Self-help and daily living

When your child has arthritis

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This booklet provides information and answers to your questions about your child and arthritis.

What do I need to know about if my child has arthritis?

If you're told that your child has arthritis you'll probably have lots of questions. In this booklet we'll tell you all you need to know; we'll describe the different types of arthritis, outline the best treatment and offer practical advice on living with and supporting a child with the condition.

At the back of this booklet you'll find a brief glossary of medical words – we've underlined these when they're first used in the booklet.

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At a glance

When your child has arthritis

Arthritis affects 1 in 1,000 children and young people in the UK.

What is juvenile idiopathic arthritis (JIA)?

- **Juvenile** means that the arthritis began before the age of 16 years old.
- **Idiopathic** means that the cause is unknown.
- **Arthritis** means that one or more joints are inflamed (i.e. they can be swollen, painful and stiff, and there may be limited movement).

JIA is really a group of illnesses put under the same name because they share similar symptoms. There are several different types of JIA: oligoarthritis, polyarthritis, systemic-onset JIA, psoriatic arthritis and enthesitis-related JIA.

How is it diagnosed?

Diagnosis is usually made based on your child's medical history and a physical examination. Doctors will try and do as few tests as possible to allow them to be sure of their diagnosis. However, they may need to do some blood tests. Other tests may be needed if your child has systemic-onset JIA to rule out other illnesses. Regular eye tests are very important to check for inflammation in the eye (uveitis).

What treatments are there?

The best care for your child is a combination of medicines (drug treatments) and an active exercise programme.

Medications may include:

- non-steroidal anti-inflammatory drugs (NSAIDs)
- disease-modifying anti-rheumatic drugs (DMARDs)
- biological therapies
- corticosteroids.

Exercise is important for people of all ages to keep you fit, and it's helpful in arthritis to keep muscles strong and build stamina. This will help your child to get swollen, painful joints moving again and slow down the effects of arthritis.

How can I help?

Looking after a child with arthritis can be challenging on the whole family. You may find the following helpful:

- It's important to stay positive and not see your child as a patient.
- Be flexible with plans – arthritis can be unpredictable, with good days and bad.
- Find time for yourself, your partner and other children in the family.
- Be aware of and use the support offered by your hospital team, support groups, your child's school, the government and other families in the same situation.

What will happen in the future?

Many children and young people will grow out of JIA as they enter adulthood, although it's difficult to predict this for each individual. It's important for you to reassure your child and encourage them to become more involved in their own treatment. Young people growing up with arthritis may become concerned about the following:

- an increasing desire to be more independent
- adjusting to life with a long-term (chronic) condition
- body image issues
- bullying or teasing
- physical problems such as extreme tiredness (fatigue)
- cigarettes, alcohol and illegal drugs
- sex and relationships.

It's important that you're able to talk to your child about these issues, or let them know where to go to get advice. Their hospital team, GP or school will listen to any concerns and give helpful, practical advice.

Part One: About the condition

What is juvenile idiopathic arthritis (JIA)?

Arthritis in children is called juvenile idiopathic arthritis, or JIA. It's really a group of illnesses which have been put under one name because they share similar symptoms:

- **Juvenile** means that the arthritis began before the age of 16 years old.
- **Idiopathic** means that the cause is unknown.
- **Arthritis** means that one or more joints are inflamed (i.e. they can be swollen, painful and stiff, and there may be limited movement).

Most children and young people won't have lasting problems from childhood arthritis and will lead full, active lives as adults.

What does JIA mean for my child?

JIA can begin at any age, although it most commonly shows up in younger children. It can develop in boys or girls, although most types are more common in girls. For the vast majority of these children, arthritis isn't the same as in adults.

Even though we're still unsure what causes JIA, we know a great deal about it and how to treat it. With the right management most children and young people with JIA can lead independent, active lives.

The best care for your child is achieved through the whole family working together with health professionals to find the most suitable medicines, keep up the right exercises and tackle other issues as they arise. You can make a real difference to the way your child comes through JIA.

What does the future hold?

It's very difficult to predict how arthritis will affect your child because every young person has a different illness and responds differently to treatment.

There's no cure for JIA but many children and young people go into what doctors call remission, which means their symptoms disappear – sometimes forever. Up to 3 in 5 children will have few or no physical problems as adults, but for some children and young people, arthritis can cause some longer-term problems, including:

- continued use of medicines to control their arthritis

- joint damage
- bones becoming thinner (osteoporosis)
- the need for joint replacements.

What are the different types of JIA?

There are several types of arthritis grouped together under the umbrella term JIA. The different types of JIA tend to have different patterns and effects.

Oligoarthritis

This is the most common form of JIA. But what does the name mean?

Oligo = few.

So this form of JIA is where only a few joints (less than 5) are swollen.

Who gets it?

Oligoarthritis most commonly develops in under-5s, and girls are affected more than boys in this age group. In older children (for example age 8 and above) this type of arthritis is more likely to affect boys.

Key information

What you should know about oligoarthritis:

- Oligoarthritis affects about 60% of children and young people with arthritis and most commonly affects one or both knees, the ankle and wrist joints and sometimes the elbows and small joints of the hands and feet.
- This form of arthritis is often mild and is the most likely to go away and leave little or no damage to the joints.
- This type of arthritis has the highest chance of your child developing chronic anterior uveitis (inflammation of the eye), so they'll need regular eye checks with an ophthalmologist (eye specialist). This eye inflammation doesn't cause a red or painful eye but still can cause reduced vision if it isn't treated, so regular checks are very important.

What should I look for?

In young children the first sign for parents may be when a child stops walking after learning to toddle, or never actually takes to walking. Some children with oligoarthritis don't complain of pain but they can seem moody and difficult. Stiffness of the joints in the morning is quite common.

What will happen in the future?

Many children and young people with oligoarthritis never have more than 4 joints affected throughout their childhood. This is called **persistent oligoarthritis**. Most will recover with few or no lasting effects after 3–4 years, provided they have adequate treatment including physiotherapy and exercise. For the remaining children, the disease spreads to more joints after the first 6 months. This is called **extended oligoarthritis**.

Polyarthritis JIA

This is the next most common type of JIA. But what does the name mean?

Poly = many.

So polyarthritis is where many joints are swollen. There are two forms of the condition, depending on whether your child tests positive or negative for rheumatoid factor (RF). This will be shown by a blood test.

Who gets it?

About 1 in 5 children with arthritis (20%) has polyarthritis. Polyarthritis can begin at any age. When it occurs in the teenage years, particularly in girls, it may be similar to adult-type rheumatoid arthritis. Early treatment to slow the disease and prevent long-term damage is important.

Key information

What you should know about polyarthritis (rheumatoid factor **negative**):

- Most children and young people with polyarthritis will have a test which shows negative for rheumatoid factor (RF-negative).
- This form of JIA can start at any age and can be a very mild illness, or it can be more severe.
- It usually affects the joints of the hands and feet. It may affect the hips, knees, neck, elbows, shoulders or jaw. The tendons in the hand can also become sore.
- It may come on suddenly, where several joints may become sore and swollen at the same time, or it can steadily involve more joints over a period of months.

