



chat
children have arthritis too
A guide for parents



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Cover models Clare Allen, Shirin Ayoubi, Nicholas Brown, Justin Edgar-McNerney, Amelia Holgate and Alexander Stone – also pictured with their parents – are all young people with arthritis

LLOYD'S



Introduction



Welcome to the second edition of *CHAT – a guide for parents* – full of useful facts and information to help inform you about juvenile idiopathic arthritis (JIA) and what it may mean for you, your child and your family.

Even though initial diagnosis can be a relief after a period of uncertainty, the next steps can be the hardest, as you face up to the fact that your child may have to work harder than other children his or her age to enjoy an ordinary life, as well as deal with the day-to-day challenges JIA may throw your way.

As a parent, you will undoubtedly benefit from learning as much as possible about your child's condition. There will be many questions about JIA as he or she grows up, and your knowledge and support will prove invaluable to keeping the disease in perspective, and enabling your child to grow into a healthy, happy, well-balanced adult.

CHAT has been specifically designed with parents in mind. It aims to provide you with the basic foundations and stepping-stones which will help you become familiar with JIA and how it may affect your child, both physically and emotionally.

The booklet includes information on the disease itself, as well as the many forms of treatment and therapy available. Each section provides an insight for parents to gain a balanced understanding of living with JIA. It also includes quotes and real life experiences from youngsters and parents who have first-hand experience of living and coping with JIA. We hope you find it both useful and informative.

Note: JIA is the umbrella term for the many different types of arthritis affecting children aged 16 and under. For ease of reference, where the term 'arthritis' is mentioned in this booklet, it refers to JIA.

Arthritis Care

Children's Chronic Arthritis Association

The Lady Hoare Trust for physically disabled children

Understanding your child's arthritis

Discovering your child has arthritis can be hard to come to terms with. As well as learning to understand and manage your child's pain, you and your family will need to get used to unfamiliar medical terms, understand complicated explanations, meet new people, spend time in hospitals and stay on top of medication. It can be a steep learning curve at the best of times.

Juvenile arthritis is a complicated disease which can have serious effects both physically and psychologically. However, there is much you and your child can do to take charge of the disease and live a fulfilling life.

This section aims to explain the disease to you in clear and simple terms. The various explanations have been provided in order to give you greater confidence when talking to doctors and other health professionals, as well as help you understand how arthritis may affect your child.

What is juvenile arthritis?

Juvenile arthritis, also known as juvenile idiopathic arthritis (JIA), is the condition where one or more joints become inflamed (swollen, red and painful) for at least six weeks in children under 16, once other known causes of arthritis have been ruled out.

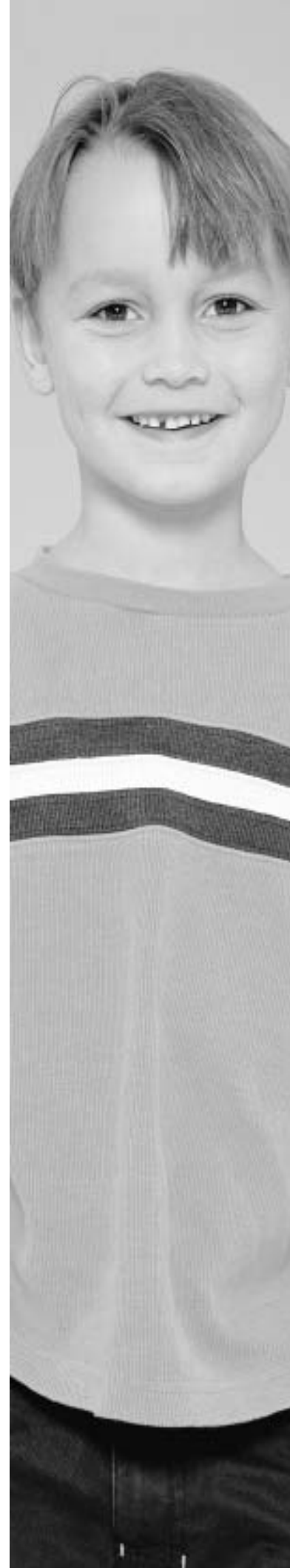
The precise cause of juvenile arthritis has not yet been identified. Needless to say, however, it is an area of active research.

Other known causes of arthritis include septic arthritis, where there is direct infection of the joint; reactive arthritis, where an infection elsewhere in the body results in inflammation of joints; and connective tissue diseases such as systemic lupus erythematosus (SLE or Lupus).

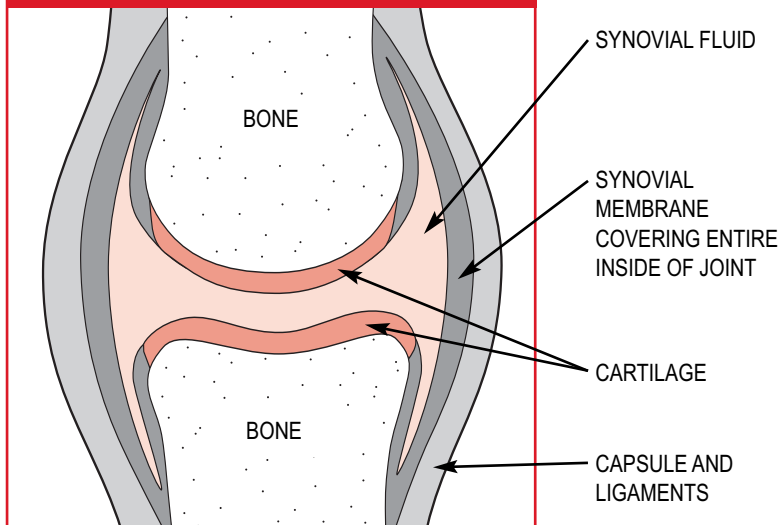
In the UK, approximately one in every 1,000 children has JIA.

Inflammation and auto-immune reactions

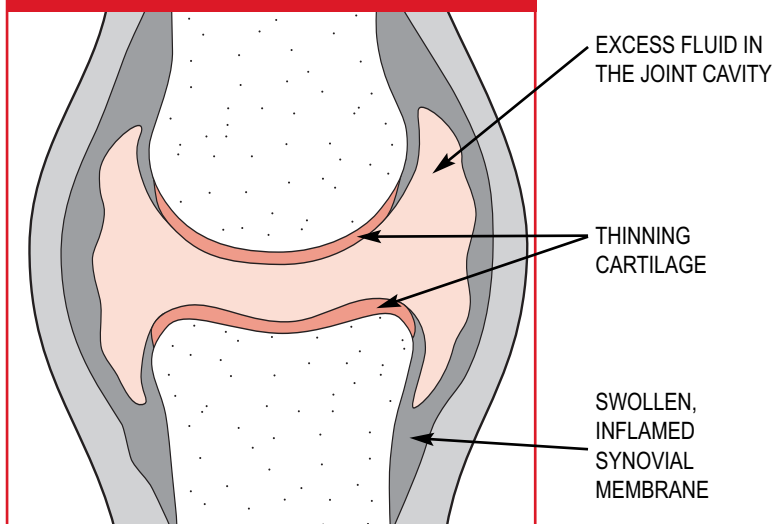
Inflammation of the joints, accompanied by pain, swelling, warmth and occasional redness is caused by an auto-immune reaction, whereby the body's immune system turns and attacks the body itself. Excess fluid is produced in the joint cavity, resulting in joint swelling and loss of elasticity of the soft tissues around the joint. The swelling stretches the soft tissues and can result in deformity and restricted movement. If this inflammation continues, it can cause thinning of the cartilage of the joint, seen on X-rays as reduced joint-space between the bones. Eventually, damage to the bones may occur. Treatment for JIA is therefore aimed at reducing the inflammation to prevent joint damage, as well as controlling the pain and stiffness that arthritis produces.



Anatomy of a normal joint



Juvenile Idiopathic Arthritis



Who does JIA affect and why?

JIA can start at any age, ranging from small babies through to teenagers. JIA is not directly inherited and it is very rare for more than one family member to be affected by it. It is still not known exactly why the condition occurs, despite active medical research. It seems that both genetic and environmental factors are important. Progress in molecular genetics has allowed the demonstration of clear genetic associations with the various sub-types of JIA. Many different genes are involved but it is clear that arthritis is not directly inherited and it is rare for JIA to occur in more than one member of a

family. The current view is that the different sub-types of JIA result from the interaction of environmental factors, such as infection, with genetic predisposing factors.

What are the signs?

Arthritis can be hard to detect in a young child, who may just appear to be unwell, grizzly, badly behaved or off their food, but limping or walking on their toes, showing reluctance to walk (or use the hands normally when playing) can be early indicators. Not using one hand at all, or preferring to use the non-dominant hand, not being able to grip tightly or having difficulty with tasks that require both hands such as unscrewing a lid could also be signs.

If you recognise any of these signs, your first port of call should be your GP. If your child is diagnosed with arthritis, the GP will then refer you on to a specialist in rheumatology who will be able to treat your child appropriately.

The different types of JIA

JIA is an umbrella term describing all the different types of arthritis which can affect children and young people. These are described in more detail below.

Oligo-articular JIA (including mono-articular JIA)

Oligo-articular JIA (previously known as pauci-articular JCA in the UK) is the most common type of JIA, accounting for approximately 50 per cent of cases in the UK. It affects four or fewer joints in the body, whereas mono-articular JIA affects only one. Typically, both oligo- and mono-articular JIA affect large joints such as the knee, ankle or wrist and may result in pain and swelling of the joints, or a limp.

Young girls under five are most likely to develop oligo-articular JIA. Both types of arthritis may be associated with uveitis, an inflammation in the eyes (see section on The Eye).

Treatment is usually with corticosteroid injections into the affected joints (see section on Drug Therapy) and/or oral non-steroidal anti-inflammatory drugs.

Polyarticular JIA **RhF negative and RhF positive polyarticular JIA**

RhF negative and RhF positive polyarticular JIA can affect any joint in the body, and may result in related pain, swelling and stiffness. Both forms usually affect more than four joints in the first six months of juvenile arthritis being diagnosed, and can lead to difficulties in writing and using the hands, for example carrying and lifting objects, as well as walking. These types of juvenile arthritis can start at any age, and girls are more prone to developing it than boys.

Steroids and non-steroidal anti-inflammatory drugs (NSAIDs), known as first-line agents, can be used to treat the pain and stiffness in the joints. In many cases additional drugs, known as second-line agents (for example methotrexate), may be used to help prevent joint damage.

Systemic onset JIA

Systemic onset JIA is a type of arthritis that begins with systemic symptoms, such as fever, rashes, poor appetite, lethargy and enlarged glands. It is often the hardest type of JIA to diagnose, as early signs can often lead to it being mistaken for an infection. Also known as systemic arthritis, this form of the disease may affect young boys or girls of any age, and accounts for around 10 per cent of all cases of juvenile arthritis.

Treatment with high-dose non-steroidal anti-inflammatory drugs (NSAIDs) can be used to control fevers. Often oral (taken by mouth) or intravenous (injected into a vein) corticosteroids are needed to control the disease. Second-line agents will usually be required.

Enthesitis related JIA

Enthesitis related JIA affects less than 10 per cent of youngsters with juvenile

arthritis in the UK, mostly teenage boys.

It can cause arthritis of the hips, knees or ankles, often with inflammation of tendon attachments to the bones, known as entheses. This may be associated with acute uveitis, an inflammation of the eye (see section on The Eye). Some boys with this type of arthritis go on to develop inflammation of the joints at the base of the spine and the lower lumbar region.

Enthesitis related JIA arthritis is known to be strongly associated with a particular genetic factor known as HLA B27 which can be identified by a blood test.

Treatment is usually with non-steroidal anti-inflammatory drugs and steroid injections into the affected joints. Second-line agents may also be required.

Psoriatic JIA

Psoriasis is a common, scaly, red skin rash, typically affecting the extensor surfaces of the knees and elbows. It may sometimes be associated with a particular type of arthritis known as psoriatic arthritis. This type of arthritis accounts for less than 10 per cent of children with juvenile arthritis.

The arthritis may affect any number of small or large joints, but characteristically affects the joints nearest the fingertips. The fingers and toenails may also be affected, with small, visible dents (pitting) occurring, or a thickening and loosening of the nail. Treatment and prognosis will depend on which joints are affected.

Thanks to Dr Kate Martin, consultant paediatrician, Gloucestershire Hospitals NHS Trust



Therapy and treatment

Visiting the clinic

There are many different methods for treating JIA, including drugs, physiotherapy, occupational therapy and, occasionally, surgery. Every child with JIA requires individual treatment to ensure he or she is able to enjoy a happy, active and healthy life.

Whether the treatment aims to reduce pain and disease activity, maximise joint movement and muscle strength, or otherwise assist in ensuring your child remains as independent as possible, the many forms in which juvenile arthritis can be treated are determined through his or her visits to the clinic.

