



chat

children have arthritis too

2 parents

Arthritis in teenagers



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Cover models Debbie Pinder and Paul Fraine are both teenagers with arthritis

Introduction

Discovering your son or daughter has arthritis can be devastating. Although a diagnosis can initially be a relief, the implications of living with arthritis are only just being realised.

Having information about the disease – and what to expect for your child – is essential. Questions about treatment and education, as well as fears for the future may be foremost on your mind and may continue long after diagnosis has been made by a doctor.

Having arthritis does not mean an end to an enjoyable life for your child or your family. Young people with arthritis need to lead as ordinary and as full a life as possible. Keeping school and social life going is extremely important, especially for your son or daughter's psychological development.

Resisting the urge to do everything for your teenager is important. Letting them learn independent coping skills of their own is vital for their long-term development.

A thirst for information is normal but it is not always clear where to get information from. There is a wealth of information and support out there. Knowing where to find it is the key.

This booklet aims to give parents of teenagers with arthritis information about the issues that affect them and their children. Where this booklet does not go into detail about issues, it provides signposting to further information or other relevant organisations.

Arthritis Care
Children's Chronic Arthritis Association
Lady Hoare Trust

Medical matters

'I think it's essential to have good relationships with health professionals. I wanted to know in detail about the condition – asking questions, wanting answers and explanations. It became a two-way support for my daughter.'
Parent

'Having a name for the problem has helped to relieve some of the anxieties and even some of my son's difficulties. Not knowing what was wrong was dreadful.'
Parent

'My son was diagnosed with JIA just over a year ago. I believe he's had it for most of his life. It took two years of persistent visits to GPs, hospital clinics and health centres to get a diagnosis. At times I was made to feel responsible and neurotic about my observations of his difficulties. The impact on my entire family has been immense.'
Parent

Juvenile idiopathic arthritis (JIA) is defined as inflammation of one or more joints for at least six weeks in a child under the age of 16 when other known causes of arthritis have been excluded. JIA is an umbrella term which describes all the various different forms of arthritis which can occur in children and teenagers. The number of children known to have JIA in the UK is one in every 1,000.

You may know JIA under its old name of juvenile chronic arthritis. To make things easy, the condition is referred to as juvenile arthritis throughout this booklet. See page 35 for a fuller explanation.

To manage your son or daughter's juvenile arthritis the family will have to learn to adjust to a new way of life. You will get used to seeing GPs, rheumatologists, physiotherapists and occupational therapists to name but a few, and maybe a few complementary therapists too.

At first the process can be daunting and it may seem that health professionals are speaking a different language to you.

Learning as much as you can about juvenile arthritis and how it will affect your child will help you enormously. It will assist your communication with health professionals and it will help your understanding of what they are saying about what is happening to your child.

It is important to get as much out of appointments as possible. Involving your child in discussions about their treatment will enable them to take more control over their juvenile arthritis.

Dealing with doctors

Having a good relationship with your child's doctors is very helpful. Being able to talk openly with a doctor and discuss treatments is important.

Below are some tips on how to help doctors and, at the same time, get the most out of your child's treatment.

- Tell the doctor why you have come. Try and be as precise as possible. Writing

down your child's symptoms and what you both want to say to the doctor can make it easier to ensure you cover everything you want. It can also help to write down what your doctor tells you.

- If you have found lots of information on the internet about your son or daughter's condition, make a summary of the points. Bear in mind that not all the information available on the internet is accurate. Doctors and health professionals often talk about 'peer-review', which means that information is published in paper or electronic form only after it has been accepted by the editor of a journal, with advice from experts in that particular field. While some information on the internet is 'peer-reviewed', not all of it is, and may, therefore, be misleading or even wrong.
- Question the doctor closely when they offer advice. Ask for information on how to manage on a day-to-day basis. Your child, or you, may feel strongly about particular forms of treatment. If so, say so. Usually treatment options can be discussed.

Learning to take care of your own health is an important part of growing up. To look after yourself properly, you need to be able to communicate with health professionals.

However, for many young people, this is easier said than done. Young people often know what they want to say, but do not have the confidence or skills to do it. Clinics can be intimidating places and transferring the responsibility of care from parent to son or daughter is not always easy. However, it is important that parents help their child move towards independence. Here are a few suggestions that may help:

1. Get an agenda

Find out what concerns your son or daughter has before the appointment. Writing down a list of questions ensures nothing gets forgotten. Health professionals are happy to talk about a

whole range of things to do with arthritis, not just medical issues.