What you should know about polyarthritis (rheumatoid factor **positive**):

- About 1 in 10 children with polyarthritis (10%) are RF-positive. Overall, this is less than 5% of all JIA.
- Most children who are RF-positive are girls, usually aged 10 or older.
- Early treatment is important to slow down the disease and prevent long-term damage.
- This group of children can have quite a severe form of disease which needs to be actively treated with medication to avoid damage to the joints.

What should I look for?
Children with polyarthritis can seem generally unwell, tired and may develop a slight fever when their joints are affected.

What will happen in the future?
The symptoms may continue into adult life but the condition can go into a state where all the symptoms disappear. This is called remission. About a quarter of children with RF-negative polyarthritis will go into remission, while the rest will continue to have some joint problems.

Enthesitis-related JIA
This form of JIA affects the places where tendons attach to the bone (these places are called entheses), causing inflammation. It often affects the joints of the leg and spine.

Who gets it?
Enthesitis-related JIA usually affects boys over 8, but can occur in girls and in younger children as well. It usually affects boys more than girls.

Key information
What you should know about enthesitis-related JIA:

- It mainly affects the lower limbs, in the hips, knees, ankles and sacroiliac joints (where the base of the spine joins the pelvis).
- There may be a family history of ankylosing spondylitis or inflammatory bowel disease because of a particular genetic marker called HLA-B27.
- About 3 in 4 children with enthesitis-related arthritis (75%) carry the HLA-B27 gene.
- In contrast to the uveitis seen with the other types of JIA, this type is associated with a red painful eye – acute anterior uveitis.

What should I look for?
This type of arthritis can start like many other forms with back ache and joint pain, for example in the tendons at the heel. If your child develops a painful red eye, they should see their doctor immediately.

What will happen in the future?
Although some children will get completely better, about 30–40% will have problems in adulthood. Children with family members with ankylosing spondylitis may have more chance of developing future problems.

Psoriatic arthritis
Psoriasis is a scaly skin rash, and with this you can also get joint pain known as psoriatic arthritis.

Who gets it?
Fewer than 1 in 10 children with arthritis (10%) has psoriatic arthritis. This type of JIA usually develops at around 8–9 years old and is more common in girls.

Key information
What you should know about psoriatic arthritis:

- This is a rare form of arthritis, linked with the scaly skin rash of psoriasis, although the psoriasis may not develop until later.

- Sometimes the fact that another member of the immediate family has psoriasis suggests that psoriatic arthritis is the cause in the child's case.
- This arthritis usually affects the fingers and toes, but it may affect other joints too.
- Uveitis is also fairly common but it's the painless type that doesn't look red.
- The joints may be affected before the skin rash appears – your doctor may look closely at fingernails and toenails for early signs of psoriasis and may ask if anyone in your family has the condition.

What should I look for?

The most obvious thing to look for is the skin rash associated with psoriasis.

The different types of JIA tend to have different patterns and effects.

What will happen in the future?

Some children with the condition get completely better and can come off all medication, but between 30–40% will have ongoing disease into adulthood.

Systemic-onset JIA

This is the rarest type of JIA. The word systemic means affecting the body as a whole, rather than particular parts. This is the most difficult type of childhood arthritis to diagnose and children and young people may be ill for some time before doctors make an exact diagnosis.

Who gets it?

About 1 in 10 children with JIA (10%) has systemic arthritis. It occurs in boys and girls equally and often starts in under-5s.

Key information

What you should know about systemic-onset JIA:

- In this form of arthritis, joint pain is part of a general illness involving fever, tiredness, rash, loss of appetite and weight loss.
- Very occasionally, the inflammation can affect the covering of the heart and, even more rarely, the covering of the lungs.
- 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 for you and your child.
- Once diagnosis is confirmed treatment can begin quickly to bring down the fever and make your child feel better.
- The long-term development of this form of JIA can be difficult to predict but usually the fever and rash will settle, although the arthritis may sometimes continue for several years before settling.

Figure 1
Systemic arthritis often starts with a persistent fever.

What should I look for?

Systemic-onset JIA usually begins with a particular kind of fever lasting several weeks. Usually the child has a very high temperature (up to 40°C or 104°F) once or sometimes twice a day, often in the evenings (see Figure 1).

You may notice a blotchy, salmon-pink rash on the child's thighs, arms or body. This often appears at the same time as the highest temperature. Glands in the neck, armpits and groin may be swollen. Not surprisingly, children with systemic-onset JIA may be generally miserable, irritable and off their food. Problems with the joints may appear at the same time as these symptoms, but they may appear later.

What will happen in the future?

Some children recover after one bout of systemic-onset JIA and suffer no long-term problems.

Others will have repeat episodes of illness (flare-ups) for several years. Some go on to develop arthritis in many joints (polyarthritis) without further fever attacks.

Undifferentiated arthritis

Occasionally, children and young people don't fit neatly into the above groups and their condition is defined simply as undifferentiated arthritis. It may not seem a very useful category, but it's one that doctors sometimes have to use.

How is JIA diagnosed?

As there's no specific test to indicate JIA, doctors have to base their decisions on what your child tells them, what you tell them about your child, what they find through an examination and, in some children and young people, on tests they carry out to rule out other possible illnesses.

What tests are there?

Doctors will try to do as few tests as possible to allow them to be sure of their diagnosis. Even so, they may need to do some blood tests to make various checks. These may need repeating to keep a watch on the condition.

Blood tests

Blood tests can be upsetting for some children, but normally an anaesthetic (numbing) cream (such as Ametop or Emla) or 'magic cream', or anaesthetic spray, is put onto the skin to numb the area before blood is taken so your child shouldn't feel anything.

The most common blood tests are:

- **Full blood count (FBC)** – measures haemoglobin to find out whether your child is lacking in red blood cells (anaemic) and measures the number of white cells and platelets, which may be high (raised) if your child has inflammation.
- **Erythrocyte sedimentation rate (ESR)** – measures how quickly the cells in the blood settle when they're left to stand in a tube (this shows how much inflammation the arthritis has caused).
- **C-reactive protein (CRP)** – measures concentrations of this protein in the blood, which can show inflammation or disease activity.
- **Urea and electrolytes (U&E)** – measures how well the kidneys are working.
- **Liver function tests (LFT)** – measure how well the liver is working.
- **Autoantibodies test** – checks for certain antibodies, such as:
  - rheumatoid factor (RF) antibodies for polyarthritis
  - anti-nuclear antibodies (ANA), especially if your child has oligoarthritis, to find out whether they're at greater risk of chronic anterior uveitis.

Doctors will need to do tests to be sure of the diagnosis, but they'll try to keep these to as few as possible.

Eye tests

It's essential that all children with JIA have regular eye checks to look for inflammation in the eye. This has to be done by a specialist eye doctor (an ophthalmologist). The type of uveitis associated with the majority of JIA is chronic anterior uveitis, which is painless and not associated with any redness of the eye. This means it's difficult to diagnose without a special test called a slit lamp examination. If it's left untreated, chronic anterior uveitis can cause blindness, although regular tests and effective treatment mean this is very rare.

The eye checks are painless, although your child may find them a bit uncomfortable or simply not want to sit still. The ophthalmologist will check your child's general vision and then examine their eyes for signs of uveitis using a slit lamp microscope. The ophthalmologist may also put in drops to enlarge (dilate) the pupil to look at the back of the eyes. This can sometimes cause blurring for a while but this should clear in a day or two.