Following diagnosis of JIA, your child will need to be monitored, either as an outpatient at a clinic or as an in-patient on a ward, in order to develop a specific course of appropriate treatment. Knowing what to expect on the first visit can help you and your child overcome any fears and worries you may have. Your presence and reassurance will, as always, be invaluable to your child's confidence.

What to expect

A typical clinic visit, either as an out-patient or as an in-patient on a ward, will begin with measuring your child's height and weight. A detailed assessment of their physical symptoms and general health will follow, and an analysis of their social well-being and any other related issues.

Through building up a detailed picture of your child's condition, the doctor can make sure that the treatment is exactly right. Referral to an occupational therapist or physiotherapist should come after this initial visit.

The doctor or other health professional may also examine your child's joints in order to establish levels of inflammation and joint movement. These results will be recorded and referred to in future trips so the disease can be effectively monitored.

Depending on the initial assessment and examination, the doctor may wish to X-ray your child and/or take urine and blood tests. The X-rays will enable your doctor to spot any bone-damage or swelling of tissues around the joints which will affect the type of treatment.

Blood test	Purpose
Auto-antibodies	Antibodies are produced by the body to fight infection. The body can also produce auto-antibodies against itself. Some auto-antibodies are associated with JIA: rheumatoid factor (RF), and antinuclear antibody (ANA). Levels of auto-antibodies can help to determine the different types of JIA.
C-reactive protein test (CRP) and Erythrocyte sedimentation rate test (ESR)	CRP and ESR both test for different amounts of inflammation in the bloodstream.
Full blood count	Tests levels of haemoglobin to see if a child is anaemic – which can be due to the presence of arthritis as well as poor appetite or drug treatment. Also tests white blood cell count and platelets to determine degree of inflammation.
Liver function tests	Measures the liver function, particularly important with methotrexate (see following section on Drugs).
Urea and electrolytes tests	Checks the condition and function of the kidneys.

Common blood tests

Different types of blood tests allow for accurate and detailed analysis of JIA. They are an important part of correct treatment and are effective in accurately diagnosing the health and well-being of your child. The most common types of tests are listed alphabetically in the table on page 6.

Thanks to Dr Clarissa Pilkington, paediatric rheumatology consultant, Great Ormond Street Hospital, London

Drug therapy

The development of new and more effective drugs used for arthritis has improved treatment dramatically over recent years. Although there is still no cure, the outlook for children with JIA is much better than it has ever been before.

Understanding the basics of drug treatment

Just as there are different types of arthritis, there are many different kinds of drugs available to treat both the symptoms of the disease and the actual disease itself.

The overall aim of all arthritis-related drug treatment is to switch off the inflammatory process which occurs in the joints. As a consequence, pain is relieved and damage to the joints and long-term complications are reduced.

New, improved treatments are being developed and made available all the time, and the choice of drug is dependent on the type of JIA. The choice of treatment will vary according to the pattern and severity of your child's arthritis. For example, a child with oligo-articular arthritis may have no more than a steroid injection to the joint, whereas most children with polyarticular arthritis will take methotrexate and those with systemic arthritis will probably be prescribed steroids.

Side effects and doses

It is important to remember that most

children on drug treatment don't have any problems with side effects, whereas untreated arthritis can be damaging. Many of the most common and predictable side effects can also be treated very easily when they do occur.

Side effects can relate to the dose, so doctors will always choose the lowest dose of medication possible for effective treatment. Doses for drugs are calculated on the weight of the individual child, and may at times seem quite large. However, this should not be a cause for concern. Children's bodies handle drugs very differently from adults'.

Questions and worries

Many parents worry about making the decision to put their young child onto medication, but drug treatment is the most effective way of treating arthritis as it can control most aspects of the disease and even bring about remission (where the disease rate is significantly slowed down) in many cases.

Gathering as much information as possible is an important part of learning about your child's arthritis. However, not all information on the internet is accurate, and some of it can be misleading or simply untrue.

Your doctor will be happy to discuss any information you may have uncovered when you visit the clinic. Take a summary of your findings so that your doctor can answer any questions you may have.

Regional variations and governing bodies

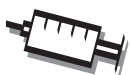
Whether you live in England, Northern Ireland, Scotland or Wales, you can find out more information about the various governing bodies responsible for producing guidance on a range of medically related matters, including drugs for JIA.

NICE – the National Institute for Clinical Excellence – produces guidance on the use of drugs for the NHS in England and Wales

Key



Tablets



Injection/Infusion



Liquid



Side effects


(www.nice.org.uk). The Health Technology Board for Scotland (technology appraisals) and Scottish Intercollegiate Guidelines Network (clinical guidelines) develop guidance for the NHS in Scotland. Visit www.htbs.org.uk and www.sign.ac.uk respectively. The Northern Ireland Executive is in the process of deciding who will develop guidance for the NHS in Northern Ireland. Visit www.northernireland.gov.uk for more information.

● **Non-steroidal anti-inflammatory drugs (NSAIDs)**

Most children with arthritis will use NSAIDs at some stage. For a small number of children they may be sufficient on their own, but the majority of youngsters will use NSAIDs in addition to other treatments.

NSAIDs are pain-relieving drugs which also reduce inflammation in the joint lining, in turn reducing swelling, pain and stiffness. Some are slow-release, gradually allowing them to be spread around the body throughout the course of the day, whereas others need to be taken more frequently.

The choice of the particular drug can depend on the doctor's own preferences, the age of the child and the type of preparation available which is suitable for the child. For instance, babies and young children often find it easier to take a liquid or melt preparation, whereas older children and teenagers might prefer a drug that can be taken once a day as opposed to more frequently, if appropriate.

 The side effects for all NSAIDs are similar, with the most common ones including upset tummies, heartburn, indigestion, skin rashes on sun-exposed areas, occasional wheeziness and mood swings. However, most children don't experience any side effects. The most common NSAIDs for use in children with juvenile arthritis are ibuprofen, naproxen, piroxicam and diclofenac.

Ibuprofen is a popular choice in younger children as it is available as a liquid, but it is short-acting and has to be given three or


four times a day. It may be helpful in systemic arthritis to control the fever.

Naproxen is taken twice a day, only available in tablet form, and is commonly prescribed for children who can take tablets.

Piroxicam is taken once a day, therefore particularly useful for schoolchildren, and comes as a melt preparation which dissolves in the mouth.


Diclofenac comes in different forms, the most popular being dispersible tablets and slow-release tablets which are very effective for children over 10 years old. The slow-release tablet is taken twice daily, as opposed to the thrice-daily standard tablet.

● **Steroid joint injections**

 Steroid joint injections are a very commonly used type of treatment, and are very effective in providing fast relief from inflamed joints. Steroid injections can be directed to exactly where they are most needed, and can target the problem area without having to affect the whole body.

Children with oligo-articular arthritis may find that a joint injection is the only treatment they need, and many hospital units now offer children with this type of arthritis steroid injections as first-line therapy. Joint injections are also used in children with polyarticular arthritis, to settle down a joint during flare-ups or while waiting for other medications to work.

The injections can be carried out using either local anaesthetic, sedation or general anaesthetic, and may be done in the outpatient clinic, day ward or theatre depending on the number of joints being treated, the age of the child and the hospital unit.

 There are no common side effects, other than a slight marking of the skin at the site of the injection.

● **Disease modifying anti-rheumatic drugs (DMARDs)**

DMARDs are powerfully effective,

second-line drugs that have revolutionised the treatment of children with juvenile arthritis, many of whom will find their disease goes into remission as a direct result of taking it. Methotrexate is the most commonly prescribed but there are others as detailed below and on page 10.

Methotrexate

Methotrexate is the most commonly used drug for treatment of juvenile arthritis in children, and about 70 per cent of children with polyarticular arthritis will benefit from taking it. Most children prescribed methotrexate will start to see benefits in between four and six weeks, although it can take up to 12 weeks before they start to reap the full benefits.

As well as proving effective for treating JIA, methotrexate is also effective for controlling uveitis (see section on The Eye). Some children will be prescribed methotrexate even if they have no joint problems, for this reason alone.



Methotrexate can be taken either as a

tablet, a liquid or an injection once a week. These days, more and more hospitals are administering methotrexate by injection as it seems to be more effective and carry fewer side effects. Most big hospital units run a home-training programme where parents and their children can be taught how to carry out injections at home, eliminating the need for regular hospital or clinic visits for treatment.



Methotrexate is more effective and has fewer serious side effects than other second-line drugs. When taken, it can cause short-term side effects of nausea and a feeling of not being 'right', although this can usually be treated with other drugs. Some people find that they can reduce nausea by taking methotrexate at night instead of first thing in the morning. For others, however, the nausea becomes more apparent with prolonged use, and they may have to come off the drug eventually because of this. However, most children can

take methotrexate successfully for many years without experiencing any problems. Many children do go into complete remission on methotrexate, and there is no evidence of any long-term serious side effects.

Folic acid is usually prescribed with methotrexate to reduce the side effects.

Alcohol and pregnancy on methotrexate

For older children who may be sexually active, it is vital to use contraception while on methotrexate, as it can be harmful to a growing baby.

Methotrexate should be stopped at least three months before becoming pregnant, if it is safe to do so. Always speak to your doctor before stopping taking any medication.

A combination of alcohol and methotrexate may damage the liver. Young people prescribed this drug may be advised to modify alcohol intake.

Blood tests

Methotrexate can upset the blood count and liver function, although this is very rare. Blood tests need to be taken regularly to monitor improvement and detect side effects early on.

Other DMARDs

Other second-line drugs, also known as disease modifying anti-rheumatic drugs (DMARDs), are occasionally used for particular groups of children with arthritis. **Sulphasalazine** may be used in the enthesitis-related arthritis group of children, and has proved effective in those who develop arthritis after their 9th or 10th birthday. It is an alternative to methotrexate.



Common side effects are rashes as well as headaches and nausea. Regular blood monitoring will be required. **Ciclosporin** is occasionally used for children with severe arthritis, sometimes in combination with methotrexate. It may

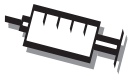
'Drugs enable me to be more mobile, but are a constant reminder that I have arthritis even when I am well. The hardest part is remembering to take them – it can be a real hassle.'

'When our daughter was very young, we had to make all the decisions on her treatment. It was very upsetting, not knowing what the long-term effects were, but there was no option but to try and do as much as possible to make her feel better.'

Key



Tablets



Injection/Infusion



Liquid



Side effects

help some children with systemic arthritis, as it works on suppressing the immune system. It can also be used to control uveitis (see section on The Eye).



Most common side effects can include kidney problems and raised blood pressure, so children need to be carefully monitored. It may also cause excess hair growth (hirsutism).

Anti-malarial drugs (hydroxychloroquine and chloroquin) are only used very occasionally in children with arthritis. Your doctor will be able to advise you if he or she feels your child could benefit from them.

Cyclophosphamide can be helpful in children with severe systemic arthritis who have not responded to any other treatment.



Cyclophosphamide is given as a monthly intravenous infusion in hospital, and needs close monitoring as it carries significant side effects.

Gold injections and penicillamine are now rarely used to treat children with arthritis, but could be used in children with more serious disease.

Intravenous gammaglobulin is occasionally helpful in controlling systemic illness, when the response to corticosteroids is poor.



It is given by intravenous infusions in hospital, usually on a monthly basis.

● **Steroids**

Steroids are very powerful, fast-acting anti-inflammatory drugs and, when used carefully, they can be very beneficial for children with certain types of arthritis.

Steroids are very good at providing rapid relief to the inflamed joint, and can be used for a newly diagnosed child with arthritis to cover the period before the other drugs, like methotrexate, have a chance to work. The majority of children with systemic arthritis will need steroids to control their disease.



Despite the benefits, children taking steroids for a long time will nearly always experience some side effects.

However, children on steroids must take advice from their doctor before stopping taking the tablets suddenly, and need to carry a card, necklace or watch to show they are taking this type of medication. Weight gain and a rounding of the face occur in most children on steroids for more than a short course of treatment. Mood changes can occur in young people on high doses. Other side effects can include osteoporosis, cataracts and stretch-marks (most of which respond well to other forms of treatment). In addition, long-term steroid use can interfere with overall growth, particularly in younger children. All side effects are related to the total dose and the duration of the treatment, and doctors will try and minimise the dose and usage accordingly.

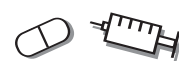
You must seek medical advice if your child is taking steroids and has been in contact with anyone with chicken pox.



Steroids are given either as tablets or can be dissolved for younger children, and are usually taken once a day, in the morning, in line with the body's natural surge of steroids at that time.

Taking it this way causes fewer side effects. Increasingly, for severe arthritis, steroids can be taken via intravenous drip or pulse – a high dose given over a short period, which brings rapid relief. Children can thus take bigger doses and have fewer side effects than if the steroids are taken orally.