2. Make a plan

Agree a plan with your son or daughter before going to the clinic. Make it clear that you need to work as a team and that you both need to talk to the doctor and ask questions. Decide what you are both happy to talk about and work out who will say what. If your child is not used to talking to health professionals, get them to just ask one or two questions. As they become more confident, encourage them to do more of the talking.

3. Support your son or daughter

Encourage health professionals to direct their conversations to your son or daughter rather than to you. If you find that they are speaking to you more than your child you can suggest to the doctor that they talk directly to them or make sure that they sit slightly in front of you to indicate they are the focus of the conversation. If the doctor asks you a question, redirect to it to your son or daughter.

Many young people find it difficult to disagree with health professionals. When decisions are made, make sure your child is given a say.

4. Discuss the appointment afterwards

After you have seen a health professional, it is useful for you and your son or daughter to discuss what happened at the appointment. Ask yourselves what went well and what was not so satisfactory.

Some young people find it useful to keep a record of their visits – who they spoke to, what was said, what they agreed to do, what the health professional agreed to do.

Bridging the gap

Transitional care for young people with juvenile arthritis is a growing service throughout the UK. It recognises the medical, psychosocial, educational and career needs of adolescents as they move from child-centred to adult-centred care. Whether your child moves straight from a paediatric to an adult clinic or via an adolescent clinic will largely depend on local availability.

The transition process ideally begins when your child is 10 or 11 years of age and continues until they are an independent adult in their 20s. Parents are an integral part of this process.

Early aspects of transition in healthcare include gradually involving your son or daughter in decisions about their health. It also includes letting them make their own appointments and take responsibility for their medication themselves.

Own questions

As children become teenagers, it is very important for everyone concerned to recognise that they may have their own questions regarding their arthritis and the way it is treated.

As your child becomes older, they may become concerned with more sensitive issues, such as sex, alcohol or drugs, which they may find difficult to discuss with parents but would like some privacy to discuss them with someone in their healthcare team. Such issues are especially important for people taking drugs like methotrexate (see page 7).

Young people need to be able to visit rheumatology clinics independently. Advance planning, with discussion between the young person, the parents and the health professional, is vital. Out-patient visits often allow for a young person to be seen on their own first, with the parent(s) joining the consultation towards the end, giving the opportunity for their concerns to be addressed.

Drugs

Taking medication is an important part of managing arthritis. Drug treatment is now aimed at controlling all aspects of the disease and, if possible, bringing about remission. Drugs help relieve the symptoms of arthritis, prevent further problems and even slow down the disease process. They cannot cure arthritis however.

The drugs each person is prescribed – and how often they take them – differs depending on their disease type and how they react to the drugs. Rheumatologists and GPs work with each individual to establish the most appropriate drug programme for their circumstances.

As with all medication, drugs used to treat arthritis can sometimes cause short-term and long-term side effects. However, in general, the risk of major side effects from drugs used to treat juvenile arthritis is relatively low. That said, while some side effects are predictable or common, others are unexpected, unpredictable and occur at any time during treatment.

There are many different kinds of arthritis and different drugs are used to treat different types. There are two main category of drugs: those which control the symptoms of the disease and those which can affect the disease itself.

The former, which are known as first line drugs, are used to treat most types of arthritis. Included in this group are analgesics (pain killers) and non-steroidal anti-inflammatory drugs (NSAIDs).

Second line drugs, which are also known as disease modifying anti-rheumatic drugs (DMARDs), aim to suppress the progression of inflammatory arthritis.

Pain killers (analgesics)

Painkillers relieve pain. They come in varying strengths – simple ones, like paracetamol, can be bought over the counter in chemists but stronger ones are only available on prescription.

Stronger analgesics, like codeine or

tramadol, can cause side effects including nausea, vomiting, drowsiness, constipation and, in very rare cases, breathing difficulties. They may become less effective if used long term.

NSAIDs

NSAIDs relieve pain and reduce inflammation and they are often taken in addition to painkillers. Their main action in arthritis is to reduce inflammation in the joint lining which then reduces swelling and relieves pain and stiffness.