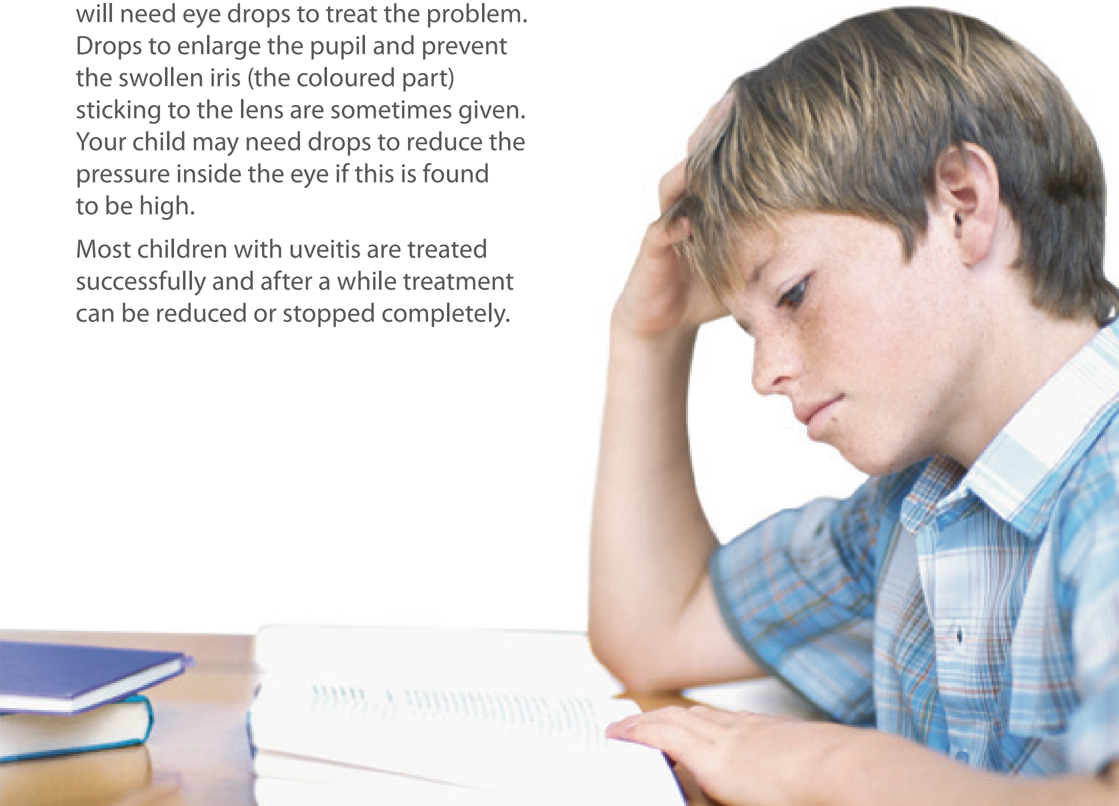
If the checks show up uveitis, your child will need eye drops to treat the problem. Drops to enlarge the pupil and prevent the swollen iris (the coloured part) sticking to the lens are sometimes given. Your child may need drops to reduce the pressure inside the eye if this is found to be high.

Most children with uveitis are treated successfully and after a while treatment can be reduced or stopped completely.

Other tests

If doctors suspect systemic-onset JIA your child will undergo several tests to rule out other, more serious, illnesses. This may include:

- taking a bone marrow sample to rule out leukaemia
- magnetic resonance imaging (MRI) or ultrasound scans, used to check how much a joint is affected
- x-rays, which are often done when the child first comes to hospital
- a bone scan, which may help to rule out more serious illnesses that can cause pain in joints or bones.



What treatments are there for JIA?

The key to the best care for your child is early treatment with effective medicines, an active exercise programme and making sure they keep up with things like school and leisure activities.

Making sure your child has the best treatment as soon as possible will slow down the disease and reduce long-term damage to their joints. In the same way, starting exercises early and sticking to them will make your child as mobile as possible and protect their joints from damage.

Drugs

The rheumatology team will take care to use the medicine which works best to control arthritis in your child with the fewest side-effects. There are several kinds of medicines involved.

Non-steroidal anti-inflammatory drugs (NSAIDs)

NSAIDs help reduce pain, stiffness and swelling, which helps prevent lasting damage. The most commonly used NSAIDs are ibuprofen, diclofenac and naproxen. Most are taken by mouth in liquid or tablet form. Most children and young people with JIA take NSAIDs. If your child has mild arthritis, this may be the only medicine they need.

Drugs may be available under several different names.

Each drug has an approved (or generic) name but manufacturers often give their own brand or trade name to the drug as well. For example, Nurofen and Panadol are brand names for ibuprofen and paracetamol respectively, which are the approved names. The approved name should always be on the pharmacist's label even if a brand name appears on the packaging, but check with your doctor, nurse or pharmacist if you're in any doubt.

What are the side-effects?

Every medicine has some side-effects. With NSAIDs these may include:

- loss of appetite
- stomach pain
- rashes (especially when out in the sun)
- wheezing may sometimes increase if your child is prone to asthma.

Talk to your doctor if you notice your child has any of these. Sometimes the doctor will give your child a medicine called a proton pump inhibitor (PPI) such as omeprazole to protect their stomach from side-effects. Occasionally NSAIDs may cause some inflammation in the kidney.

Local steroid injections

Local steroid injections into a joint are commonly given and are very effective. They can reduce pain and swelling immediately. The steroid is injected directly where it's needed and so very little affects the rest of the body. This means that harmful side-effects are avoided. Young children are usually given a light general anaesthetic for joint injections. Older children may have just a sedative, gas and air (entonox) or a local anaesthetic. It may be a bit uncomfortable but shouldn't be painful. Sometimes doctors may remove the fluid which has collected inside a joint at the same time to reduce discomfort.

What are the side-effects?

Side-effects from steroid injections are rare but can include thinning of the tissue under the skin (atrophy) where the injection takes place.

Corticosteroids

Corticosteroids, often called steroids, reduce inflammation. They can be given as tablets, as an injection into a vein (drip), or as injections into a joint (see above). Steroid tablets are rarely given long-term to children and young people with arthritis because they can have harmful, long-term side-effects. Exceptions to this include systemic-onset JIA and severe polyarthritis.

Doctors may occasionally prescribe short courses of steroid tablets to dampen down a flare-up quickly, perhaps if you're going on holiday or your child is taking exams. The most common kind is prednisolone.

Doctors may give your child steroids by drip (called methylprednisolone) if they're seriously ill or other drugs aren't working. Children with systemic-onset JIA are sometimes given steroids by drip to quickly reduce the fever. Your child will stay in hospital while the medicine is given.

What are the side-effects?

Steroid tablets can cause lasting side-effects, including making your child more prone to infection and osteoporosis. Steroid drips can cause similar side-effects. Steroid tablets can sometimes make acne worse and may cause stretch marks.

Your child should be given a **steroid card** if they're on steroid tablets for any length of time. It's important to have this available if your child is ever seriously ill. Older children and young people should carry it with them at all times.