Prednisolone



Prednisolone is the steroid tablet usually used in the UK. It works both as an anti-inflammatory and immuno-suppressant. Taken orally, it is relatively fast-acting, showing positive results in a matter of days. The intravenous steroid preparation is known as **methylprednisolone**.

● Anti-TNF drugs

TNF (tumour necrosis factor) is a substance in the body widely believed to play a central role in the process of inflammation which occurs in arthritis. New drugs have been developed which block the TNF, called anti-TNF drugs. They seem to be effective in controlling arthritis – 39 per cent of patients with an inadequate response to conventional DMARDs experience a 50 per cent improvement in the condition when using anti-TNF and 15 per cent experience a 70 per cent improvement.

Etanercept has very quickly become the established anti-TNF treatment for children. Etanercept is recommended by NICE for children over four with active disease with multiple joint involvement who have either not responded well to methotrexate, or who have been unable to tolerate it.



Long-term side effects are not yet known. However, a national database is being set up to collate information from every patient prescribed etanercept. Parents may be asked to consent to information on their child's progress being sent anonymously to the database.



Etanercept is given twice a week by injection at home. There is no oral preparation. Benefits can be seen within a couple of weeks in some children, but may take up to a few months in others.

● Immunisations and drugs for arthritis

Many of the effects of drugs in arthritis work by acting on the child's immune system. Because of this, live vaccines (MMR, BCG and oral polio) should be deferred if your child is taking methotrexate, ciclosporin, cyclophosphamide, anti-TNF drugs or steroids in more than a very small dose. Families and siblings must also be careful as any vaccines they take can put the child with arthritis at risk. Check with your GP or rheumatologist.

Most children should already have been vaccinated against MMR before they get arthritis, and an alternative polio vaccine can be offered. Some other vaccines can be safely administered to children on medication, however, including vaccines for meningitis and flu.

If you are planning a holiday or trip abroad, or want to know more about any other immunisations not mentioned here, please speak to your doctor.

● Growth hormones and osteoporosis

Occasionally, children with arthritis – particularly those with systemic arthritis – can be prescribed hormones to help them grow. Your doctor will be able to determine whether this form of treatment is necessary for your child.

Osteoporosis, the thinning and weakening of the bones, can occur in children who have had troublesome arthritis, even if their arthritis has been successfully treated. As a result, children and teenagers with arthritis may be offered regular screenings using a dexameter scan, to detect any damage early on. Treatment is available using a group of drugs called the bisphosphonates. It is hoped that bisphosphonates, which are the mainstay of adult osteoporosis treatment, will help children with porosis and prevent steroid-induced osteoporosis. Research is being carried out on this at present.

Calcium and vitamin D supplements may also be prescribed for youngsters showing signs of bone thinning.

Diet and vitamins

There is no evidence of benefit from any type of exclusion diet or special diet for arthritis. However, as with any other child, a healthy, balanced diet is important. Indeed, some children with arthritis, as those with any form of chronic disease, may need more calories to grow properly.

If their diet is adequate and your child is

'I've been on methotrexate for ten years, and it's really changed my life. People worry about the side effects, but they can usually be sorted out quite easily – and they're never as bad as the arthritis itself.'

'Parents worry about putting their children on drugs, but I know that my arthritis is really bad and I'm happy to take any drug that can help me.'

eating well, there should be no need to give your child vitamin supplements. However, there is no evidence that they do any harm, and some parents may feel reassured through giving carefully selected supplements, such as a daily dose of cod liver oil. Always be sure to not exceed the recommended daily allowance (RDA), especially for Vitamins A and D.

In order to maintain maximum bone health, you should ensure your child has a good calcium intake through milk, cheese or fish for example. If not, your doctor may prescribe calcium supplements.

for Complementary Medicine (see back page for contact details).

Thanks to Joyce Davidson, consultant paediatric rheumatologist, Alder Hey Hospital

Complementary therapies

Complementary therapies can be used alongside conventional therapies and prescribed drugs, and some parents find them a useful addition to their child's treatment. Some forms of complementary therapy may well benefit your child, easing stiffness and pain and even perhaps alleviating some drug side effects. Others may help teach your child beneficial relaxation techniques or ways to improve their posture and balance. However, as yet there is no medical evidence to support claims that complementary treatments can cure arthritis.

The range of complementary therapies is vast and there is much to choose from, including many types of massage, the Alexander technique, yoga, acupuncture and aromatherapy. Other therapies might be more medicine-based, including homeopathy or nutrition-based therapy.

Most doctors will understand if you want to try complementary therapies. Remember, however, to tell your doctor before your child starts any form of alternative medicine, as some can interfere with conventional medicines.

Some forms of complementary therapy are available on the NHS, so do speak to your GP and see if you can be referred. Alternatively, you can obtain a list of registered practitioners from The Institute



Physiotherapy

We all benefit from exercising our joints and muscles, helping us maintain a good range of movement, muscle strength and flexibility. For children with JIA, exercise is exceptionally important, and the benefits of physiotherapy can usually be seen after just a few weeks.

Physiotherapy can work on both the physical and psychological aspects of a child's illness, helping improve function and increasing independence as they learn to do more and more. Your son or daughter will also find it easier to be motivated to do the exercises on their own once they begin to see and feel the beneficial results for themselves. The physiotherapy treatment programme is as important as the medication, and like medication needs to be prescribed specifically for your child.

Physiotherapy can provide exercises and treatments for all areas of the body, both upper and lower limbs as well as the trunk and spine. It will also work on improving movement, strength and stamina as well as reducing pain and is vital to improve co-ordination and independent function.

Treatment

On your first visit, the physiotherapist will want to assess your child, examining any areas of muscle weakness and stiffness or loss of movement in his or her joints, before devising an appropriate treatment plan.



This may include an exercise programme in the physiotherapy department and/or hydrotherapy pool, and, most importantly, should include a regular home exercise programme for your child.

Exercise and motivation

Exercise is really key to enabling your child to lead a normal and active life. A child with JIA may have to work a bit harder than one without, and shouldn't avoid exercise just because they have arthritis.

Physiotherapists may recommend certain exercises for your child which focus on specific tasks they may find difficult, such as going up or down stairs, balance or moving from sitting to standing positions. The aim of the therapist will be to teach the young person their own exercises so that they have some input and control over their arthritis and its treatment.

Younger children will need some help and encouragement from parents, but as your child gets older they will be able to do many of the exercises by themselves. However, if stretches are prescribed, they often require the help of another person to maximise their effectiveness.

For children with arthritis, the benefits of a specially designed physiotherapy exercise programme cannot be overestimated. However, remember that physiotherapy services may be limited, which makes home exercise especially important.

An exercise programme can be designed specifically for your child's abilities and needs, and is extremely important in order to reduce pain, maintain muscle strength and maximise independent function.

But for many children, getting them motivated is key. You can try encouraging your child to do their exercises to their favourite music, before or during a TV programme, or with a specially designed exercise video for variety (see Stretches on page 14).

You may find a home-made chart is useful for logging completion of the home exercises. You may also want to give small

'I absolutely hated physio to start with because it was so painful, but it does get better. Once you start to see a difference you realise that it's worth it.'

'When I started my physio I found it useful but tedious. I just got on with it, when I remembered. The benefits were easy to see. It enabled me to get moving quicker in the mornings and keep myself supple.'

'When I was younger, my mum used to join in and do the exercises with me every day. These days getting motivated to do physio can be pretty hard – and it is painful – but it does make a big difference to my joints.'

'There are good days, and there are bad days when she has to rest.'

rewards to your child for an extra boost once they have completed the chart successfully.

For children who have had arthritis for a number of years, their physio exercises may become a struggle and, for those with more severe forms of the disease, the amount of exercises required can take a lot of time to complete, as well as be painful and awkward. Try and be as understanding and supportive as possible. If your child realises why they need to do the exercises they may well be happy to do them without any fuss. Your physiotherapist will be able to help you with this.

Stretches

Stretching can be a great way to relieve stiff joints, and is especially beneficial first thing in the morning after a good night's sleep. Certain stretches are better for particular parts of the body, and can be adapted to suit your child's needs. Your child may find it easier to do them in a warm bath, where the water can help support aching joints and soothe pain at the same time. Stretching joints and muscles properly will reduce his or her pain and stiffness, increase their range of movement and make the daily tasks like washing and dressing easier to do unaided.

It is important that you and your child are shown how to do the stretches by a qualified physiotherapist, as incorrect technique can cause more harm than good.

Muscle building

Muscles allow the joints to move and be supported in the best way to prevent them from becoming damaged and worn. Children with arthritis can develop weakness in their muscles for many reasons, resulting from their joints being stiff, painful and difficult to move. Muscles become weak very quickly if they are not used properly or regularly exercised. In JIA there are many reasons why the muscles cannot be used properly. Primarily pain stops the muscles working well. Loss of

movement in the joint and stiffness also mean the muscles cannot be used effectively and this is all exacerbated by the fact that the messenger chemicals (cytokines) in the body that tell the joints to be inflamed also tell the muscles to get weak. This all combines to make children with JIA susceptible to becoming weak and unfit quickly. Once this happens the joint has a higher risk of wear and tear damage, and often becomes more painful. Muscle weakness can start to develop as early as 2-4 days after the joint swells, and after several weeks of this continual swelling loss of muscle tissue (atrophy) occurs.

Muscle weakness can only be corrected by specific exercises to the appropriate muscles. These exercises need to be developed upon the principle that children respond best to a programme of high repetitions and low weights (for example, 30 repetitions combined with 5lb of maximum weight).

The exercise programme also needs to combine different methods of muscle work together and will need to be progressed with resistance. This often means that the way the limb is lowered in an exercise is as important as the way it is lifted. Muscles are required to stabilise joints as well as create movement. Both are equally important and will need specific exercises to ensure both functions are efficient.

Children with JIA will need to work extra hard to keep their muscles fit and strong through regular and specific exercises, and your physiotherapist will be able to advise you on what is best for your child.

Stamina

As well as building muscles, your child will need to work on improving his or her stamina. This can help him or her do more activities for longer periods of time, with less pain. There are two types of stamina which are important to consider. The first type is general stamina (for example; how long you can run before you are out of breath). General stamina depends on

aerobic capacity as well as muscle strength. The other type is the stamina of specific muscles: it is important that muscles are not just strong for a few hours, but that they are strong for the whole day. This type of stamina is addressed by increasing the number of repetitions of each exercise, and again by progressing further with the addition of weights.

A physiotherapist can teach your child to improve his or her stamina and strength through a recommended exercise programme. Other normal activities, including most cardiovascular or aerobic exercise (continuous exercise which makes a person slightly breathless) can also help build stamina. Pilates, yoga, swimming, walking, cycling and other non-contact sports like tennis and badminton can help maintain good joint range of movement and improve muscle strength as well. However, swimming and other aerobic sport don't necessarily build bone density, which can be improved by other forms of weight-bearing exercise.

If you are in any doubt as to the appropriateness of a particular exercise, your physiotherapist will be happy to discuss it with you.

Hydrotherapy

Exercising in warm water, known as hydrotherapy, can be fun and effective. The warmth of the water (either a swimming pool or a warm bath will do) may help to relax muscles, which helps the child to do



more effective stretches, and may also help to reduce muscle spasm and so reduce pain. Hydrotherapy should ideally be carried out under the instruction of a qualified physiotherapist, but your child can benefit as well from regular swimming which can be great aerobic exercise as well as good fun.

Your physiotherapist may recommend hydrotherapy as part of your child's overall treatment plan, and will be able to let you know where your nearest hydro centre is, and any suitable classes.

General principles

As a general principle, any exercise programme should be started slowly to allow time to adapt to the exercises and should then be progressed gradually until maximum strength and fitness is achieved. This should be regarded as a rehabilitation phase and should be completed 4-7 times a week. Once full fitness and function is gained then the programme can be viewed as a maintenance programme and the number of repetitions and weights maintained in completing the programme 2-3 times a week. It is also important to remember that complex activities like walking, swimming or Pilates may use many muscles, but not specifically to keep them both strong and fit throughout the whole movement range they control.

The body is also extremely proficient at adapting. Some muscles are naturally stronger than others and can compensate for the weakness, causing it to increase. This then leads to muscle imbalance, which causes further pain and loss of function. Therefore a specific home exercise programme should complement other activities, but should not be replaced by them.

Pain relief

Pain is one of the major symptoms of arthritis, and learning to cope with it can be one of the hardest challenges facing your



child. Your son or daughter may suffer from pain if one or more of their joints is inflamed, damaged, has been inactive for a long period of time, or has been subjected to variations in its normal range of movement, for example through limping in an attempt to alleviate pain.

Although drug treatment is an important part of managing pain, there are other means which your physiotherapist may suggest which can provide effective relief from it. Many of these causes of pain are removed with appropriate exercises and stretches. However, there are also other useful methods of pain relief outlined as follows.