Your doctor will advise which is the most appropriate anti-inflammatory for your child to take, and the correct dose. Some are taken several times a day, while others are slow release and only taken once a day.

Many people have no problems with these drugs, but some NSAIDs can cause side effects, such as stomach upset, heartburn, indigestion, rashes and wheeziness. Rarer side effects include mood disturbance and kidney scarring. If your child develops any worrying symptoms you should talk to their doctor as soon as possible.

Your child may not be advised to take NSAIDs if they have asthma. This should be discussed with their doctor.

If your child is taking NSAIDs you can help minimise side effects by making sure they take the medicine with or after meals.

Some of the most commonly prescribed NSAIDs are ibuprofen, naproxen, piroxicam, diclofenac and indomethacin.

A new breed of NSAIDs, called COX-2 inhibitors, has been developed to be safer for the stomach than traditional NSAIDs.

COX-2 inhibitors have not been tested extensively on children so far, but are thought to have the same benefits with fewer side effects.

DMARDs

DMARDs reduce the activity of arthritis, therefore reducing pain, swelling and stiffness. They are slow acting drugs, taking

weeks or even months for their full effect to be felt.

DMARDs include a group of drugs called immunosuppressives – so-called because they suppress the immune system which is the body's own defence system.

Several different immunosuppressive agents can be used in the treatment of inflammatory disease.

If your daughter or son is sexually active, they must make sure they use reliable contraception while on methotrexate. Methotrexate can cause damage to a growing baby and should be stopped at least six months before becoming pregnant. You should both discuss this with their doctor.

Steroids

Another line of drugs sometimes used to treat arthritis is corticosteroids, commonly called steroids. These resemble cortisone – a natural substance produced by the body's own glands.

Corticosteroids are used in arthritis because they are involved in regulating our inflammatory and immune responses.

Corticosteroids can be used in three main ways – as an injection into a joint (to control local inflammation), as an injection into a vein or as tablets taken daily to combat more generalised inflammation and to damp down the immune system. For more details on the different types of steroids available see page 10.

Drugs in detail

Below is a description of some of the more commonly prescribed DMARDs and steroids for young people with juvenile arthritis. The descriptions detail the range of side effects that might occur with each drug. A lot of these side effects are uncommon and your child may well not experience them. However, it is important to be aware of them.

Methotrexate

Methotrexate is a slow acting DMARD which can take three to 12 weeks to become effective. The most usual way of taking methotrexate is as a tablet one hour before food, once a week, on the same day each week. It is increasingly common to give methotrexate by injection if higher doses are required. Young people may be taught to inject themselves.

Methotrexate is more effective and has fewer side effects than most other second line drugs. Some people feel mildly unwell several hours after taking this drug, or even a day or two later. This feeling usually settles after a few hours. If your child feels sick or has indigestion after taking the tablet, they could try taking it after a meal.

Your child may experience side effects of methotrexate which may go away as their body gets used to the drug, like skin rashes, itchy skin, nausea or vomiting. Other, less common, side effects include a sore mouth or mouth ulcers and diarrhoea. You should consult with your child's doctor if your child experiences any side effects. The higher the dose used, the greater the possibility of side effects. The dose of methotrexate given depends on the person – your child's doctor will determine your child's dose. Taking a vitamin called folic acid can reduce the likelihood of mouth ulcers, stomach irritation and diarrhoea.

If your child notices any fever, unexplained bruising, cough or shortness of breath, they should report to their clinic or doctor as soon as possible. If they ever

'I was naturally very concerned about my child taking strong medication. I was worried about side effects but I had to accept that the medication would hopefully reduce the pain and inflammation.'
Parent

'My biggest fear at present is the drug therapy. I have had no room for discussion about side effects, alternatives for the future. It feels sometimes like I am in a catch 22 situation. Drugs and side effects or deterioration of my son's health.'
Parent

'Suddenly having to take lots of medication doesn't bother me but I try not to take it in front of people who will ask me too many questions or tease me.'

Teenager

'Most of the time I count myself lucky that my son's condition is so well managed by drugs – but I can't help but worry about their long-term effects.'

Parent

have any severe symptoms contact their doctor at once. Contact with chicken pox or shingles should also be reported. Your child should avoid immunisations which involve live vaccines like polio and rubella. Other vaccines, for meningitis and flu for example, are safe and recommended.