Disease-modifying anti-rheumatic drugs (DMARDs)

These medicines slow down the progress of arthritis and may even stop it completely. They also reduce pain, swelling and stiffness. They act slowly, usually taking months to take effect. They may be used early to reduce the impact arthritis will have on your child or as a second line of defence if NSAIDs aren't working.

The most commonly-used DMARD is methotrexate. This has made a vast improvement in the treatment of JIA. Methotrexate is used in children and young people with most types of JIA, and more than two-thirds of children respond well to it. It's taken weekly as a tablet, liquid, or as an injection under the skin (subcutaneously). Parents can be taught to do these injections, if they wish, and older children can learn to do them for themselves. Methotrexate takes at least 8–12 weeks to start working.

Another DMARD that's occasionally used is sulfasalazine, which works well for boys with enthesitis-related JIA who carry the HLA-B27 gene.

What are the side-effects?

It's helpful to look at the side-effects of the most common DMARDs individually.

The side-effects of **methotrexate** include:

- feeling or being sick just before or after taking methotrexate (this is the most common side-effect, and although it's unpleasant, the sickness isn't harmful)
- skin rashes
- itchy skin
- sore mouth
- mouth ulcers
- diarrhoea
- thinning of hair.

Very occasionally, methotrexate can affect the bone marrow or liver. Your child needs regular blood tests to check for this. These are usually done every month. The tests show up any risk before damage is done.

If your child hasn't had chickenpox and is on methotrexate, steroids and/or biological therapies, and has come into close contact (e.g. 15 minutes in same room) with someone who has or who then develops chickenpox, you should contact your doctor or the specialist nurse for advice. Once your child is on methotrexate they **must not** have any 'live' vaccines, such as MMR, oral polio, BCG or chickenpox. However, sometimes it's possible to have the vaccinations before starting the medicine. You can ask your doctor or the specialist nurse about which vaccines are safe to have while on methotrexate.

Anyone taking methotrexate should avoid alcohol or keep it to a minimum, as taking alcohol and methotrexate together can cause liver damage. This may be something to consider for teenagers.

The most common side-effects from **sulfasalazine** are:

- feeling sick
- headaches
- diarrhoea.

Less common side-effects include skin rashes, stomach pain, mouth ulcers and loss of appetite, as well as effects on the bone marrow and liver. Regular blood tests are necessary whilst taking this drug.

Biological therapies

Biological therapies is a name given to some newer drugs that have been available for about 10 years. Just like DMARDs, they slow down the progress of arthritis and reduce pain, swelling and stiffness. Like DMARDs they work by suppressing the immune system, and they're called biological therapies because they were developed from research into the biology of arthritis. For example, it was found that a particular substance in the body, called TNF or tumour necrosis factor, is very important in causing JIA and other forms of arthritis, so doctors developed anti-TNF drugs to treat these forms of arthritis. So far only one biological therapy, called etanercept (trade name Enbrel), is widely available for children in the UK. It's given by injection under the skin twice a week and can be effective in 1–2 weeks. It works by blocking TNF. Currently, etanercept is mainly used when methotrexate has failed. Other biological therapies, such as infliximab, adalimumab (which are both anti-TNF drugs too), and newer biological therapies like abatacept, tocilizumab and anakinra, are now becoming more available for children and young people with JIA.

What are the side-effects?

Side-effects of **etanercept** include:

- a blocked or runny nose
- headaches
- dizziness
- rashes
- stomach pain or indigestion
- itching or swelling at the site of injection.

Scientists believe etanercept may lower the ability to fight serious infection, but so far there have been very few reports of this. As it's a new drug, long-term side-effects aren't yet known, but doctors are collecting information to find out about these.

Physiotherapy and occupational therapy

At your first physiotherapy appointment, the physiotherapist will assess your child's joint movement, muscle strength and how they walk and manage other activities. Based on this assessment, and after talking to you and your child, the physiotherapist will design an exercise programme to suit your child's needs. The physiotherapist will explain and demonstrate the exercises and show you how to supervise them at home.

With your consent, your physiotherapist may contact your child's school to discuss how they can take part in PE classes. There's no reason why your child shouldn't join in with their classmates. It's important that your child is involved in activities that are normal for their age group.

Physiotherapists are also able to help with pain control and can also suggest an assessment by an orthotist or podiatrist if they feel that insoles or other orthotics may help your child's pain or mobility

(see What equipment might help my child? section of this booklet).

A team of health experts will ensure that your child receives the best possible care.

What equipment might help my child?

Your physiotherapist or occupational therapist can advise on different ways to help your child keep mobile. Some special equipment, like wheelchairs, crutches and splints, should be avoided where possible as it can make your child feel different and allow muscles to weaken.

In some cases you may find that a wheelchair is useful to manage long walks or shopping trips. However, it's important not to rely one.

Special splints to support wrists or legs are sometimes helpful. Some children wear a wrist splint occasionally at school to rest the wrist while keeping the fingers free to write. Rarely, a splint is used for the back of the leg to keep the knee stretched, usually worn at night. Your occupational therapist or physiotherapist will assess your child to see if splints are necessary.

Your occupational therapist can also discuss the effect of arthritis on school, play and leisure activities, and future vocation and career. They can also suggest aids or adaptations to help your child at school, such as special seating or a tilting desk.

Will my child need to go to hospital?

Your child will need to visit hospital regularly for check-ups and exercise advice. Usually this means going every 3–6 months to an outpatients department for specialist advice.

Children and young people with arthritis rarely have to stay overnight in hospital. This usually only happens if they're very ill with systemic-onset JIA or if it's more convenient to stay a few days while having various tests and treatments. Hospitals will encourage you to stay with your child and will also provide facilities for play and school lessons.

Who'll be involved in treatment?

To provide the best package of care your child will need a team of health experts working together (a multi-disciplinary team). This will probably include:

- your family doctor (GP)
- hospital doctors who specialise in rheumatology (rheumatologists) and children's medicine (paediatricians), or you may see a specialist who's an expert in both (a paediatric rheumatologist)
- physiotherapists
- nurse specialists
- occupational therapists
- social workers
- psychologists

- play therapists
- youth workers
- ophthalmologists
- an orthopaedic surgeon (in a few cases).

The team should work together with you and your child's school to provide the best all-round care and help you cope with the effects of the illness on the whole family.

Will my child need surgery?

Most children and young people with JIA never need an operation for their arthritis. Very few, those with severe arthritis, do benefit from some form of surgery. When other forms of treatment haven't worked, a surgical procedure can be very effective.

Joint replacements are occasionally performed when a joint becomes very painful and deformed after many years of arthritis. Hip and knee joints are the ones most often replaced. These operations are done under a general anaesthetic. Joint replacements are usually done only after growing has stopped, so they're very rarely used in young people.

A **synovectomy** is where the lining of a joint (synovium) is removed under general anaesthetic. It's performed very rarely these days, but can be useful for a child with one badly inflamed joint if local steroid injections haven't worked well enough.

What about healthy living?

A healthy lifestyle with regular exercise, sleep and rest, and a balanced diet with plenty of fruit, vegetables and fibre, is important for everyone and particularly growing children.