Cold and hot packs

Cold and hot packs can be specially designed and bought from local chemists, or home made, using bags of frozen peas or hot water bottles. As long as they fit snugly around the joint, it doesn't make much difference which you use.

Try wrapping the cold pack in a wet tea towel to prevent ice-burn, and place on the affected joint for 15 minutes (or between five and 15 minutes for very young children). The same effect can be gained from using a hot pack. Children differ as to which they prefer, so allow them to choose the most effective method for themselves.

For very sore or swollen hands try holding them in a bowl filled with cold water and ice cubes, alternating this treatment with a bowl of hand-hot water, taking five minutes in the ice water and another five in the hot water, repeating several times.

For really sore joints, alternate the hot/cold treatment but apply the cold pack for 10 minutes and then the warm pack for between 20 and 30 minutes.

TENS (Transcutaneous electrical nerve stimulation)

TENS is a non-invasive method of pain control, using electrical impulses to block the pain pathways to the brain, therefore

reducing the level of pain experienced. It can be effectively used for specific joints, one at a time. Discuss TENS with your child's physiotherapist if you want to try it out before buying your own TENS unit.

Splints and other pain management techniques

Physiotherapists often work very closely with occupational therapists (see section on Occupational Therapy for more information), especially if your child requires the use of splints at some stage, or help with managing pain through other means. Don't forget to speak to your physiotherapist about this if you think your child could benefit.

Taking a break

Just as exercise is important for improving movement in children with arthritis, periods of rest are equally beneficial, and the muscles must be allowed to rest and recover in between periods of activity. Therefore it is rarely necessary for the exercises to be done seven days a week, and the weekend is often a good time to have some time off.

Physiotherapists are often happy to allow your child to take a therapy holiday if they are doing well, and review progress in a specified period of time. However, it is important to remember that if this 'rest' lasts for too long, then muscle strength can be lost and, after six weeks of discontinuing a specific programme, the previous strength gained will be lost.

Physiotherapy exercises can become monotonous and boring after they have been repeated time and time again. Most physiotherapists are only too happy to change your child's exercises for new ones which can serve the same purpose, so don't be afraid to ask if you think your child could do with a change to the old routine.

Balance

Balance can also be affected by JIA – usually because of swelling, pain, stiffness

and muscle weakness. The home exercise programme will be able to include some exercises designed to improve the balance of your child and the easiest of these is to encourage your child to stand on one leg, without shoes and socks, and without holding on, balancing for up to one minute.

This will help your child's general co-ordination, and encourage confidence in activities that require standing on one leg, such as climbing the stairs and walking.

Pacing activities

Another important approach to managing your child's arthritis is remembering that your child may become more tired than other children and that they should perhaps pace (spread out) the activities that they do. It is often useful to try to get the most important activities done at the beginning of the day and to allow adequate rest periods throughout the day.

This is important to remember when fitting in the home exercise programme, as often leaving it to the end of the day will mean that your child is too tired to complete the programme effectively. Without the home exercise programme they will not be able to regain strength and fitness, and the vicious cycle of reduced fitness and increased tiredness will start.

Fit for life

Remember that the home exercise programme that has been prescribed for your child is as vital to the effective management of your child's arthritis as taking the correct medication. Without this aspect of care your child will not be able to manage life in the same way as their friends and family. The exercise programme should be able to assist in all physical aspects of your child's life.

Thanks to Sue Maillard, specialist physiotherapist paediatric rheumatology, Great Ormond Street Hospital and Jan Scott, rheumatology physiotherapy specialist, Birmingham Children's Hospital

Occupational therapy

Occupational therapists (OTs) assess children's everyday occupations, such as going to school, playing, helping with household chores and enjoying hobbies, in order to understand how these have been affected by their arthritis. Obviously these demands will change with age, so an OT will also assess what is developmentally appropriate and what is important to the child as he or she grows up.

A wide variety of factors can inhibit a child with juvenile arthritis, and an OT will analyse and assess your child's requirements individually before making the appropriate recommendations. Through working with an OT, your child can learn valuable skills to enable him or her to lead a healthy and happy life, and positively adapt to living with JIA.

The aims of the treatment

With a holistic approach, occupational therapy concentrates on treating the whole person, taking into account both the physical and psychological aspects of the disease. Juvenile arthritis has the potential to have considerable social and emotional impact on your child's life, and your OT will be specially trained to intervene and minimise any negative effects these might have on your child. OTs will design and implement treatments, which are usually activity-based. They may look at improving hand function, by improving strength and range of movement, or they may provide support to help manage pain, such as teaching relaxation or other coping strategies.

Some children will be affected by their arthritis more than others and may need to wear splints or occasionally use a wheelchair. Although it is rare, some children may require adaptations to their physical environment to enable them to be as independent as possible. An OT will be able to provide recommendations and assistance on what is best for your child

'Wearing splints at night used to be uncomfortable, but I've been wearing them for so long now, I can't get to sleep without them.'

'I wear black lycra splints sometimes during the day – they help me carry on working when my wrists get painful.'

and help to make any adjustments if they are needed.

Splints

Splints are less and less common, but some children with arthritis can benefit from wearing them on their affected joints at some point in their lives. Splints have many different functions and can be used to support and protect painful or swollen joints, ease pain, and may help to prevent deformity. An OT will be able to take your child's situation into consideration if he or she has been advised to wear splints, as they will need to fit in to your child's life as naturally as possible. Splints worn in public places like schools might make your child feel different from his or her peers. Your OT will be able to discuss these concerns with you and your child before providing the most acceptable splint possible for the situation. For example, school children may find wearing a sporty-looking or brightly-coloured splint for day-time use more acceptable than a plain one. Your OT will also be able to give you useful advice on encouraging your child to wear the splints and benefit from them as much as possible.

The physical environment

The physical environment can hinder a child with arthritis in any number of ways. Your child may find it painful and awkward to sit cross-legged on the floor in assembly with the rest of their classmates. Their school may be particularly large and awkward to get around, or not be properly

equipped with lift or ramp access. Whatever the situation, your OT will examine the physical environment your child lives, plays and works in, and will make recommendations where improvements can be made. The needs of a baby or toddler with arthritis will be very different from the needs of a young teenager, and an OT can take this into account at the assessment stage. From learning how to play, wash and dress, to going to school, making friends and doing homework, to getting a Saturday job or careers' advice, an OT can provide expert guidance to improve your child's world.

First steps

At a young age occupational therapy takes a different shape from that offered to an older child, but it is vitally important that interventions begin as soon as possible so your child's development can progress in line with other children of the same age. For example, an infant needs to explore his or her environment in order to develop skills, but will quickly stop trying to crawl or walk if his or her knee or wrist is hurting. An OT can work alongside other therapists to teach techniques and play activities to help your child develop at the optimum pace and enjoy play activities – the major occupation at this age.

The early years

As children begin nursery and infant school, their everyday occupations change dramatically as more demands are placed upon them. They may begin to realise that they are a little different from their peers since they may not be as independent, or may not be able to enjoy all of the same activities.

The OT will liaise with the school or go into school, if necessary, to assess the child in the environment. They may suggest treatment activities, for example to increase hand function/handwriting, or recommend changes to the environment such as the position of the child in class or through the



Many different types of splints are available



provision of small pieces of equipment such as an angled desk-top surface or pen grip. The OT will also have input into the child's individual education plan. Any barriers to play and leisure activities should also be identified to ensure the child enjoys a full and active social life.

Changing needs and SENCOs

Children old enough to attend secondary schools face a whole new set of challenges. As well as the social issues involving bigger and more complex social groups, and greater numbers of unfamiliar teachers, there can be awkward physical aspects to consider, such as the larger school environments, greater volumes of books to carry, and a lot more written work to complete. The section on Education provides more information on this aspect of your child's life.

Early teens

Young teenagers all need additional privacy and independence as they grow up. Your son or daughter might want a Saturday job, careers advice, or simply someone independent to confide in about friends, relationships or other aspects of their lives.

The OT will be able to offer a wide range of support options to suit your growing child. This may involve looking very carefully at self-care and domestic activities to see if any techniques or devices could be used to increase independence. It may be to offer advice on how your child can learn to pace properly to conserve energy for more important tasks. It may mean looking at your child's lifestyle to ensure there is a good balance between work and play, or teaching your child effective ways of managing stress. From physical to emotional support, an OT can provide a young teenager with the support and tools they need to develop into well-balanced and happy young adults – whatever they want to do.

Disease education

Disease education is important for children of any age, and should be continuous and appropriate for their developmental stage. Children who were diagnosed as babies may not necessarily have an accurate understanding of juvenile arthritis as they grow, and although they may have had the disease for a number of years, they may not be aware of what it really means.

As your child grows and becomes more aware of their physical being, an OT can work with you both to help your child understand more about their disease and empower him or her to manage their own arthritis. This can be key to building self-confidence and achieving independence.

Finding an OT

Some hospitals will have their own OTs who are experienced in working with children and your consultant can make a referral. In other areas, community consultants or GPs can refer you. It is important that your child is referred to an OT with paediatric and/or rheumatology experience if possible, and that your child should have priority on any waiting list due to the long-term nature of the disease.

Different types of OT are able to provide

'To me, operations have always been quite exciting. I've had about five big ones so far, and although I know they won't cure my arthritis, they've always worked really well and reduced the pain. Each one has enabled me to move around a lot better than I could before.'

'I think it's really important that the doctors explain what is going to happen and why. My mum also asked lots of questions, which really helped calm me down and understand what they were going to do.'

'Before my elbow replacement, my mum was more nervous than I was. I just wanted to get it over and done with, but I'm sure my mum would have preferred it if she could go through it for me instead.'

'It helped having the operations explained in detail. It gave me the confidence to explain it to my daughter in a non-medical way. My biggest concern was that operations left scars, and I was worried whether her friends and peers would understand.'

assistance in different ways: NHS OTs are focused on providing therapy input, whereas social service OTs are more concerned with making adaptations to the physical environment. In some areas these services may be integrated. Your doctor will be able to advise which type of OT is best for your child.

Thanks to Janine Hackett, specialist occupational therapist, Birmingham Children's Hospital Paediatric Rheumatology; Kerry Grady, senior occupational therapist, formerly of Paediatric Rheumatology, Chaucer Unit, Birmingham Children's Hospital and Sarah Skinner, senior occupational therapist, Royal Victoria Infirmary.

Surgery

Most young children with juvenile arthritis respond well to the more common treatment options available to them, from drugs and steroid injections to physiotherapy and splinting. However, sometimes surgery is needed in children with more severe effects of the disease to relieve them from pain and improve movement and joint function.

For those who need it, surgery is able to significantly improve joint mobility and function, thereby enabling children to enjoy a more pain-free and active lifestyle. Around 20 per cent of children with JIA will benefit from some form of surgery at some stage to improve their function and mobility.

When is surgery necessary?

Although rare in children with juvenile arthritis, occasionally the time may come when medication is not controlling the disease activity adequately. As a result, joints can become increasingly affected, in turn leading to reduced activity levels through the development of deformities and pain. In these cases surgery can help dramatically, and usually takes one of several forms: either operations on the soft tissue around the joint, or on the bones or the joint itself.

Soft tissue release operations

Surgery most common in young patients involves operating on the soft tissue, namely the muscles, tendons and capsules surrounding the joints. Although the need for this type of operation is quite unusual in children under 16, a soft tissue release operation can have significant benefits, releasing tension in the joint and allowing it to move freely. Soft tissue releases are effective as long as the disease activity is kept under control through general medication and intensive physiotherapy is provided after the surgery.

Osteotomy

During the most vigorous growing years, some children with juvenile arthritis can develop deformities in their bones. An operation called an osteotomy can be carried out (but is very rare), by a surgeon, who will be able to reset the bone to the correct position.

Joint replacement operations

If the time comes when a child is finding it hard to move adequately and they are in constant pain, it may be necessary to consider a joint replacement operation. Joint replacement is rare under the age of 16, but can be beneficial for some youngsters. This usually applies to children where joint damage has already occurred, when their arthritis hasn't stabilised on the usual treatments. The most common areas for this type of surgery are the hips and the knees.

Joint replacement can provide life-changing improvements for children who have become increasingly immobile and are experiencing high levels of pain. Any child requiring this type of surgery would first be assessed by the surgeon. An operation would only be performed after careful consideration and consultation between you as a parent, your child and the specially appointed medical team.

Thanks to Mr Johan Witt, consultant orthopaedic surgeon, The Middlesex Hospital, University College Hospitals London

The eyes and uveitis

Any child who has been diagnosed with juvenile arthritis requires an initial eye screening test, on referral from a rheumatologist, as soon as possible after their diagnosis, to detect for an auto-immune condition called uveitis.

What is uveitis?

Uveitis is a rare but potentially disabling inflammation which involves the inside of the eye. A small number of children with JIA can develop uveitis. Younger children are at greater risk, with those under three years old running a higher chance of developing uveitis at some stage. However, the majority of children with uveitis (over 90 per cent) will maintain normal vision providing they receive the correct treatment early on.