Regular blood tests will be done every four to six weeks because methotrexate can, very occasionally, alter the bone marrow or the liver. The tests will show up any danger and allow the drug to be stopped before any damage is done.

Your son or daughter may be advised to avoid alcohol while on methotrexate. As both alcohol and methotrexate can damage the liver, taking them together increases the risk of liver damage. However, many young people drink alcohol without any apparent side effects in their liver, so a sensible compromise would be no more than 5-10 units a week.

Young people who are sexually active must use contraception while taking methotrexate and for six months after treatment is stopped. If in the future they want to become pregnant they must stop taking methotrexate six months beforehand as it can damage a growing baby. If they do have unprotected sex then they should seek advice urgently from their nurse or doctor.

Sulphasalazine

Sulphasalazine is a slow acting drug. Improvements usually begin six to eight weeks after your child has reached the effective dose.

Not everyone will experience side effects, but the most common ones are nausea and headaches. There is a special coating on the tablets which minimises the nausea, but sometimes the dose may be reduced. Loose stools may also be a problem for some people.

Less common are feelings of being unwell, a loss of appetite, skin rashes and abdominal pain. If your son or daughter

experiences any of these side effects they should report them to their rheumatologist or GP. In the case of a skin rash, they should stop the drug immediately. If they develop a sore throat and mouth this should be reported to their GP as soon as possible.

Most problems caused by this drug are reversible and clear up once the drug has been stopped or reduced in dosage.

Your child's doctor will arrange for them to have monthly blood tests for the first three months that they take the drug. Following that, the blood tests will be done about every three months. Sulphasalazine may turn urine orange or dark yellow. This is nothing to worry about. It can also cause yellowing of contact lenses if they are not daily disposable ones.

Sulphasalazine can cause a fall in sperm count but this is reversible on stopping taking the drug.

Anti-malarials

Anti-malarials, hydroxychloroquine and chloroquine, are slow-acting drugs. They are rarely used for children. However, they are more commonly used with Lupus (SLE). They are sometimes taken in combination with other DMARDs. Anti-malarials take three to six months to produce their maximum benefit, although they may start to work within four to six weeks.

They are taken once or twice a day. It is best to take them with food, as they have a bitter taste, and they may make you feel sick otherwise.

Anti-malarials are among the mildest and least toxic of the DMARDs. Risk to the eyesight is very negligible but screening may be suggested for some children. Indigestion, diarrhoea, headaches, skin rashes or occasional blurred vision are side effects that may occur.

Cyclosporin

Cyclosporin is used to limit the disease in juvenile arthritis, and is usually taken in combination with methotrexate. It is

usually taken in capsule form, twice a day, although it is also available as a liquid.

People normally start on a low dose, and your doctor will increase it as necessary. The actual dose will depend on your body weight. It may take up to four months to produce a beneficial effect.

A rise in blood pressure is a possible side effect of cyclosporin, as it reduces kidney function. The risks increase the longer the treatment is used. Your doctor will arrange regular blood tests and checks on your child's blood pressure to monitor these.

Other side effects can include nausea, diarrhoea, gum overgrowth, tiredness and excess hair growth. Cyclosporin can also produce a mild tremor. Some people experience a burning sensation in their hands and feet early in the treatment.

Azathioprine

Azathioprine is rarely used for children. In cases where it is, it is a slow acting drug, whose effects may not be noticeable for eight weeks or longer. It is taken as a tablet, once or twice daily, with food.

Its most common side effects are nausea and loss of appetite. If these occur, discuss the situation with your child's doctor.

Weakness and fatigue, jaundice and any unusual bruising or bleeding are less common side effects. You should contact your doctor as soon as possible if your child experiences any of these.

If your child develops a rash or a fever or if they ever have any severe symptoms, contact their doctor at once. Any side effects will gradually disappear once the drug is no longer being taken.

Regular blood tests will be done as azathioprine may reduce the number of white cells and platelets which might make your child more prone to infections and to bruise and bleed more easily.

Cyclophosphamide

Cyclophosphamide is rarely used for children. However, it may be given as an

intravenous infusion for the treatment of very severe arthritis. Its full benefits might not be apparent for six weeks or more.