Diet

There's no evidence that children and young people with JIA benefit from a special diet or by avoiding certain foods. In fact, it can be harmful to cut out particular foods as they may be needed for your child's health.

It's important to avoid putting on too much weight as this puts extra stress on the joints. If your child's weight does become a problem, the best advice is to keep offering a healthy diet, including enough calcium and vitamin D for healthy bones, and avoid junk foods and other foods which are high in sugar or fat. Exercise is also important to keep to a healthy weight.

Exercise and rest

Regular exercise is important for everyone and will form a vital part of your child's treatment for JIA. Exercising helps to move stiff joints, strengthen weak muscles and build a healthy heart. A personal exercise programme for children with arthritis will help them to be fully involved in all activities with their peers.

You may find your child isn't always keen to exercise, especially during flare-ups. It's important to remember that exercises will help ease the pain, reduce the stiffness and improve your child's prospects of an active, independent future. The following tips may help to keep your child exercising regularly:

- Keep positive about the exercises and try to make them fun for young children – part of play and not a chore.
- It's often easier to keep to a daily routine, so you may find a regular session at the same time every day works well – perhaps before a favourite TV programme.
- Stretches first thing in the morning may be helpful to ease morning stiffness.
- You may find that a star chart or special treats are helpful rewards for younger children.
- You should encourage your son or daughter to take part in sports – any non-contact physical activity is good exercise, especially swimming, cycling, dancing and walking.

Children and young people with JIA don't need extra rests unless they're in a bad phase of their arthritis and feeling ill or particularly tired. They may need some extra rest if this happens, otherwise they should be encouraged to be as active as possible. If they're having trouble sleeping, your physiotherapist or occupational therapist will be able to help.

Dental care

Children with JIA tend to have more trouble with their teeth, partly because they can find it difficult to brush properly. Take care to help them with this and make sure they have regular check-ups with a dentist.

Children and young people with hand arthritis may find an electric toothbrush easier to hold and more effective. Another good tip is to wrap elastic bands around the handle of a regular toothbrush to widen the grip.

Can complementary medicine help?

You may hear, or read on the internet, about complementary or alternative therapies which claim to treat JIA. You may even hear about therapies that promise miracle cures. It's important to treat these claims with caution. **There's currently no cure for JIA, either in mainstream or complementary medicine**.

Finding a therapy that may help is really a matter of personal choice for you and your child. You'll need to talk to your doctor or rheumatology team before trying something new.

Part Two: Living with JIA

Will JIA affect family life?

Looking after a child who has arthritis can be hard on the whole family at times. For your child, there may be lots of emotional difficulties in growing up, as they might not be able to do everything other children can do. For you as a parent, it can be frustrating and tiring to cope with the ups and downs of your child's illness, hospital appointments, daily exercises, school matters and finances. While brothers and sisters can be very supportive, they may feel they get less time or attention than their sibling.

Your health team, support groups and other families in the same situation can help you talk through these issues.

What can I do?

Trying to stay positive is a good start. Encourage your child not to see themselves as ill or a patient when doing ordinary things like playing with friends, going to school or tidying their room.

Arthritis in children can be unpredictable, and so you may need to make plans that can easily change. For example, if you've planned a day out as a family, decide on the day whether to go to the seaside or cinema.

It's important to find time for yourself, your partner and any other children in the family. Try to find some special time for the other children, and make sure they have treats too.

Joining in with your child's exercise routine as a family can help make it more fun – and, after all, it's important for everyone to keep fit and healthy.

Who else can help?

Your hospital team can help your family cope with all aspects of your child's illness, not just the medical treatment. As well as the team members listed previously, the team may include:

- a psychologist, who can help you talk through any worries
- a social worker, who can help with practical matters (e.g. benefits), parental counselling and support.

Families in similar situations can help if your child has just been diagnosed with JIA and you want to talk to people who've already been through the experience. Your hospital team or the Children's Chronic Arthritis Association (CCAA) (see Where can I find out more? section of this booklet) can put you in touch with a local family. The CCAA also organises family events.

Your own family and friends can also offer support. Other family members may be happy to babysit or organise day trips occasionally. Do take up offers of help from friends and neighbours, and remember: they're offering help because they care, not because they think you can't cope.

Children with JIA do just as well academically as their classmates in school and many go on to college or university without any problems.

How will my child cope with school?

Most children and young people with JIA manage perfectly well in mainstream school and college. Better treatment means only very few children – those with severe arthritis or with other problems as well – need to go to a special school.

However, schools and Local Education Authorities (LEAs) do vary in how much help they can offer your child. Your hospital team should talk with the school to help teachers understand your child's illness and needs. Ideally this will include an assessment by an occupational therapist.

It's important to inform your child's teachers as soon as a diagnosis has been made. This will prepare the school for the fact that lessons may be missed due to illness or hospital appointments. The school should be understanding about this and provide extra help if needed.

Every primary and secondary school has a special educational needs co-ordinator (SENCO), who'll organise help in the classroom or any aids your child needs. It's no longer necessary to have a Statement of Special Educational Needs to get support in the classroom. Your child should only need a statement if they have severe long-term problems. If you think this is likely, it needs to be arranged before your child is 16. They'll then continue to have support until age 19.

Moving to secondary school

Moving from primary to secondary school needs careful planning. Secondary school children often have to cope with more stairs, more pupils and more moving around for lessons. It's a good idea to talk to secondary schools early (at the end of Year 5 or beginning of Year 6) to make sure they're prepared.

The school's SENCO should help as well as the school nurse, and it's a good idea to get the help, advice and support from an occupational therapist and physiotherapist (see Figure 2).

What financial help is available?

You may be entitled to certain benefits as a family caring for a child with disabilities. These may include:

- Disability Living Allowance (at a lower or higher rate)
- Disabled Child Premium
- Enhanced Disability Premium
- Childcare Tax Credit
- Disabled Child Tax Credit
- Enhanced Disability Tax Credit.

Figure 2
Discuss your child's schooling with teachers and the SENCO.

It's important for your child to become involved in their own treatment as they grow up.

When your child reaches 16 they may be entitled to further benefits which will be paid directly to them. As benefits laws change often and family circumstances vary, you need to check what you're entitled to.

Where can I go for financial help?

Your social worker should help. Otherwise visit your local Citizens Advice Bureau or Jobcentre/Jobcentre Plus office, or ring the Benefit Enquiry Line for advice (see Where can I find out more? section of this booklet).

You may be able to get grants for certain items and expenses through the Family Fund (see Where can I find out more? section of this booklet). Other financial help may include a reduction in a television licence in your child's name, adaptations to your home through your local Social Services department, the Blue Badge scheme for preferential parking, road tax exemption on your vehicle (if your child has the higher rate Disability Living Allowance), help with travel to school and parental leave from work.

Growing up with arthritis

Many children and young people will grow out of JIA as they enter adulthood. However, at least a third will have some continuing problems as they become young adults.

If growth is badly affected by JIA or its treatment, it's important to reassure your child that they can catch up with their friends. Further treatment using growth hormone may be an option, although this is only effective when the joint inflammation has been controlled and when the dose of steroids (if required) is low.

Growing up with a long-term illness is challenging. Your son or daughter will need encouragement to do things for themselves, like going out alone, arranging social activities and coping with money.