JIA-associated uveitis is a form of eye inflammation that does not appear in adults. It has a very different set of problems from the adult types of uveitis, and requires a different management plan. Your ophthalmologist will advise you on any necessary treatment plan for your child.



Testing for uveitis

Early, regular and accurate eye-tests need to be carried out in order to minimise any potential risk to your child's sight. These tests can be carried out by an ophthalmologist, using a special piece of equipment called a slit-lamp microscope – the only instrument able to detect the early signs of uveitis. The examination, which takes around 30 seconds, is straightforward and painless. Following the initial test, your child should then receive regular, three-monthly screenings which can detect any early signs of uveitis. Access to such

'The eye tests are pretty straightforward – but you do have to sit still for quite a while, which can be awkward if your arthritis is really bad.'

'The drops they give you at the eye-test make everything blurry for the rest of the day, so it's hard to go to school or do anything until they've worn off.'

'Shopping for shoes for our daughter used to be a nightmare. They seemed comfortable enough in the shop, but they soon became uncomfortable. Thankfully today's fashion is more user-friendly, and we have a much wider choice.'

treatment may vary depending on your local services. Screenings are usually enough to detect its development and enable effective treatment to be started.

Treatments available

Great advances have been made in the treatment of uveitis over the last 15 years. There continue to be advances in the drug treatment of other forms of uveitis, and there have been advances in the laser treatment of some of the corneal problems associated with the disease.

Only around one in five children with uveitis find their condition persists for over five years. Milder disease usually clears completely with several months of topical steroid drops. More severe uveitis can usually be treated effectively, and about half of the children are treated with immuno-suppressant drugs. Effective drug treatment is now possible as more and more children are being diagnosed early on, enabling effective treatment before they develop any complications which may require surgery.

Is uveitis hereditary?

There are many genes involved which are slightly different to the genes involved with arthritis, but only about one in a hundred people have another family member who has uveitis.

How do I find an ophthalmologist?

Your GP or rheumatologist should be able to refer your child to a registered ophthalmologist who will be able to examine and, if necessary, treat your child. Depending on where you live, ophthalmologists can be in great demand, so it is important to act quickly as soon as your child is diagnosed to make sure they receive prompt treatment.

Thanks to Mr Clive Edelsten, consultant ophthalmologist, Great Ormond Street and Ipswich General Hospital

The feet and podiatry

Your child may need to see a podiatrist since juvenile arthritis can affect any one of the many joints in the feet. Although foot problems are not necessarily painful, nor necessarily problematic in the long term, it is often helpful to see a podiatrist who can arrange for your child's feet to be treated properly.

Signs and symptoms

The foot is a complex structure, and any one of its 35 individual joints can become affected by arthritis at some stage in a child's life. Flat feet can indicate the presence of the disease in this area, although in reality nearly all babies and young children are flat-footed, regardless of having juvenile arthritis.

Other symptoms can include swollen ankles, misshapen feet and stiffness upon walking. It is important to treat the feet while the disease is in its early stages, before the joints are affected too badly. However, treatments are effective at any age, and centre on treating the joints while they are still flexible.

Treating feet

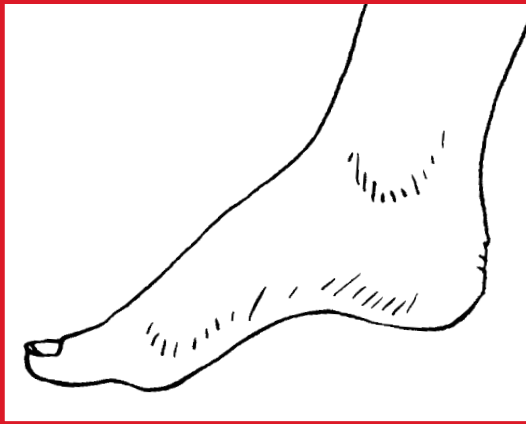
A podiatrist will be able to assess your child's feet and make any necessary treatment recommendations. Although treatment will vary from small babies to older children, the basics are the same, and will be to provide maximum support to the foot. Podiatrists aim to minimise joint damage and improve the joint's position if any damage has already taken place. They will work with your physiotherapist to make sure any treatment complements any exercises your child may be doing.

Flat feet and highly arched feet

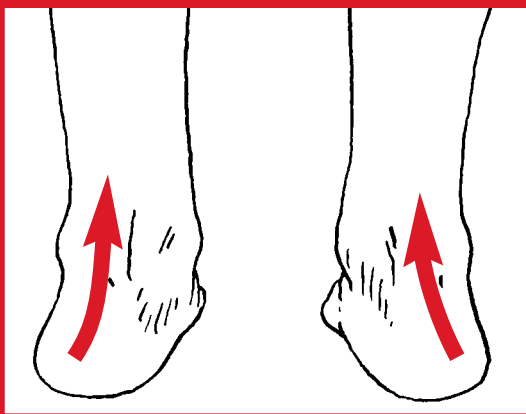
Juvenile arthritis usually causes feet to adapt to one of two extremes: flat or highly arched.

Flat feet, where the arch is absent, can be

This foot position absorbs very little shock during walking



Flat feet have a low arch and roll in at the ankles so that the heel is tilted outwards



uncomfortable and awkward to walk on. The foot tends to roll in at the ankles while the heel is pushed outwards. The reduced instep makes flat feet less able to absorb shock, and they are usually weaker, requiring more support.

Highly-arched feet, where the instep is more obviously curved, will usually show a slight bend to the front of the foot, and toes pointing inwards. Children with highly arched feet are more likely to sprain their ankles due to the outward tilt of the heel, which compensates for the foot's shape.

Both flat and highly arched feet can be successfully treated. The most common treatment is with an orthoses or specially moulded insoles which support the foot in a good position for walking.

Footwear

The right footwear can really make a

difference. As long as it keeps the foot stable, the heel in place by a tightly fastened strap or lace, and the toes lying flat, almost any comfortable shoe can be worn. While boots provide good support to the ankles, well-fitted trainers can have excellent shock-absorbing soles.

A podiatrist will be happy to discuss existing shoes your child may be wearing already, plus offer advice on other suitable footwear.

Finding a podiatrist

Podiatrists tend to work with rheumatology teams in hospitals and health centres. Your GP or rheumatologist should be able to refer your child to a podiatrist although, in some parts of the country podiatrists are hard to come by and plentiful in others.

Check with your GP or rheumatologist if there is a registered podiatrist in your area. You can also check out listings of UK State Registered podiatrists at www.podiatrypages.co.uk, and listings of podiatrists for Scotland, Wales and Northern Ireland at www.feetforlife.org.

Thanks to Jill Ferrari, lecturer, London Foot Hospital



Independent living

'As parents of three kids, we've made it a priority to try and treat everyone the same. Obviously it's not always possible, but it seems to work most of the time.'

'I've always been quite independent and strong willed. I like to make sure I can do as much for myself as possible. As I've got older I've become more independent in some ways, like learning to drive and going to university, but I've also started to lose my independence in other ways as my arthritis gets worse.'

'I see so many people with arthritis, or any illness, who have been wrapped up in cotton wool, and I'm so glad that I never was. I'm glad I've been pushed to do things for myself.'

Gaining independence

Every parent understands the importance of letting their child grow up to be an independent young man or woman, in control of his or her own destiny and how they choose to live their life.

Children naturally become increasingly independent with age. Having arthritis can make becoming independent much harder in many ways, although by no means impossible. You can encourage your child to develop their self-determination to succeed. Where their arthritis may try and hinder them, the quest for independence drives many on to achieve goals they might otherwise have believed impossible.

Education and schooling

School days can be the best days of our lives, yet children with juvenile arthritis can find them some of the hardest without the right support. Being absent from school due to illness, or receiving 'special' treatment through bespoke equipment and extra tuition can quickly lead to a child feeling singled out from their peers. Coupled with the varying ability to join in with physical team activities and sports, a child with arthritis can soon begin to feel isolated and different from their classmates.

Happily, schools are increasingly able to play a part in helping your child get the best education possible. Educating and sharing understanding of juvenile arthritis can lessen the sense of difference your child may feel. This, coupled with strong parental support, can help your child develop the confidence to face any of life's challenges head on.

Most schools are only too happy to liaise with physiotherapists or occupational therapists who can talk to the whole class or school about JIA. Many benefits can be reaped from such help for schoolchildren to understand the condition in real terms – not only does it dispel prejudice, it can also lead to increased support and acceptance for your child from their peers.



Special educational needs

Children with juvenile arthritis may be considered as having special educational needs (SEN) – and legislation has been improved to ensure that parents receive specific help and guidance to understand what this implies and the support that is available in school.

Parents of children under the age of five, not yet at school, can seek specialist advice from their local education authority. Doctors, health visitors or social workers can make the referral, which it is vital to do as early as possible in order to get the best start for your child.

An OT may also liaise with you and your school to make sure your child's needs can be met by the chosen school.

Although the emphasis now is to try and place all children in a mainstream school, some children with juvenile arthritis may need to go to a special school or unit which is better equipped to deal with their individual needs.

However, in most cases, a child's needs can be met by their LEA school, and may simply include some extra help and advice from local health professionals such as the physiotherapist and occupational therapist. However, for children who require more support in school, an assessment for a statement of special educational need (known as a statement) may be made by the LEA, taking advice and recommendations from everyone involved in the child's care, including parents, medical teams, educational psychologists and teachers.

Following the outcome of the assessment, the statement may be drawn up. This legal document, which is designed to assist and support your child in the ways he or she requires, details any necessary support which needs to be put in place in their school. The statement is subject to review, at least once a year, by the LEA, to ensure that your child's changing needs are met. Parents and any agencies and staff involved with your child's educational provision will be invited to attend the review, and amendments to the statement may be made.

Anyone involved in the care of a child with arthritis can request initiation of a statutory assessment, including parents. Members of the medical team, other involved agencies, including teachers, may also make this request on your behalf. For more information please refer to the Department for Education and Skills booklet *Special Educational Needs – A guide for parents and carers* (details are provided at the end of this section).

Learning support assistants

A learning support assistant (LSA) may be provided for in the statement. A suitably experienced LSA, paid for by the LEA, will be appointed by the school to provide assistance for your child, for a time determined in the statement. Whether it is for part of the week or part of each day, the LSA will provide the support and assistance your child needs to function properly while in the school environment.

Individual education plan

All pupils with statements require an individual education plan (IEP). This plan is drawn up by school staff to address your child's needs, detailing both short- and long-term objectives for their schooling.

At secondary school level, the IEP will include the need for specialist careers advice, at which stage input from physiotherapists and occupational therapists is important.

IEPs are rewritten every year. After your child reaches his or her fourteenth birthday the annual review will include a transition plan to prepare you and your child for the move into further or higher education. Your active involvement in drawing up this plan is vital to its success.

The learning environment

There are many ways in which schools can help your child overcome any physical difficulties.

Your child's statement can include provision for suitable computer equipment, such as a lap-top computer, and these requirements can be updated as and when required. It is advisable to seek a specialist assessment of your child's individual needs, and your LEA, occupational therapist or special educational needs co-ordinator (SENCO) will be able to provide details of what is available in your area.

A SENCO is one or more carefully appointed members of school staff who will take responsibility for making sure your child's special educational needs are identified, suitable educational programmes arranged and their effectiveness monitored. The SENCO will first assess your child and his or her environment. They will then make recommendations for any changes which may make life easier for your child, while minimising any unwelcome special treatment that may set them apart from their peers.

With regard to the physical environment, an occupational therapist and physiotherapist can make an assessment for your child, from access to buildings and toilet facilities to the heights of desks and chairs. Your OT might also decide to intervene and work with your child to teach him or her techniques to make hand-writing easier, develop their self-confidence and other coping strategies to generally make their life easier. Again, you can discuss your child's specific needs with your SENCO or LEA to find a suitably equipped school.

'The hardest thing about school was getting around, as it was on three floors and there was no lift.'

'Some teachers were overly understanding and drew attention to me, which was the last thing I wanted, while others just ignored the problem. I would have preferred them to talk to me individually to find out what help I needed.'

'I was on so many painkillers at school, which made me very forgetful and sometimes fall asleep in class. Thankfully my teachers and friends were very understanding.'

'Most of my friends are finishing their degrees this year, but I've just finished my first year. Despite my arthritis, I've made sure I can still go to university. OK, I did it later than everyone else, and didn't move away like other people, but it doesn't matter.'

'Although there was a bit of schooling in hospital, I was worried that my daughter would fall behind. However, after support from the school, she was able to continue at home whilst convalescing. Keeping an open communication with school, teachers and pupils can really lessen the worry for both parent and child.'