Cyclophosphamide is only prescribed under close supervision as it causes toxic effects in some people. Your son or daughter's doctor will arrange routine blood tests to check for these. This drug will probably produce some side effects but the severity varies considerably. Nausea is a common reaction.

A rare, but important, side effect of cyclophosphamide is inflammation and bleeding of the bladder wall (haemorrhagic cystitis). If this occurs your child may have pain passing water and blood in their urine. This should be reported to their doctor at once, as should hair loss or irregular menstruation.

If your child gets a sore throat or fever on this drug they will need a blood test. Contact their doctor at once.

Cyclophosphamide can suppress the activity of bone marrow and reduce the number of red blood cells, causing anaemia. Any side effects gradually subside once the drug is no longer being taken.

In men, cyclophosphamide can lead to permanent sterility so this drug is used with caution in young, sexually active males. Men can have their sperm stored if they need the drug. It can also reduce fertility in women, can be passed through breast milk and so affect a baby, and can result in premature menopause and the attendant risk of osteoporosis.

Steroid injections in the joint

Steroids may be given by injection directly into a joint to reduce inflammation, swelling and pain. Injections are most likely to be used where only one or a few joints are involved.

The doctor will examine the joint carefully before cleaning the injection site. A small volume of steroid, sometimes mixed with local anaesthetic, is injected into the joint (intra-articular) or near the

joint (peri-articular). It is a good idea to rest the joint for 24 hours afterwards. In children, or where multiple injections are necessary, young people may be sedated while being injected.

Steroid injections can give dramatic results. However, even if the joint feels less painful and moves more freely, it should still be treated with care. The muscles controlling the joint should be as strong as possible. Giving steroids by injection concentrates the steroid in the relevant place – minimising the amount dispersed in the body. Because of this, the side effects which may occur with steroids taken by mouth are unlikely.

Occasionally there is a thinning of fatty tissue beneath the skin, or a loss of skin colour at the site of the injection.

Steroid tablets

Prednisolone is the most commonly prescribed steroid. When taken orally, it acts as a powerful anti-inflammatory and suppresses the immune system by reducing the activity of certain types of white blood cells. Benefits are usually noticed within a few days.

It is important that an even level of steroids is maintained in your child's system, so tablets should be taken regularly as prescribed. They should not stop taking steroid tablets unless advised to by their doctor – it is dangerous to stop them suddenly. Steroids taken by mouth stop the normal production of cortisone from the adrenal glands. Gradually lowering the dose will allow the glands to recover.

For this reason your son or daughter should always carry a steroid card which records how much prednisolone they are on and how long they have been taking it (get one from a doctor or pharmacist) or wear a Medic Alert bracelet. This way, if anything should happen to your child, they will still get their steroids.

If steroids are lost from the body, for example by vomiting or diarrhoea, your

child should consult their doctor.

The longer someone takes prednisolone, and the higher the dose, the more likely they are to have side effects. If your child is on very low doses they may never have any problems. Steroids can modify the symptoms of other diseases, so if your child notices any unusual symptoms they should not ignore them.

Some people experience mood changes while taking steroids. Some have a sense of euphoria, others become depressed or more emotionally sensitive and find they get angry or weepy easily.

The most common side effects include increased weight, facial changes and reduced absorption of calcium (which can lead to osteoporosis). As a result you should make sure your child takes measures to avoid osteoporosis, including increasing their calcium intake and doing regular weight-bearing exercises like walking.

People on steroids may be more prone to developing cataracts. Hair quality may be affected so it is advisable to tell hairdressers that your child is taking steroids and to avoid having hair permed.

People on steroids are also more prone to infection and illnesses. High doses of steroids can affect blood pressure, diabetes, moods and sleep patterns. Exposure to chicken pox also poses a risk if your child has not had it and is on higher doses of steroids. The doctor will need to know of any changes you or your child notice.

There are some vaccines you must not have if you are taking corticosteroids including rubella, BCG for tuberculosis and oral polio vaccines. Other vaccines are safe and recommended, and will protect your child from serious disease like meningitis and influenza vaccines.

The relative risks of treatment versus disease should be weighed up by you, your child and their doctor before using steroids.

Although it is best not to take prednisolone during pregnancy, it is safer than some other drugs.

