 with no regrets.

The experiences I had growing up have really helped me to have a positive outlook on life. I feel I am easy going – I had to mature early and now don't get stressed by little things. Overall I think that all my experiences have given me much more appreciation of other people's problems.

Louise (aged 21)

I was diagnosed as having JIA when I was 6. Between the ages of 6 and 12 my arthritis was a painful nuisance. For example, by the end of games lessons, my ankles and knees hurt or when teachers were picking girls to do the can-can in the class they didn't pick me. Certainly arthritis marked me out as different, something which I resented strongly, because to me arthritis was an irritation and not a central part of my life.

It was from 15 years of age that I remember the arthritis starting to take over. Gradually my mobility got worse. My hips and knees needed replacing. I look back on those years and feel sadness because it was a tough and painful

time. I was actually given the choice between extensive surgery or an electric wheelchair. Thankfully with the support of my family, I chose the first option.

Thankfully for me, my parents were happy to support me while I went back to college. I then continued on to University where I did a degree in communication. I firmly believe that it doesn't matter that I qualified later than my peers. It certainly hasn't affected my career prospects. I've been working now in Public Relations for 2 years and have recently moved into my own flat. Independence has been something I've had to work for and as a result means a great deal to me. Arthritis can be a painful nuisance: but it is not the sum of Louise C.

Sandra (aged 46)

I've had JIA for nearly 40 years. I was diagnosed when I was 4 years old. I had to go to hospital clinic a lot but was able to go to the local school and join in most activities, medication and physiotherapy permitting. By the time I was 11, my arthritis was under control and I enjoyed a relatively pain-free adolescence (if there is ever such a thing) with dancing, hiking, camping, and cycling. I learned to play two instruments, rang church bells and studied for my A levels. By the time I was 20, I had married, and had one daughter and another on the way. However, it was after the birth of my daughter that I began to get more joint pain which eventually led to a series of hip operations and I started back on medication.

Twenty-one years later, my daughter has married and made me a grandmother, and my son has completed his degree and has a good job, while my husband and I are looking forward to our silver wedding next year. During those 25 years I have learned to drive (eventually), have passed an Open University degree and have brought up two children as well as having a busy full time job as a manager in a local authority for the last 10 years. I have served on various committees, am a school governor and have worked with young people in a voluntary capacity for the last 12 years. During all that time, I have had short spells of time in hospital, and continued to exercise and take my medication. I have always enjoyed the support of all my family, especially my long-suffering husband and find belonging to an arthritis self-help group to be invaluable. I look forward to have more grandchildren to share and a second honeymoon next year and maybe the year after that as well!

Nicholas (aged 17)

I have had arthritis since I was 12. It started in my feet and I was really shocked when I was told I had arthritis. My gran has arthritis and she had to have new knees so I was really scared. I had to have steroid injections into my knees and ankles – it was really hard telling my mates why I was missing school – I'm sure they thought I was skiving, when I was going to the physiotherapist or the clinic for blood tests or see the doctor. I hated having arthritis and wanted it to go away. I wanted to be a fireman but the career officer said 'forget it'.

I've been taking methotrexate since I was 13. I know it has helped my arthritis, but I hated it because I knew I couldn't drink [alcohol] with it – what was I supposed to do when my friends were going out for a laugh at the weekend? I wanted to be just like them and have a few drinks, so I stopped taking the tablets. I got scared though because my arthritis got worse. Then when I started it again, I was still drinking and used to lie to the doctor and say I didn't drink [alcohol] at all. I didn't like telling her lies but I was scared she'd stop the methotrexate and then my arthritis would get worse again. I didn't know anyone else of my age with arthritis and hated being different. I was really fed up. Then one night at the pub I met David with his girlfriend who was my best friend's sister. David is 28 and has arthritis. He has new hips and knees. He drives a car and has a job. His arthritis is much worse than mine, but he was a laugh. He is on methotrexate too. He told me I could drink [alcohol] a 'bit'. He told me to check with the nurse at the clinic. She said it was OK to drink 5 units a week and that lots of teenagers ask the same question. I talked with her a lot and I understand more about my arthritis and that methotrexate is helping me to feel better. I feel better in myself and know that I have to accept my arthritis is there, but I can still get on with my life. I'm going to college to do A-levels and want to be a journalist.

USEFUL BOOKS, BOOKLETS AND ADDRESSES

USEFUL BOOKS

After 16 – what's new: choices and challenges for young disabled people

David Fulford-Brown, edited by Alison Cowen. The Family Fund Trust, PO Box 50, York YO1 9ZX. Phone: 01904 621115. ISBN 0953607801. Free to young disabled people and their parents/carers, £10 to others.