Coping with absence

Periods off school caused by the effects of juvenile arthritis can make a child feel isolated from both social and learning experiences. Teachers can offer support at such times by sending home schoolwork. Just as important, however, is the encouragement they can give to classmates to stay in touch with your child by sending cards, letters and emails, or dropping by for a visit – these gestures can help your child feel that they belong to the school community, even though they may be unable to attend lessons.

As a parent you can help your child through periods of absence by encouraging them to talk about their feelings. Your support can help motivate your child enough to give them the drive and determination they need to do well in their learning. Teachers can also help to nurture and monitor your child's development, and counsellors can help your child explore their potential and keep their arthritis in perspective with the rest of their life.

Home tuition

The unpredictable nature of JIA can lead to short or prolonged absences from school, and as a parent you can play a vital part at these times by staying in contact with your child's teacher, and the school's SENCO. They will be able to help minimise disruption to your child's learning, as well as ensuring that school staff fully understand your child's situation.

Providing your child is feeling well enough, arrangements can be made wherever they are to continue their learning. Children's hospitals and paediatric wards in general hospitals usually provide some education during periods of admission. However, it is important to inform school teachers of a forthcoming hospital stay, so that they can arrange to send on classnotes and schoolwork to your child during periods of absence.

In November 2001 the DfES issued guidance which sets out minimum national standards for the education of children unable to attend school because of medical needs.

When your child is well enough to study, but is unable to go to school, home tuition may be an option. The DfES guidance document *Access to Education for Children and Young People with Medical Needs* advises on the provision of home tuition. Check with your school or LEA for more information.

Don't let the system get them down

Anxiety and worry about school can affect any child, but is particularly pertinent to children with JIA as a result of long or regular periods of absence.

Through understanding the difficulties that face your child, you can help by offering them the extra support they might need. Encourage them to talk about any concerns they may have, if not to you then to an understanding friend or their LSA. As a parent you can provide invaluable reassurance that your child is in control of his or her own life, and that you are there to support them day-by-day.

The SEN and Disability Act Codes of Practice

The SEN and Disability Act Codes of Practice relate to all schools. They outline procedures and guidance on both identifying and assessing special educational needs, and ensuring pupils are not discriminated against because of a disability. Health and Social Services are also expected to have regard to the codes when assisting LEAs and schools. You can obtain a copy from the DfES via their website: www.dfes.gov.uk (or see back page for full contact details). The codes will help you understand SEN issues and how schools and other agencies are expected to deal with them.

Further information

Education protocols and policies can vary, depending on where you live in England, Northern Ireland, Scotland or Wales. Details of individual organisations can be found at the back of this booklet, and will be able to provide up-to-date information on all aspects of education wherever you live.

Copies of the booklet *Special Educational Needs – a guide for parents and carers* can be ordered via the DfES website on www.dfes.gov.uk or by calling 0870 000 2288.

Thanks to Mel Lewis, deputy headteacher, The Hospital School, Great Ormond Street Hospital for Children

The world of work

First jobs can be exciting times. Having arthritis does not necessarily mean your son or daughter will not be able to find suitable work or enjoy a rewarding and successful career. Depending on their abilities and the severity of their arthritis, there are many different types of jobs that may be appropriate, and a whole set of laws to protect the rights of people against discrimination by employers.

Your teenager may find that a Saturday job suits them, enabling them to meet other people and earn some money at the same time. They might take on a voluntary placement, where they can gain valuable experience in the area they are interested in, while putting something back into society or gaining experience for their chosen career. They might decide they are more suited to working from home, and many companies are more and more happy to be flexible with their employees – an approach which can be greatly beneficial for people with arthritis due to the unpredictable nature of the disease.

Legal rights

The Disability Discrimination Act (DDA) 1995 has given disabled people many more rights in the workplace. Under the Act,

employers with 15 staff or more cannot legally discriminate against people with a disability, whether they are an applicant or an employee. The Act also makes employers responsible for making any necessary adaptations to their working environment to enable someone with a disability to carry out their duties freely.

The Disability Rights Commission (DRC) is campaigning for full civil rights for disabled people, and publishes a leaflet called *A brief guide to the Disability Discrimination Act 1995*, containing all sorts of useful information on fair treatment by employers. See page 40 for full contact details.

Jobcentres

Jobcentres can provide your son or daughter with all the information on finding work, as well as any disability services which may be appropriate.

For those who may be unsure about what type of work would suit them, or which direction to take, the local careers advice service can provide all sorts of help and advice. You can find their contact details in the Yellow Pages.

Connexions Direct

Connexions Direct offers a wide range of careers advice as well as confidential advice, support and information for 13-19 year olds living in England. They can help with a range of personal issues, including career and learning options. They can also search for local career service centres and welfare organisation centres across Northern Ireland, Wales and Scotland and can be a good starting point. Their details can be found at the back of this booklet.

Skill (The National Bureau for Students with Disabilities)

Skill is an independent charity that promotes opportunities for people with any kind of disability in learning and employment. It helps people over 16 with any kind of disability throughout the UK.

'I've done a lot of voluntary work. It's good because I can do it as and when I want to, and I can do it from home. If I'm not very well, they're very understanding because they've all got arthritis as well.'

'I learned to drive in between doing my GCSEs. It was quite funny being able to drive to school in my school uniform. All my friends were waiting outside the gym and there was me in my mum's car.'

'When I got my first Motability car, I didn't know what to say to people about how I'd managed to afford it. I made up so many stories. Now I don't care what people think, but the people who were a bit funny with me were also the first people who needed a lift home.'

'I didn't want to keep on relying on my parents all the time to pick me up from school and take me to my friends, which was why I learned to drive as soon as I could.'

'Motability is a great scheme – there's no way we could have afforded to buy our daughter a new car like the smart one she's got now.'

The charity provides a free information and advice service to help disabled people to overcome financial and physical barriers, ignorance and discrimination so that they can study, train or find work. Their details are listed at the back of this booklet.

The Employment Service

The Employment Service runs an Access to Work scheme, which provides help on all employment matters, both on a practical and financial level. They can also provide your son or daughter with a support worker if they need practical help, equipment or adaptations to suit individual needs, help with work-related expenses and many other useful benefits. You can find their details, under the disability service teams of your local Social Services, in the phone book.

More information on all aspects of employment and working can also be found in Arthritis Care's own booklet *Working Horizons*.

Driving and transport

Having the freedom to get about independently plays a vital part in any growing teenager's life. Many young people with arthritis are allowed to drive a year earlier than other youngsters. For your son or daughter, being able to take their test at 16 can be a great confidence boost, as well as a huge step on the way to achieving independence.

Motoring around, going wherever they want to go, can be a very positive experience for your child, and there are a number of schemes in place to help them choose the right form of transport and pay for it in an affordable way.

To qualify for the schemes, your son or daughter must qualify for the higher rate mobility component of DLA (Disability Living Allowance). If so, they can qualify to apply for their provisional licence at 16 instead of the usual 17, in addition to getting assistance to suit their

transport needs.

Motability

Motability is a charity specially designed to enable disabled people (those on higher rate mobility component of the DLA) to afford their own new or used vehicle, be it a car, powered wheelchair or scooter, through an easy-to-use contract hire or hire-purchase scheme. The scheme is extremely popular, especially with young people, as it can offer the financial assistance they might need to be able to buy their own vehicle at an early age.

The Queen Elizabeth Foundation Mobility Centre provides an information service and assessment of disabled people, training courses and driving tuition.

MAVIS (Mobility Advice and Vehicle Information Service) can offer information on all aspects of public and private transport, as well as advice and practical training for disabled and would-be drivers and passengers.

There are many other organisations which can offer advice and help for people with mobility problems. Contact details of some of them can be found at the end of this booklet.

Public transport

Access to public transport can be a major problem for people with mobility problems. Buses, trains, coaches and tubes



can all be tricky to use, and your son or daughter may need to plan their journey extra carefully to make sure they can use the transport all the way to their destination.

Improvements to public transport are slow, but are being made all the time, and the Government's accessibility regulations for trains, buses and coaches have already ensured that many new vehicles are now usable by disabled people. Other legislation and Government plans promise further improvements in the years ahead. For the time being, however, finding other ways to be independent is the most popular choice for many young people with arthritis.

Benefits

As a parent of a child with juvenile arthritis, you may be entitled to claim a number of social security benefits to provide you with financial support. There are a wide range of benefits available, and it can be a complicated process finding out which ones you could claim. The information below should provide you with a good starting point to find out more about benefits and how they can help you and your family.

Depending on your own personal circumstances, and the severity of your son's or daughter's arthritis, you may be able to claim benefits such as Tax Credits, Income Support, Carers Allowance, Child Benefit and Disability Living Allowance, to name but a few. It is always worth checking to make sure you are receiving what you are entitled to claim – many people don't claim what they are entitled to – and there are many different sources of information which can help you find out what you need to know.

A good first port of call is your local Benefits Agency – the executive agency of the Department of Social Security (DSS) in England and Wales. They will be able to advise you and send you information on all the benefits you could claim. Your local

office will be listed in your phone book. Also, the freephone Benefits Enquiry Line (BEL) can answer all your questions on benefits, and can be reached on 0800 882200 (UK) or 0800 220674 (Northern Ireland).

The Disability Alliance is a really useful and comprehensive source of authority on social security benefits for disabled people. As well as publishing the Disability Rights Handbook (copies should be available in your local library) they have a useful checklist and full, up-to-date details on all benefits available depending on your own personal circumstances. Visit their website at www.disabilityalliance.org.uk

The Family Fund is an organisation which can provide families in the UK, who are caring for a severely disabled or ill child under 16 years old, with grants and information to help with their care. To find out if you might qualify, you can call them on 0845 130 4542 or visit their website at www.familyfund.org.uk.

Alternatively, you could check out Arthritis Care's own *Benefits for Beginners* booklet, which carries detailed information on everything you need to know about benefits and how to go about claiming them (see contact details on back page).

'It's really worth looking into benefits properly – I had no idea how much money I could claim. I can't work, as I need to be around 24 hours a day to help my daughter, and we'd really struggle otherwise.'

Family matters



'My big brother does really nice things for me when I'm not feeling so great. When I'm really lucky he brings me a drink and something to eat in bed so I don't have to get up to take my pills.'

'We manage to overcome the challenges of our daughter's arthritis as a family by taking each day as it comes.'

JIA – a psychological perspective

As we have seen throughout this booklet, children and young adolescents with arthritis can face greater stresses and practical demands than their peers, and the chronic nature of the disease can have a psychological and social impact on a child and their family.

The effects of JIA in your family can be far-reaching, and both parents and siblings of a child with juvenile arthritis can be affected by the disease and its treatment, not just in terms of the practical difficulties associated with symptoms, treatment and possible disability.

Often, these experiences can bring about positive results, such as closer relationships and increased skills and responsibilities among family members. However, there can also be difficulties, worries and concerns, many of which can be overcome with a little help from the right place.

Being a parent of a child with arthritis can, at times, be incredibly stressful, upsetting, and worrying. It is important to seek help and support if you feel you need it, and there are plenty of organisations to contact who will understand your specific concerns. Some of these organisations are listed on page 40 of this booklet.

Arthritis Care, the Children's Chronic Arthritis Association and The Lady Hoare Trust are experts in providing practical help and advice as well as emotional support on any arthritis-related issue. They can also supply you with a range of other contact details for other organisations who can help you along the way.

This section aims to provide an overview of how the many different mental health professionals, including clinical psychologists, social workers, family therapists and psychiatrists, can provide support to you and your family when you may need it.

Parents

It is natural as a parent to worry about the long-term effects of JIA and its treatment on your child. Stresses and concerns about growth, education, ultimate occupation, possible disability as well as ability to have families are commonly reported, although these sorts of long-term worries do not tend to be shared by the children themselves. Instead, children focus very much on the present, resulting in some difficulties with doing physiotherapy and taking medications. These can have negative short-term side effects such as pain or nausea, versus the longer term, and therefore 'unseen', positive effects of minimising active disease and its effects on joints.

You may benefit from support with coping with personal thoughts and feelings about your child's illness and treatment. Coping with your role as the parent of a sick child at home or in hospital, whilst balancing the needs of all family members, can be very challenging.

Parental and child beliefs about illness and treatment are associated with emotional and social functioning, as well as your child's pain levels. It is important that you are given the opportunity to discuss beliefs and concerns about the disease and how to reduce any negative effects it is having on the family. A clinical psychologist can help you come to terms with all these aspects of your child's arthritis.

Siblings

Parents of children with JIA face the difficult task of needing to provide similar levels of love, attention and concern to their other children. In practice of course this is not always easy, with the varying demands of the arthritis often taking precedence over other events. However, according to research, there is no direct relationship between disease severity or level of disability and sibling adjustment. What is important is the quality of the relationship between siblings, and the



degree of disruption to family life which occurs as a direct result of their brother's or sister's arthritis.