Steroids given intravenously

Methylprednisolone is a steroid which is commonly given intravenously in hospital. It is usually used for severe arthritis and is given for a short term, probably only a few days, on entering hospital.

New drugs

A number of new drugs have been licensed which may be useful for young people.

Etanercept

Etanercept is a new drug which acts by blocking the action of tumour necrosis factor – a chemical which is believed to play an important role in driving the inflammation and tissue damage that occurs in juvenile arthritis.

Treatment involves twice weekly injections which can be self-administered. Beneficial effects can be noticed quickly, often within one to two weeks.

Side effects include redness and/or itching, and pain or swelling where the drug is injected. Because it is a new drug, the long-term side effects are not known.

Infliximab

Infliximab is a new drug similar to etanercept. It is currently licensed for adults with rheumatoid arthritis. It is administered by a two hour infusion into a vein by a health professional once every eight weeks.

Beneficial effects can be noticed quickly, often within one to two weeks. Infliximab is often prescribed alongside methotrexate.

Side effects can include fever, rash, headache and nausea. The long-term side effects are not known.

Leflunomide

Leflunomide is a new DMARD similar to methotrexate. It acts to slow the progression of structural joint damage and reduce the symptoms of rheumatoid arthritis. However, this drug is not licensed for use in children.

It is taken daily in tablet form. The effects are noticeable more quickly than with some other DMARDs, sometimes as early as four weeks. Regular blood tests are carried out to monitor the effects of the drug.

Side effects do include diarrhoea, rash, hair loss and nausea. Because it is a new drug, long-term side effects are not known.

Surgery

Although the majority of people with juvenile arthritis do not need surgery, a small number will. These tend to be people with the more severe forms of the disease. For these people, surgery can help relieve pain and maybe limit the progression of their arthritis.

Young people that do require surgery are usually seen a number of times in



'I worry far more than my daughter when she goes for an operation. She treats it all as a holiday because she knows she will be looked after. I worry myself sick. We just cope in different ways.'
Parent

'I've had a number of operations and, although they are scary at the time, they have really made a difference to my life.'
Teenager

'Since my daughter's hip replacement there has been a huge reduction in pain and a great increase in mobility – which is the most important thing.'
Parent

combined clinics with an orthopaedic surgeon and their rheumatologist before a decision is made about them having an operation. Input from a physiotherapist and occupational therapist (OT) is also useful.

Surgery should only be considered after conservative treatments such as splinting, drugs and physiotherapy have failed. The general indications for having an operation are pain, deformity and loss of movement.

The goals of surgery are to relieve pain, maintain the position and range of movements of joints, to prevent stiffness and deformity and to minimise muscle and bone wasting. If all other treatments have proved unsuccessful surgery can bring positive outcomes.

A number of surgical procedures can be carried out to improve your child's mobility and reduce pain. If your child does need surgery when they are a child or a teenager, it does not mean that they may never need surgery as an adult. Surgery carried out in childhood can sometimes influence the course of the disease, while surgery in adulthood tends to be for treatment of fixed deformity or pain.

Some of the types of surgery available for children are listed below.

- Examination under anaesthetic – your child may not be able to move a joint because of pain rather than because of a fixed problem with a joint itself. It can be useful to examine the joint under an anaesthetic to assess this more fully.
- Injections – steroids or other drugs can be injected into joints, sometimes with great benefit. Many injections are best performed under an anaesthetic.
- Synovectomy – the synovium is the lining of a joint and can become inflamed as part of the disease process in juvenile arthritis. On some occasions this lining can be removed to allow the joint to become less painful and move more freely. In recent times, steroid injections have replaced the need for many synovectomies. Open operations

are rare as synovectomies can be performed by keyhole surgery using an arthroscope (a small camera). This is known as an arthroscopic synovectomy.

- Soft tissue release – juvenile arthritis involves not only the joints but also the muscles and tendons around the joints. Releasing contracted tissues around a joint can often be very effective in relieving pain and improving the range of motion in a joint. Soft tissue release is most frequently performed around the hip joints.
- Correction of bone deformities – where a bone or joint has become deformed, the bone can be realigned to make the limb straighter.
- Joint replacement – when a joint becomes really painful and other forms of treatment have proven unsuccessful, the joint can be replaced. Replacement of the hip, knee, wrist and hand joints are the most common, but recently the shoulder, elbow and ankle have been able to be replaced. Joint replacements only last between 10 and 25 years on average. As a result, they may need to be revised on at least one occasion and these revision operations are more difficult and less successful than the primary procedure.
- Spinal operations – the neck can become unstable or fused in juvenile arthritis and this may require stabilisation surgery.