Taking control of treatment

It's also important for your child to become involved in their own treatment. As they get more independent they may become less keen to do exercises or take medicines. It's important to try and make sure they keep at it. Involve them in decision-making processes, for example encourage them to ask their own questions, and make sure they understand the reasons for their treatment and the risks involved with stopping.

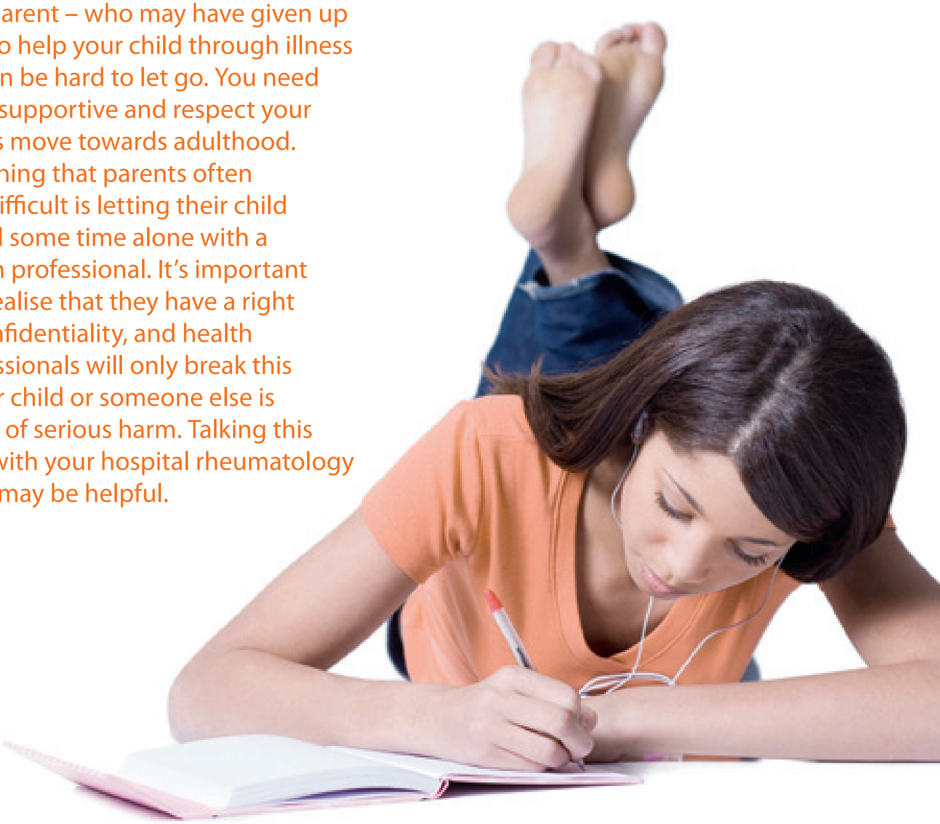
Growing up also means moving from child- to adult-centred care. This should be a gradual change towards attending hospital appointments on their own and becoming involved in making their own decisions about treatment. A gradual move towards independence should start early, at around 11–12 years old, as your child starts experiencing change as they enter secondary school. Remember, rheumatology clinics are safe places for them to start practicing communication and problem-solving skills – these are all important for the world of work and adulthood.

! As a parent – who may have given up a lot to help your child through illness – it can be hard to let go. You need to be supportive and respect your child's move towards adulthood. One thing that parents often find difficult is letting their child spend some time alone with a health professional. It's important you realise that they have a right to confidentiality, and health professionals will only break this if your child or someone else is at risk of serious harm. Talking this over with your hospital rheumatology team may be helpful.

Becoming a teenager

Becoming a teenager can be full of anxieties for any young person and their family. Children with arthritis are no different and so family tensions can be heightened at this time. Coping with arthritis may add extra challenges. Your hospital rheumatology team can offer support in dealing with any issues that may arise.

Let's have a look at some of the issues that can affect a young person with arthritis:



Body issues

Arthritis can affect the growth of individual joints and some drugs can cause visible side-effects such as skin wasting (atrophy) at the site of joint injections. Steroid tablets can sometimes make acne worse or cause stretch marks.

Severe arthritis and steroids can delay puberty for a few years in some children. Girls may begin their periods and develop breasts later. For boys, facial hair and voice-breaking may happen later.

Young people may feel anxious about developing relationships if they feel they look different.

What can I do?

Since most teenagers are very conscious of their bodies and body image, and want to be like their friends, these can be upsetting problems. They may need lots of reassurance and confidence boosting.

Bullying or teasing

Some teenagers may find telling friends, partners or employers about their arthritis is difficult as they don't want to be bullied or teased. Talking about this issue is the first step to stopping it.

What can I do?

You can help by talking through how to bring up the subject. Let your child know there are people who can help and make sure they know who to go to if this should ever happen to them.

Physical problems

Some young people will find that arthritis causes physical problems which limit what they can do. They may find keeping up with friends on a shopping trip difficult, for example, or be embarrassed about having to ask you for lifts when their friends are travelling independently.

What can I do?

Helping your child fit in with social activities or find alternatives is important (see Figure 3). Advise your child to talk openly about their limits with their friends, so that activities can be planned with them in mind. Suggest that your child travels with a close friend on public transport, instead of giving them a lift on their own.

Cigarettes, alcohol and illegal drugs

Most young people will first come across these as they become teenagers. Avoiding them altogether is very difficult for young people trying to fit in with their friends. Young people with arthritis need to be aware of how their condition or medication can be affected by these things.

What can I do?

It's best to be honest and open about the risks without laying down the law. But your teenager also needs to know the extra risks in drinking alcohol or taking drugs while taking their medication. For example, taking excessive alcohol and methotrexate together can cause liver damage.

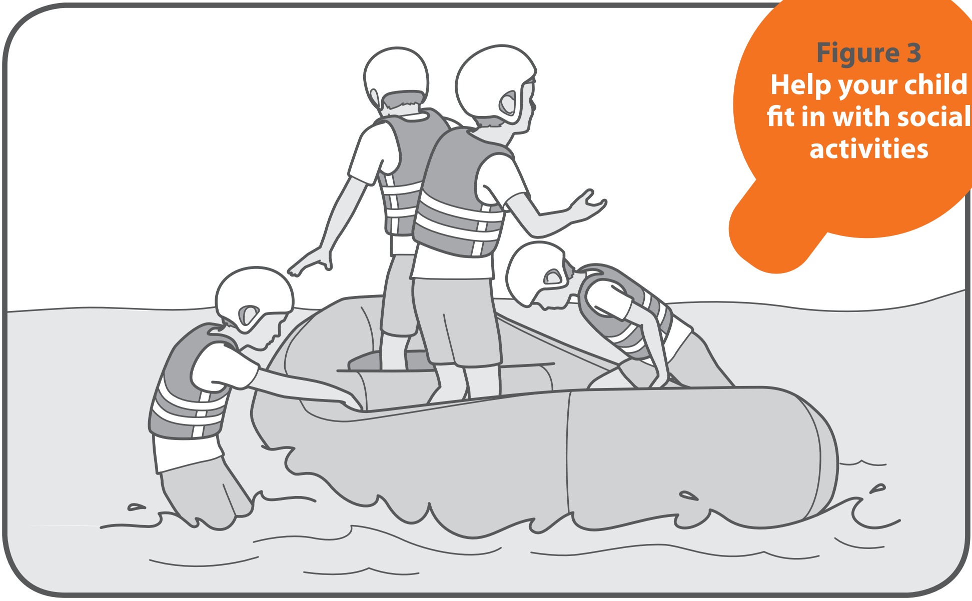


Figure 3
Help your child fit in with social activities

If you or your child have any questions or concerns about drugs or alcohol there are many sources of information and people who'll listen in confidence, including the hospital team.