Siblings may also have their own concerns, including worry about whether they will get JIA, and how to explain their sibling's arthritis to peers. JIA often demands changes in responsibilities within the family, and siblings can naturally feel resentment and guilt. Provision of the opportunity to discuss concerns and feelings, either individually or as a family can help siblings cope with their own thoughts and feelings about JIA, its treatment and the impact it is having on family life.

Pre-school years

With very young children, psychological support may be provided by working mainly with parents to enable you to provide the right environment for your child and encourage them to develop emotionally, socially and physically. These are important developmental tasks for pre-school children, achieved through exploring and learning to understand their environment. This may involve greater challenges for a young child with juvenile arthritis, and you can be supported in your

attempts to step back if you are tending towards being over-protective, so you may achieve a helpful balance between concern and facilitating your child's normal development.

Pre-school children with arthritis need to develop socialisation skills gained mainly through play activities with other children. You may be anxious that your child is more vulnerable than others, and hold them back from interacting normally with other children their age. Also, you may find yourself placing fewer demands and behaviour boundaries on your child with arthritis, than with your other children. At any age, treating a child with a chronic condition as if they were acutely ill can result in longer-term problems and, while short bursts of increased attention and reduced expectations are acceptable for days or weeks, for prolonged periods this may lead to more regressed behaviour patterns, as well as difficulties with resentful siblings in the long term.

The school years

School years can be difficult times for children with juvenile arthritis. As we have seen in the section on Education, there is a common misconception that arthritis only affects older people. The flare and remission nature of JIA can also be difficult to explain to others, particularly peers. Being able to participate in active sports such as football one day and then to be in too much pain or be too stiff to be able to sit on the floor in assembly the next, can be confusing for peers and teachers. It can often lead others to question the genuineness of a child's symptoms.

During the school years, the aim is to support the child so they may function as fully and independently as possible. Children with arthritis do not tend to get behind academically, despite often significant absence from school, providing they receive adequate support from the school, their parents and any other professionals involved in their learning.

'I found it hard learning to be a mother of a child with arthritis, especially with things you wouldn't normally consider difficult, such as sitting up at a table, sitting on the toilet and getting up and down stairs. It was also a delicate balance making sure the other siblings were allowed to carry on with their daily routines and needs whilst also considering my daughters' individual needs and frustrations.'

'Although she has had to endure a lot of pain and suffering, she thinks only of others and never herself – she is without a doubt one in a million.'

Maximising your child's potential may include the provision of a laptop computer, or formal partial attendance at school for when they are having a flare. Building social relationships at school and becoming competent through individual achievements can help your child develop, but physical limitations and reduced participation in team activities can lead a child to develop feelings of isolation and lower self-esteem. Reduced class attendance may mean your child has to work harder to develop consistent friendships at school. Missing out on games or being unable to take the bus or cycle home can make a youngster feel less independent. Developing favourite extra-curricular hobbies and activities can help to refocus a child's attention, and build their confidence and self-esteem through other capabilities in addition to their school life.

Despite the fact that many children with arthritis surpass their peers academically, they can sometimes be treated differently by teachers and peers, who may expect them to be less able than other pupils. Reduced expectations on the part of parents, teachers and peers may inhibit progression through normal developmental milestones. It is important that child, family and school system do not take their worst days of functioning as a baseline, but instead aim expectations midway so that these are met and exceeded at times, to boost your child's confidence and build on his or her abilities.

Conquering fears

Many children, especially those of school age, are frightened of needles, blood tests and other medical procedures. This is a natural response to something which can hurt, and as a one-off does not cause many problems. Unfortunately, juvenile arthritis and its treatment can involve ongoing monitoring, involving frequent, regular blood tests or medications administered by injection, often with no immediate reward, such as pain relief or feeling better, for the



affected child. Referral to a clinical psychologist or other professional who specialises in phobic responses can treat your children's fears of such procedures effectively, so that treatment and monitoring can occur without trauma to your child or your family and enable your child to conquer any fears or worries.

Turning into teenagers

Teenagers have specific needs according to their own stage of development, and their treatment needs to be tailored to them. Adolescents tend to want to push the boundaries, and will require more freedom and independence to enable them to develop into well adjusted young adults. JIA or its treatment can lead to fluctuating weight and early or delayed puberty which, in addition to possible shorter stature or swollen joints and use of mobility or dexterity aids, can add to the negative impact of having juvenile arthritis, when your adolescent is already highly conscious of his or her own body image.

Parents of adolescents with arthritis can help them grow into independent young adults by being aware and responsive to their developmental need for independence, and by allowing your

teenager increasing amounts of freedom. Adolescence is characterised by a need to reduce dependence on parents and family with fuller integration with a peer group. This usually involves pushing boundaries with rules and behaviour, which can often worry parents if it also affects their teenager's attitude and response to their illness and treatment.

The usual experimental behaviours, perhaps involving alcohol or sexual activity, have additional risks or implications for adolescents with JIA, which may need to be discussed with a health professional, perhaps without you present. Adolescents may feel increasingly uncomfortable about discussing some aspects of their life with their parents. This may be in terms of their treatment decisions, relationships or contraception. Many hospitals have responded to the need to consider adolescents as a distinct group, and provide specialised adolescent services to meet teenagers' needs as they negotiate the transition to adulthood, moving from educational to occupational concerns and to adult health services.

CHAT – arthritis in teenagers carries more detail on arthritis for this age-group. See back page for contact details to order a copy.

Next steps

Families affected by juvenile arthritis have different strengths and vulnerabilities and can request referral by their GP or rheumatologist to a clinical psychologist or other mental health professional. Having the opportunity to explore thoughts and feelings about JIA and provision of support at difficult transition times can prevent difficulties becoming unmanageable, as you all come to terms with the challenges of living successfully with juvenile arthritis.

With thanks to Dr Michele Amos, clinical psychologist, paediatric rheumatology, Great Ormond Street Hospital for Children, London



Through a child's eye

Helen Johnson talks about how she has been affected by her arthritis



Picture posed by model

'My thoughts as a teenager were that I wanted to just be normal. Having arthritis was hard enough to deal with, taking daily medication was irritating and having surgery was just another way to feel different from everyone else.

Now that I am older I can understand the reasons why I needed surgery and can see the positive improvements it has made to my quality of life.

My own personal experience of operations has changed as I've got older. This is due to the support and understanding I've had. Things were explained to me, not in every detail as it would have just made me more anxious, but enough to help me understand and be able to reach a decision.

Having support from people around helps enormously. It can't take away the arthritis, it can't take away your fears, your questions or your wishes, but it does make it easier to cope with, especially when you feel you can talk it over and explain fears and frustrations – no matter how insignificant they seem.

In my teenage years I found everything quite daunting. Often I didn't understand what was being said and just the word 'operation' was scary enough. My rheumatologist would explain it to my mum, first in medical terms and then in simple terms. She would explain the operation, the procedure, advantage and both short- and long-term effects. When we got home, my mum and I would talk about it, mostly about the exact operation and the advantages, in ways that made sense to me.

I've had over ten operations on my fingers, toes, knees and hips, starting when I was 10 years old. All of my operations have been a success, although there has been some nerve damage, which unfortunately cannot always be avoided.

If I had to say if the operations had changed my life for the better, I would have to say both yes and no. 'Yes', because they have decreased my pain, improved the

movement of my joints and improved my quality of life. 'No', and this may sound a little ungrateful, because of the physical scars they leave.

All said, I am pleased I had the operations – I would not turn the clock back and say no if I could. Also, surgical techniques have improved dramatically since I was a teenager, particularly with respect to keyhole surgery and better techniques of stitching which leave minimal scarring.

I have experienced the benefits of surgery first hand and the improvement it has made to my quality of life. If I hadn't had any of the operations I would almost certainly have to use a wheelchair some of the time, if not all of the time.'

A parent's tale

Gwyneth Priestland talks about how arthritis affected the family

'Kate was 13 when she was diagnosed with JIA. At that time, the hardest part was coming to terms with the fact that our child had a major chronic disease. Both family and friends experienced all ranges of emotions: shock, disbelief, disappointment, shattering of dreams – almost bereavement – but we gradually grew to accept the presence of the arthritis and understand that we had to deal with it positively.

There was much to learn about the disease. We had great misgivings about giving our daughter drugs, but we realised that they were essential to try to control the disease. Her doses and treatment have changed dramatically over the years, but I have always remained firm about the importance of asking questions as to how the medication should be working and being made aware of any adverse reactions. Fortunately, one of the benefits of living in a small town meant we were close friends with our doctors, and were able to discuss treatment and ask questions.

As parents we both played separate but equally important roles in helping our daughter with her physio. Her father would drive her 15 miles to the nearest hydrotherapy pool three times a week before school, and at home I would encourage her to help me make bread as well as take part in other fun things like cycle races on the exercise bike with her friends. We found the little and often approach worked well.

Because Kate's arthritis was quite severe, certain operations became the only answer to improving her movement which had become restricted, limited and painful. It was with a sinking heart I would hear Kate's consultant say: "Why is it, Kate, that whenever I see you I think of operations?" We asked many probing questions before committing Kate to having any operation. She has had all manner of surgery, from foot manipulation to elbow prosthesis and knee replacement and many other minor operations. I always questioned as to whether the operation was essential at that

very time, whether it could be postponed or whether there was an alternative and what the benefits would be. Kate has always been very ready to accept surgery – I think she's understood that if it could help reduce pain and give her better movement, it was worth having it done.

I spent a lot of time explaining to Kate's teachers about what having arthritis could entail. PE lessons were out, climbing stairs could be a problem, carrying bags could be awkward and so on. Unfortunately, despite this, there were physical problems within the school which could not easily be solved. Eventually it was suggested that Kate attended another school, 20 miles away, because it was all on one level. I dismissed this idea out of hand, and stressed the importance of her needing to be with her friends, and how important it was for her to fit in just like the other children, and not being made to feel even more different and isolated.

I pushed extremely hard to arrange home tuition for Kate when she had to take a year off school. It was worth the effort. Various tutors were assigned, and they liaised with the school to work within the parameters of the curriculum. Although her main tutor wasn't a specialist in every field, she was brilliant at Kate's favourite subjects – English and history. Learning from home enabled Kate to keep up with her peers, which was really important. Her friends would call round regularly. I've never made so much spaghetti bolognese.

Her O- and A-level results were quite remarkable, allowing her to go forward to higher education and achieve an Honours degree in history at Reading University. She now holds down a very prestigious job.

Despite the fact that Kate's arthritis is life changing, it is not life-taking, and this helps us all to make the most of every aspect of our own lives. As a family we are just getting on with it. A positive attitude is all important. Kate has really proved to us that nothing is impossible, and she is an inspiration to us all.'



All grown up

Lisa Clarke is now 33, but was diagnosed with juvenile arthritis when she was 14



Picture posed by model

'Getting arthritis as a teenager was a bit of a blow. Saying that though, it really didn't sink in for a while despite the swollen joints and the horrible pain. Like so many others still believe, I thought that arthritis was only something grannies got. I soon learnt my lesson.

Immediately I was plunged into another world, but it hasn't been one I've ever resented. I seemed to accept my arthritis as something I had to live with. I have always accepted the help offered whether it is medical or physio or the Alexander Technique as they might help.

That's not to say I'll try anything – I ask a lot of questions and know a lot about my arthritis. After all, I'm the one living with it so I know it inside out.

My arthritis really affected my schooling, but, despite having huge chunks of time off, I managed to get my GCSEs and my A-levels. I know I didn't do as well as I should have done due to missing so much, but it was plenty to get me into the university I wanted.

Going away – leaving home – was probably the best thing I ever did. And that's everything to do with my parents. They brought me up to be a very confident, strong and independent person – great building blocks for a life with arthritis. They instilled in me a determination I have only really understood in the last few years. It is something that's done me well in life.

They could so easily have been over protective and overly worried. And yes, there were times they were, but really they knew I would cope. And when I couldn't, we invariably sorted something out. My parents have been there for me always. They have supported me in everything I wanted to do – and sometimes that has been financially too.

Having arthritis is a very expensive business. I know I have been lucky – they helped me buy a car so I could maintain my independence; they paid for my insurance when I couldn't afford it.

But most of all they have paid by just

being there for me while still giving me the freedom to be me.

When my arthritis was at its worst, keeping friendships going was probably one of the most difficult things. While everyone was out discovering themselves, I was not able to join in. I know I became a mouse of a person for at least three years. I don't know what changed, but one day I seemed to rediscover who I was.

Since then, keeping up with my friends has been very important to me. That doesn't mean following them around trying to physically keep up. It means catching up, having a few laughs, quiet nights in and, yes, a few mad ones out.

I've always found it's been important to me not to let my arthritis stop me achieving the things I want to achieve. And some of my aims may have adjusted a little, but that doesn't mean I give up.'