All surgical procedures are associated with possible complications. These are minimised by surgery at a centre where there is a juvenile arthritis team with appropriate experience and expertise. It is the surgeon's responsibility to explain these risks to you and your child before a surgical procedure is performed.

Any operation requires an appropriate anaesthetic and, in juvenile arthritis, an anaesthetist experienced in the problems associated with the disease is a vital part of the team.

The operation can be performed under a general anaesthetic, sedation or by local anaesthesia (either by injecting near to the area being operated on or by injecting anaesthetic into the lower spine for lower limb surgery).

Fortunately the advances in anaesthesia have made the anaesthetic used in surgery for juvenile arthritis much more safe and comfortable. Pain control after surgery has also become more comfortable, predictable and safe.

The risks of surgery, and the rate of complications, are lessened by treatment in specialist centres where there is a multi-disciplinary approach involving communication between the range of professionals involved in your child's healthcare.

The time it takes to recover from an operation depends on what procedure was carried out and, often, how severe the juvenile arthritis is. Exercise and rest are important elements of recovery. Your child will probably be referred for physiotherapy after surgery to help speed up recovery and improve movement. A physiotherapist can help your child learn the correct way to use their joint after the operation.

Long-term prognosis

Prognosis is the term doctors use for the outcome of a disease. When you are first told that your son or daughter has juvenile arthritis you may have many questions. This section covers those often asked by parents of young people with arthritis.

What does the doctor hope the treatment programme will achieve?

Ideally, doctors aim for your child to reach adulthood with their arthritis in remission and with no damage to joints. This means that their arthritis will have gone away and all their joints will move fully, freely and without pain, and with no deformity. The young person will have reached his or her expected height and weight and be emotionally and socially mature. They will have reached an appropriate level of education and be able to make stable, lasting relationships and be able to have and to bring up children.

Unfortunately this 'gold standard' is not achievable for every young person with juvenile arthritis. Juvenile arthritis is extremely variable, in its development and in its severity. A majority of children will grow into adulthood with their illness in remission although some will be left with impairment as a result of their arthritis.

Can the outcome of my child's arthritis be predicted?

Despite years of research, doctors still do not have a test that will accurately predict whether arthritis will go into remission or be a persistent problem in adulthood. Blood tests tell us how much inflammation there is in the joints but they are not good predictors of outcome.

The pattern of joint involvement does help as a predictor. If the pattern involves four or less joints and remains so, the outlook is good. A pattern of many joints being involved has a less good outlook, particularly if the joint involvement is symmetrical (occurring in the same,

'At first I was just glad to get a diagnosis. After a few months though I realised this was something we all had to get used to and learn to live with.'

Parent

'I sometimes feel really guilty about the great strain my illness has on my parents, especially my mum. When I am really bad, mum has to do everything for me. This sometimes makes me feel really useless.'
Teenager

'There is obviously the fear of the unknown. But my daughter didn't show how much pain she was in, possibly for fear of worrying me further. She became very quiet and somewhat introverted in the first few years, especially as the outcome of the illness coincided with adolescence.'
Parent

corresponding joints) in the first few months. About half the young people with arthritis in a number of joints will have some disease activity and disability in adulthood. These young people will probably still be on medication as an adult, and may have had one or more surgical procedures.

Can my child die from juvenile arthritis?

Fortunately the risk of dying from juvenile arthritis is small. Less than one per cent of children die because of their disease or its treatment. Compared to previous decades, chronic joint inflammation is suppressed more satisfactorily with the drugs, such as methotrexate, used today.

What of the future?

The future is hopeful. Newer DMARDs and improved ways of delivering treatment, as well as better physical programmes and more appropriate psychological and educational support, are all combining to improve the long-term outcome.

Further information

The Balanced Approach: a guide to medicines and complementary therapies.
Available from Arthritis Care, 18 Stephenson Way, London NW1 2HD.
Tel: 020 7380 6562.