Getting on!

A guide to choices at 16. A student guide and workbook produced by the Careers Research and Advisory Centre. Available from Plymbridge Distributors Ltd, Plymbridge House, Estover Road, Plymouth, Devon PL6 7PY. Phone: 01752 202301. ISBN 1860173357. £3.50.

It's your choice: A guide to choosing the next steps at 16

Free of charge. Published every year by the Careers and Occupational Information Centre (COIC), PO Box 298A, Thames Ditton, Surrey KT7 0ZS. Phone: 020 8957 5030.

Don't pick on me: How to handle bullying

Rosemary Stones. Piccadilly Press, London. Available in good bookshops, £5.99. ISBN 185341595.

CHAT 2 Parents – Arthritis in teenagers

For parents of young people with JIA. Arthritis Care, 18 Stephenson Way, London NW1 2HD. Phone: 020 7380 6500.

USEFUL BOOKLETS

Produced by the Arthritis Research Campaign (arc)

Complementary Therapies and Arthritis
Sexuality and Arthritis
Tim Has Arthritis
Blood Tests and X-rays for Arthritis
Diet and Arthritis
Feet, Footwear and Arthritis
Beginner's Guide to the Internet
Drugs and Arthritis (information sheet)

Produced by Arthritis Care

The Balanced Approach – A guide to medicines and complementary therapies
Our Relationships, Our Sexuality – A guide for people with arthritis

Produced by Young Arthritis Care

Empowering Young People with Arthritis – How Young Arthritis Care can help you

USEFUL WEBSITES

Arthritis Research Campaign (arc)

www.arc.org.uk

Arthritis Care

www.arthritiscare.org.uk

Children's Chronic Arthritis Association

www.ccaa.org.uk

After 16 – What's New?

www.after16.org.uk

General health

www.teenagehealthfreak.com

National Drugs Helpline

www.nationaldrugshelpline.co.uk

Brook (sexual health and contraception advice)

USEFUL ADDRESSES

Please note: the addresses in this section are grouped as follows: General; General health; Learning, working and benefits; Mobility

General

The Arthritis Research Campaign (arc)

PO Box 177
Chesterfield
Derbyshire S41 7TQ
Phone: 0870 750 5000

As well as funding research, we produce free booklets such as this and a range of many others. Please contact the address above for a list of titles or, on this web site, see [Publications for People with Arthritis](#).

Young Arthritis Care

18 Stephenson Way
London NW1 2HD
Phone: 020 7380 6500
Helpline ('The Source') for young people with arthritis: 0808 808 2000 (Mon 10am–2pm, 4–7pm; Wed–Fri 10am–2pm)

Runs support groups for younger people and a helpline service.

Children's Chronic Arthritis Association (CCAA)

Ground Floor Office, Amber Gate
City Walls Road
Worcester WR1 2AH
Phone: 01905 745595

British Society for Rheumatology

41 Eagle Street
London WC1R 4TL
Phone: 020 7242 3313

An organisation for medical professionals working in rheumatology.

GLOSSARY OF TERMS

Anaemia – a lack of red blood cells (haemoglobin). Also called a low blood count. Anaemia makes you feel tired.

Autoantibodies – these are proteins in the blood which are present with certain rheumatic conditions. Rheumatoid factor and anti-nuclear factor are autoantibodies.

JIA – juvenile idiopathic arthritis. This replaces the old name juvenile chronic arthritis (JCA). Juvenile means under 16 years, idiopathic means the cause is not known and arthritis means inflammation of joints.

Nodules – small painless lumps (often on the elbows).

Occupational therapist – a therapist who helps you to get on with your daily activities (such as dressing, eating) by giving practical advice and assistance. (See **arc** leaflet '[Occupational Therapy and Arthritis](#)').

Ophthalmologist – a doctor who specialises in eye problems.

Osteoporosis – thinning of the bones.

Physiotherapist – a therapist who helps to keep your joints and muscles moving, helps ease pain and keeps you mobile.

Psoriasis – a scaly skin condition. (See **arc** booklet '[Psoriatic Arthritis](#)').

Rheumatologist – a doctor who specialises in problems with joints.

TENS – transcutaneous electrical nerve stimulation. A device which uses small pulses of electricity to relieve pain.

Transition – the process of change between being a child and being an independent adult.

Uveitis – inflammation of the eye.

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