A family affair

Caroline Cox shares how her daughter's arthritis has affected her family

'After many months spent visiting doctors, consultants and hospitals, when our daughter was finally diagnosed as having JIA, my husband and I were initially relieved. However, our feelings soon changed when we realised that juvenile arthritis was not something that could simply be treated and cured, and would not always go into remission.

There were so many questions that we didn't have any answers for at that time. Initially we were not sure which way to turn. We were desperate for help and support.

As a mother, I wondered if I could have done anything to prevent our daughter from developing arthritis. Should I have done anything different when she was a baby? All sorts of feelings and guilt and disbelief passed through my mind.

Time passed and we started to get a better understanding of how devastating juvenile arthritis could be – not just for our child but also for us as parents and as a family. Arthritis is so unpredictable that even a simple day out involves careful planning and may even have to be cancelled at the last minute. The unpredictable nature of it can be very difficult at times, and the challenges can either divide or bring you closer as a result.

On a daily basis, juggling the running of the home as well as fitting in our daughter's exercise programmes, trips to doctors and hospitals, and hydrotherapy sessions was far from easy. However, the realisation that our daughter had to come through this in her own way was enough to spur us all on. Doing anything positive to help our daughter became extremely important to all of us.

We learned that we could help with even the smallest things, and that it was vitally important that our daughter never felt frightened or too proud to ask for help. We involved our other children with aspects of our daughter's care. For example, joining in with physio and going along to the outpatients' clinic with her. We also made

decisions and planned any trips, holidays and outings together as a family.

Even though there were many times when my husband and I felt frustrated and isolated, we did develop a real appreciation of many aspects of life that hadn't been so apparent before the diagnosis.

Having a child with arthritis has changed us all in so many ways, both individually and as a family. We have learned to recognise our daughter's character, courage and commitment to leading a normal life. Our other children have a greater appreciation and understanding of children who are less fortunate than them. Each one of us knows how fortunate we are to be in good health.

No matter what happens, we all know how important it is to make the best of the good times. The bad days don't always go away, but this focus helps us enjoy every moment.'



Further Reading

CHAT (Children Have Arthritis Too)

CHAT 2 Parents – arthritis in teenagers

Provides information for parents of teenagers who have arthritis.

CHAT 2 Teachers – a teacher's guide to juvenile arthritis

Please call 020 7380 6540 to order.

Arthritis Care

ARTHRITIS CARE PUBLICATIONS

No Limits – magazine for young people with arthritis aged 15-20 published three times a year as a supplement to *Arthritis News*.

A Day with Sam

Hunsley, Debbie

Arthritis Care, 1996, reprinted 2000, 40 pages. ISBN 0952030349

A picture-book for adults to read aloud to children with arthritis who are aged seven and under.

INFORMATION SHEETS

Education contacts

List of useful organisations for pre and post 16 students.

Employment contacts

List of useful contacts.

Going to university/college

How to choose a university, arrange finances, manage your time, make tutors aware of your needs, make friends.

Going to school

How arthritis may affect the school day, how to address problems and what to tell friends and teachers.

Going to school – Information for parents

How arthritis may affect school age children, and what parents can do about it.

School needs checklist

A checklist for parents and children breaking down the parts of the school day to quantify and clarify the student's needs for teachers and others involved.

Teasing

Practical suggestions for children on how to handle teasing, with sources of help.

Websites

Useful websites on arthritis, general health information and general information.

When you have been diagnosed with arthritis

Written for young people recently diagnosed with arthritis to address feelings of denial, anger, depression, and how to come to terms with the situation.

When your child is diagnosed with arthritis

Addresses the feelings parents have to cope with – disbelief, anger, depression, and how to come to terms with the situation.

Receiving a diagnosis – teenagers

Written for teenagers recently diagnosed with arthritis to address feelings of denial, anger, depression and how to come to terms with the situation.

Guidelines for prescribing anti-TNF therapy in children and young people with juvenile idiopathic arthritis.

See www.arthritiscare.org.uk for details on ordering or phone 020 7380 6540

ARC

Tim has Arthritis

An information booklet written for 4-8 year olds. Please note this is available in PDF format only from the ARC website (www.arc.org.uk).

When your Child has Arthritis

For parents of children with arthritis.

Arthritis in Teenagers

An information booklet for 13-20 year olds.

When a Young Person has Arthritis

An information booklet aimed at teachers. See www.arc.org.uk for details on how to order or phone 01246 558033.

Choices

Kids with Arthritis: a guide for families

Available from CHOICES for families of children with arthritis. See www.kidswitharthritis.org for details on how to order.

Notes

Useful contacts

Arthritis and disability organisations

Arthritis Care

18 Stephenson Way
London NW1 2HD
The Source – a helpline for people under 26 and their families
Tel: 0808 808 2000 (freephone 10am to 2pm Monday-Friday)
Email: TheSource@arthritis.org.uk
www.arthritis.org.uk

Arthritis Care in Northern Ireland

Family and Youth Work
Catherine Wright
115 Enkalon Business Park
25 Randalstown Road
Antrim BT41 4LJ
Tel: 028 9448 1380

JOINTZ

Arthritis Care support group for parents of children with arthritis in N Ireland
Janet Harper
7 Newton Heights
Newtownards BT23 7YG
Tel: 028 9182 0369

Arthritis Research Campaign (arc)

Copeman House
St Mary's Court
St Mary's Gate
Chesterfield
Derbyshire S41 7TD
Tel: 01246 558033

Children's Chronic Arthritis Association

Ground Floor office
Amber Gate
City Walls Road
Worcester WR1 2AH
Tel: 01905 745595
www.cca.org.uk

Choices

A support group for families with children with arthritis
PO Box 58, Hove
East Sussex BN3 5WN
www.kidswitharthritis.org

Disability Rights Commission

DRC Helpline
Freepost MID02164
Stratford-upon-Avon
CV37 9BR
Tel: 08457 622633
www.drc-gb.org

The Lady Hoare Trust for physically disabled children

Unit E409, Westminster Business Square
1-45 Durham Street
London SE11 5JH
Tel: 020 7820 9989
www.ladyhoaretrust.org.uk

RADAR

Unit 12, City Forum
250 City Road
London EC1V 8AF
www.radar.org.uk
Tel: 020 7250 3222

Whizz-kidz

National disabled children's charity
1 Warwick Road
London SW1E 5ER
Tel: 020 7233 6600
www.whizz-kidz.org.uk

General

The Institute for Complementary Medicine

PO Box 194
London SE16 7QZ
Tel: 020 7237 5165
www.icmedicine.co.uk
(Send large SAE and state therapy you are interested in for a list of qualified practitioners.)

DIAL UK

St Catherine's
Tickhill Road, Doncaster
South Yorks DN4 8QN
www.dialuk.org.uk
Tel: 01302 310123

Education

Connexions Direct

Tel: 0808 001 3219 (main helpline)
Text: 07766 413219
www.connexions-direct.com

Department for Education, Northern Ireland

Rathgael House
43 Balloo Road
Bangor Co. Down
BT19 7PR
Tel: 028 9127 9100
www.deni.gov.uk

Department for Education and Skills (DfES), England and Wales

Sanctuary Building
Great Smith Street
London SW1P 3BT
Tel: 0870 000 2288
www.dfes.gov.uk

Scottish Executive Education Department (SEED)

Victoria Quay
Edinburgh
EH6 6QQ
Tel: 0131 556 8400
www.scotland.gov.uk

SKILL UK

For students over 16 years
Information Service
(Monday-Thursday 1.30 to 4.30pm)
Tel: 0800 328 5050 (freephone)
Tel: 020 7657 2337
Text: 0800 068 2422

SIGN

9 Queen Street
Edinburgh EH2 1JQ
Tel: 0131 225 7324
www.sign.ac.uk

SKILL Northern Ireland

Unit 2, Jennymount Court
North Derby Street
Belfast BT15 3HN
Tel/Minicom: 028 9028 7000
www.skill.org.uk

SKILL Scotland

Norton Park
57 Albion Road
Edinburgh EH7 5QY
Tel: 0131 475 2348
www.skill.org.uk

Mobility

MAVIS

'O' Wing, Macadam Avenue
Old Workingham Road
Crowthorne
Berkshire RG45 6XD
Tel: 01344 661000
www.mobility-unit.dft.gov.uk/mavis.htm

Motability

Goodman House
Station Approach
Harlow, Essex CM20 2ET
Tel: 01279 635999
www.motability.co.uk

National Mobility Centre

Unit B1, Greenwood Court
Cartmell Drive
Shrewsbury SY1 3TB
www.mis.org.uk
Tel: 01743 463072

Queen Elizabeth Foundation Mobility Centre

Damson Way
Fountain Drive
Carshalton
Surrey SM5 4NR
www.qesd.org/mobilitycentre
Tel: 020 8770 1151



Arthritis Care
18 Stephenson Way
London NW1 2HD
Tel: 020 7380 6500
Fax: 020 7380 6505
www.arthritiscare.org.uk
Registered Charity No. 206563

Arthritis Care is the largest UK-wide voluntary organisation working with and for all people with arthritis. Arthritis Care:

- provides a helpline service by telephone, letter and email. Freephone 0808 800 4050 weekdays 12-4pm. Tel: 020 7380 6555 weekdays 10am-4pm. Email: Helplines@arthritiscare.org.uk
- offers The Source, a helpline for young people with arthritis and their families, by telephone, letter and email. Freephone 0808 808 2000 weekdays 10am-2pm. Email: TheSource@arthritiscare.org.uk
- produces *Arthritis News*, a bi-monthly lifestyle magazine for people with arthritis
- produces *No Limits*, a magazine for 15-20-year-olds three times a year
- produces a range of information booklets on a range of topics including relationships, complementary therapies, exercise and benefits
- campaigns for greater awareness for the needs of all people with arthritis
- runs a range of self-management and personal development training programmes for people with arthritis
- runs four hotels in the UK
- runs positive future workshops and Yactive events for teenagers. These weekend residential courses are aimed at sharing experiences with others, building confidence and self-esteem, tackling new challenges and having fun.

Volunteers run local groups throughout the UK sharing information and offering support as well as raising awareness of Arthritis Care in the locality.

All Arthritis Care's work is aimed at promoting independence and empowering people with arthritis to live positive lives as well as raising awareness of the condition.



Children's Chronic Arthritis Association
Ground floor office
Amber Gate, City Walls Road
Worcester WR1 2AH
Tel: 01905 745595
www.ccaa.org.uk
Registered Charity No. 1004200

The Children's Chronic Arthritis Association is the leading charity run by parents and professionals to provide help and information for children with arthritis, their families and professionals involved in their care. We offer emotional and practical support to maximise choices and opportunities and raise awareness of childhood arthritis in the community.

We aim to give practical help and support through our support network and area family contacts in a variety of ways.

- Regular newsletters, including information about the charity, various events and many aspects about juvenile arthritis such as suggested treatments and information about drugs.
- An active support network led by parents for parents. In some areas, it is telephone contact, some areas meet regularly and some areas arrange trips for the children and fundraising events.
- A yearly family weekend to provide information, advice and support to the whole family, as well as ensuring they all have a great deal of fun.
- Increase general awareness of juvenile arthritis by fundraising events, promotional items and various conferences.
- Outings and parties for children with juvenile arthritis.
- Many new projects concerning educational and social support.

The executive committee has representation from parents and professionals. Due to this we feel there is a two-way sharing of knowledge and ideas which is of benefit to everyone. The charity is run on a voluntary basis and our membership is open to anyone and, except for some administration costs, all money goes into our various projects.

THE LADY HOARE
trust

for physically disabled children

Helping children with arthritis and limb disabilities lead full and independent lives

Lady Hoare Trust
Unit E409, Westminster Business Square
1-45 Durham Street, London SE1 5JH
Tel: 020 7820 9989
Fax: 020 7582 8251
www.ladyhoaretrust.org.uk
Registered Charity No. 1067492

The Lady Hoare Trust supports children with arthritis or limb disabilities by providing them and their families with emotional support, advice and financial assistance.

Founded in 1962 to help children disabled by the drug thalidomide, the Trust now works with any child under the age of 18 who has arthritis, joint or limb disabilities. It provides assistance to the children and their families via a network of experienced fieldworkers, as well as financial support in the form of small grants.

Through these fieldworkers, advice and information are offered to meet the very diverse needs of families with children affected by arthritis or limb disabilities. The organisation also works to raise public awareness of the needs of children who live with such conditions.

The Trust works with the whole family. The fieldworkers support the families in addressing the additional practical and emotional demands made on them by having a child with a physical disability. Fieldworkers also provide families with information about practical issues such as benefits, education or community resources, enabling the family to make informed choices. Extra support is available at times of particular stress.

Fieldworkers, usually qualified social workers, use their skills and experience to provide as much information as possible, to assist children and their families make important decisions about their lives. They respond quickly to requests for support from families and they provide assistance based on the individual family's needs. In some cases, the fieldworker is the family's first point of contact following diagnosis, and can provide continuity of support over a number of years.

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