Sex and relationships

Sex is another issue that young people face as they enter teenage years and become aware of their own sexuality. They may be worried about physically being able to have sex or what effect medication will have.

What can I do?

It's important to talk to your child about sex, explaining the importance of safe sex and discussing any worries they may have. As well as preventing pregnancy and protecting against sexually transmitted infections, contraception is **vital** for both boys and girls taking methotrexate and/or biological therapies.

Getting pregnant or fathering a child while taking methotrexate, or within 6 months after taking it, can cause harm to an unborn baby. If your son or daughter has unprotected sex they should see their nurse or doctor urgently. It's important to know that emergency contraception is effective for 72 hours after unprotected sex and not just the morning after.

The hospital team and the GP will be willing to listen to any concerns relating to sexual health and to give helpful, practical advice. Young people usually find it easier to ask their own questions around sexual health if they see the health professional on their own.

Looking ahead

Driving

Learning to drive can be a lifeline, not only in helping young people get around more easily but also as a boost to their independence. Young people on higher rate Disability Living Allowance can get a provisional driving licence and drive a car at 16 – a year earlier than normal. They can get advice on what kind of car they may need at an assessment centre. The charity Motability can point them in the right direction (see Where can I find out more? section of this booklet).

Planning for the future

It's essential for your child to think about what they want to do when they're older and how they're going to make it happen. A good education is a very important factor to be considered, but there are other important aspects to preparing for the world of work, including:

- learning to speak up for themselves – rheumatology clinics are safe places for them to start practising these skills with professionals
- being aware and knowledgeable about arthritis and how it affects their lives
- gaining work and/or volunteering experience
- becoming independent at home, at school and in health care
- knowing where to go for careers advice
- knowing their rights under the Disability Discrimination Act.

See Arthritis Research UK booklet *Arthritis – a guide for teenagers.*

Research and new developments

Treatment of childhood arthritis has made great strides in recent years. Better understanding of the illness and new medicines are making a huge difference to young people's prospects. Arthritis Research UK is a major source of funding for research in this field. Recent projects supported by Arthritis Research UK include studies on improving quality of life for teenagers, finding a genetic pattern to predict how arthritis will progress and testing which doses of methotrexate work best.

Glossary

Ankylosing spondylitis – an inflammatory arthritis affecting mainly the joints in the back, which can lead to stiffening of the spine. It can be associated with inflammation in tendons and ligaments.

Antibodies – blood proteins that form in response to germs, viruses or any other substances that the body sees as foreign or dangerous. The role of antibodies is to attack these foreign substances and make them harmless.

Anti-nuclear antibodies (ANA) – antibodies that are often found in the blood of people with forms of arthritis other than reactive arthritis. A test for anti-nuclear antibodies is sometimes carried out to rule out other conditions that can mimic reactive arthritis.

Biological therapies – drugs that reduce joint inflammation in people with rheumatoid arthritis and some other inflammatory diseases. They work by targeting specific molecules involved in the inflammatory process and include anti-TNF drugs (adalimumab, etanercept and infliximab).

Corticosteroids – drugs that have a very powerful effect on inflammation. They're often called steroids for short. The adrenal glands in the body produce a natural supply but much larger doses are used to treat autoimmune diseases. Prednisolone is the most commonly used corticosteroid.

Disease-modifying anti-rheumatic drugs (DMARDs) – drugs used in rheumatoid arthritis and some other rheumatic diseases to suppress the disease and reduce inflammation. Unlike painkillers and non-steroidal anti-inflammatory drugs (NSAIDs), DMARDs treat the disease itself rather than just reducing the pain and stiffness caused by the disease. Examples of DMARDs are methotrexate and sulfasalazine.

Haemoglobin – a protein found in red blood cells which contains the pigment that gives blood its colour. Because it can combine with, and then release, oxygen, it allows the blood to carry oxygen around the body.

HLA-B27 (human leukocyte antigen B27) – a gene which is often present in people who have conditions such as enthesitis-related arthritis.

Inflammation – a normal reaction to injury or infection of living tissues. The flow of blood increases, resulting in heat and redness in the affected tissues, and fluid and cells leak into the tissue, causing swelling.

Magnetic resonance imaging (MRI) – a type of scan that uses high-frequency radio waves in a strong magnetic field to build up pictures of the inside of the body. It works by detecting water molecules in the body's tissue that give out a characteristic signal in the magnetic field. An MRI scan can show up soft-tissue structures as well as bones.

Non-steroidal anti-inflammatory drugs (NSAIDs) – a large family of drugs prescribed for different kinds of arthritis that reduce inflammation and control pain, swelling and stiffness. Common examples include ibuprofen, naproxen, piroxicam and diclofenac.

Occupational therapist – a therapist who helps young people with arthritis to get on with their daily activities (e.g. dressing, eating, bathing) by giving practical advice on school, play, leisure, vocation aids, appliances and altering their technique.

Ophthalmologist – a doctor who specialises in eye problems.

Orthotist – a trained specialist who prescribes and fits special shoes and orthoses.

Osteoporosis – a condition where bones become less dense and more fragile, which means they break or fracture more easily.

Physiotherapist – a therapist who helps to keep young people with arthritis' joints and muscles moving, helps ease pain and keeps them mobile.

Platelets – disc-shaped cells in the blood that help the blood to clot when there's bleeding.

Podiatrist – a trained foot specialist. The terms podiatrist and chiropodist mean the same thing, although podiatrist tends to be preferred by the profession. NHS podiatrists and chiropodists are state-registered, having followed a three-year university-based training programme. The podiatrist or chiropodist can deal with many of the foot problems caused by arthritis.

Psoriasis – a common skin condition characterised by patches of thickened, red and inflamed skin, often with silvery scales. New skin cells are produced more quickly than normal, leading to a build-up of excess skin cells. The condition is sometimes associated with psoriatic JIA.

Rheumatoid arthritis – an inflammatory disease in adults (NOT children) affecting the joints, particularly the lining of the joint. It most commonly starts in the smaller joints in a symmetrical pattern – that is, for example, in both hands or both wrists at once.

Rheumatoid factor – a blood protein produced by a reaction in the immune system. Only a few children with JIA are positive for this.

Tendon – a strong, fibrous band or cord that anchors muscle to bone.

Ultrasound – a type of scan that uses high-frequency sound waves to examine and build up pictures of the inside of the body.

Where can I find out more?

If you've found this information useful you might be interested in these other titles from our range (note: the following booklets were written for adults and adult conditions and may not be totally relevant to your child):

Conditions

- *Ankylosing spondylitis*
- *Osteoarthritis*
- *Osteoporosis*
- *Psoriatic arthritis*
- *Rheumatoid arthritis*

Therapies

- *Hydrotherapy and arthritis*
- *Occupational therapy and arthritis*
- *Physiotherapy and arthritis*

Surgery

- *Hand and wrist surgery*
- *Hip replacement*
- *Knee replacement*
- *Shoulder and elbow joint replacement*

Self-help and daily living

- *Arthritis – a guide for teenagers*
- *Diet and arthritis*
- *Everyday living and arthritis*
- *Fatigue and arthritis*
- *Keep moving*
- *Meet the rheumatology team*
- *Sleep and arthritis*
- *Splints for arthritis of the wrist and hand*

Drug leaflets

- *Etanercept*
- *Drugs and arthritis*
- *Local steroid injections*
- *Infliximab*
- *Methotrexate*
- *Non-steroidal anti-inflammatory drugs*
- *Steroid tablets*
- *Sulfasalazine*

You can download all of our booklets and leaflets from our website or order them by contacting:

Arthritis Research UK
PO Box 177
Chesterfield
Derbyshire S41 7TQ
Phone: 0300 790 0400
www.arthritisresearchuk.org

Related organisations

The following organisations may be able to provide additional advice and information:

Arthritis Care
18 Stephenson Way
London NW1 2HD
Phone: 020 7380 6500
Helpline ('The Source') for young people with arthritis:
0808 808 2000
www.arthritiscare.org.uk
Runs support groups and a helpline service for younger people.

Benefit Enquiry Line for People with Disabilities
(run by Department for Work & Pensions)
Phone: 0800 882200
www.dwp.gov.uk

Children's Chronic Arthritis Association (CCAA)
Ground Floor, Amber Gate
City Walls Road
Worcester WR1 2AH
Phone: 01905 745595
www.ccaa.org.uk

Offers support for families of children with arthritis and arranges educational and recreational projects.

Citizens Advice
Can provide advice on benefits and help with filling in application forms. To find your local office, see the telephone directory under 'Citizens Advice' or the Yellow Pages under 'Counselling and Advice', or contact Citizens Advice:
Phone: 020 7833 2181
www.citizensadvice.org.uk

Contact a Family
209–211 City Road
London EC1V 1JN
Phone: 020 7608 8700
Helpline: 0808 808 3555
www.cafamily.org.uk

The Family Fund
Unit 4, Alpha Court
Monks Cross Drive
Huntington
York YO32 9WN
Phone: 0845 130 4542
www.familyfund.org.uk

Helps families of disabled or seriously ill children under 16.

Forum of Mobility Centres
www.mobility-centres.org.uk

Motability
Warwick House
Roydon Road
Harlow
Essex CM19 5PX
Phone: 01279 635999
Helpline (car scheme): 0845 456 4566
Helpline (wheelchair and scooter scheme): 0845 607 6260
www.motability.co.uk

The National Association for Special Educational Needs (NASEN)
NASEN House
4–5 Amber Business Village
Amber Close
Amington
Tamworth B77 4RP
Phone: 01827 311500
www.nasen.org.uk

RADAR (Royal Association for Disability & Rehabilitation)
12 City Forum
250 City Road
London EC1V 8AF
Phone: 020 7250 3222
www.radar.org.uk

Useful websites

Family Lives, a national charity providing help and support in all aspects of family life: www.familylives.org.uk

Got a teenager, for parent-to-parent support, informal advice, useful information and a community of other parents dealing with the same issues as you: www.gotateenager.org.uk

British Society for Paediatric and Adolescent Rheumatology:
http://www.bspar.org.uk

Printo, the international website for families of children with rheumatic disease: www.pediatric-rheumatology.printo.it

Royal College of Psychiatrists 'Surviving Adolescence' handout: www.rcpsych.ac.uk/mentalhealthinfoforall/youngpeople/adolescence.aspx

Leaflets from Young Minds
(available as pdfs online at www.youngminds.org.uk)

- Counselling for children and young people: What parents need to know
- Children and young people get depressed too
- Why do young minds matter?

Special educational needs: a step-by-step approach:
www.direct.gov.uk/en/Parents/Schoolslearninganddevelopment/SpecialEducationalNeeds/DG_4000690

Further reading

From Arthritis Care:

A Day with Sam (to be read to children with arthritis)

Chat 2 Parents: Arthritis in Teenagers (for parents)

Breakout guide: a booklet and online information site for teenagers with arthritis see http://www.arthritiscare.org.uk/LivingwithArthritis/Youngpeople/Breakout

From other organisations:

Juvenile Idiopathic Arthritis: Children with JIA in School
Contact: Clinical Nurse Specialist
Rheumatology Department,
Great Ormond Street Hospital for Children NHS Trust
Great Ormond Street
London WC1N 3JH

Video
'Physio for Kids', produced by JOINTZ (Arthritis Care's support group for parents in Northern Ireland) in liaison with the Paediatric Physiotherapy teams at Musgrave Park Hospital, Belfast and Great Ormond Street, London. £5.00 incl. p&p from Arthritis Care Northern Ireland or Children's Chronic Arthritis Association.

Notes

We're here to help

Arthritis Research UK is the charity leading the fight against arthritis.

We're the UK's fourth largest medical research charity and fund scientific and medical research into all types of arthritis and musculoskeletal conditions.

We're working to take the pain away for sufferers with all forms of arthritis and helping people to remain active. We'll do this by funding high-quality research, providing information and campaigning.

Everything we do is underpinned by research.

We publish over 60 information booklets which help people affected by arthritis to understand more about the condition, its treatment, therapies and how to help themselves.

We also produce a range of separate leaflets on many of the drugs used for arthritis and related conditions. We recommend that you read the relevant leaflet for more detailed information about your medication.

Please also let us know if you'd like to receive our quarterly magazine, Arthritis Today, which keeps you up to date with current research and education news, highlighting key projects that we're funding and giving insight into the latest treatment and self-help available.

We often feature case studies and have regular columns for questions and answers, as well as readers' hints and tips for managing arthritis.

Tell us what you think of our booklet

Please send your views to:
feedback@arthritisresearchuk.org
or write to us at:
Arthritis Research UK, PO Box 177,
Chesterfield, Derbyshire S41 7TQ.

A team of people contributed to this booklet. The original text was written by Prof. Lucy Wedderburn, who has expertise in the subject. It was assessed at draft stage by principal physiotherapist Jan Scott and clinical nurse specialist Pam Whitworth. An **Arthritis Research UK** editor revised the text to make it easy to read, and a non-medical panel, including interested societies, checked it for understanding. An **Arthritis Research UK** medical advisor, Prof. Anisur Rahman, is responsible for the content overall.

Arthritis Research UK

Get involved

You can help to take the pain away from millions of people in the UK by:

- Volunteering
- Supporting our campaigns
- Taking part in a fundraising event
- Making a donation
- Asking your company to support us
- Buying gifts from our catalogue

To get more **actively involved,** please call us **0300 790 0400** or e-mail us at enquiries@arthritisresearchuk.org

Or go to:
www.arthritisresearchuk.org

Providing answers today and tomorrow

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calls charged at standard rate

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