Children Have Arthritis Too: A Guide to Juvenile Idiopathic Arthritis. Available from Arthritis Care as before.

The Arthritis Research Campaign (ARC) produces factsheets about individual drugs. Available from ARC, Copeman House, St Mary's Gate, Chesterfield, Derbyshire S41 7TD. Tel: 01246 558033. Also available from ARC are two leaflets: *When your Child has Arthritis: A Guide for Parents* and *Arthritis in Teenagers*.

With thanks for their contribution to this section:

Dr Helen Foster, consultant rheumatologist, Newcastle Hospital.

Dr Jane Griffin, consultant rheumatologist, Chase Farm Hospital.

Dr Ann Hall, consultant rheumatologist Wexham Park Hospital.

Dr Nathan Hassan, honorary paediatric rheumatologist, Great Ormond Street Hospital.

Dr Richard Hull, consultant rheumatologist, Queen Alexandra Hospital.

Dr Janet McDonnagh, consultant paediatric rheumatologist Middlesex and Great Ormond Street Hospitals.

Dr Kevin Murray, consultant paediatric rheumatologist, Great Ormond Street Hospital.

Professor Tauny Southwood, paediatric rheumatologist, Birmingham Children's Hospital.

Mr Andrew Unwin, consultant orthopaedic surgeon, Wexham Park Hospital.

Dr Russell Viner, director and consultant of adolescent medicine, Middlesex and Great Ormond Street Hospitals.

Pam Whitworth, nurse specialist, Birmingham Children's Hospital.

Pain

Pain is one of the major symptoms of arthritis. It is influenced by a number of factors and people deal with it in different ways. Drug treatment plays a major role in managing the symptoms of arthritis but there is more that can be done.

Where arthritis pain comes from

One of the main problems reported by adolescents with arthritis is pain. Learning to cope with chronic pain may be the biggest challenge that your son or daughter faces. Pain is subjective, it affects people in different ways. The pain of arthritis can alter from day-to-day and, like the disease, it can be unpredictable.

Pain from arthritis is due to a number of different causes:

- inflammation in the joint may cause swelling, redness, local heat and loss of movement, which can often cause pain
- damaged joints can cause pain
- weakness and reduced stamina of muscles around joints can lead to muscle spasm which results in pain. Muscles strained by tensing and by trying to protect joints from painful movements can also cause pain
- periods of immobility because of pain can actually make pain worse and lead to stiffness and reduced range of movement in joints
- changes to the normal walking pattern, often caused in an attempt to reduce pain, can have enormous effects on the body and increase pain levels. Alterations to the natural alignment of the body put abnormal stresses on joints, and cause muscle imbalance and weakness, joint deformities and reduced stamina. If this continues over a period of time, your child may experience reduced function in joints which may lead to reduced independence. It is important that your son or daughter maintains good posture, muscle strength, stamina and general fitness.

Influences

Pain is very complex and there are many factors which affect a young person's experience of it. How they cope individually with pain, their expectation of what pain will bring, fear, emotional factors, anger, frustration, how a person has been brought up to react to pain and even parental distress can all affect how a young person copes with pain.

Pain can't be seen so it is difficult for others to understand. If your child is experiencing a lot of pain it may manifest itself in a number of other ways. They may be moody, uncommunicative, snappy, irritable, tearful and tired. Learning to recognise the signs will help you be more understanding of your child's behaviour.

Easing the pain

The medical treatment of juvenile arthritis should help with the symptoms of pain. However, drug treatment does not always eliminate all aspects of pain.

There are a number of steps your son or daughter can take to manage their pain. It is a matter of finding what works for them.

- Exercise helps protect joints and reduce pain. It is important that muscles are strong and work together in the correct way to ensure joints are protected when they are used, especially when weight bearing. Hydrotherapy – exercising in a warm pool under the supervision of a physiotherapist – can help loosen joints and build their strength and stamina. Stretches to joints are important to reduce stiffness and to improve circulation which is important for effective movement. Stretches also make muscle work more effectively. See page 17 for more information on the benefits of exercise.
- Cold or hot packs can help reduce inflammation in a joint or relieve a muscle spasm.
- Transcutaneous nerve stimulation (TeNS) is a non-invasive method of pain

'It's very hard to encourage my daughter to do her exercises when I can see she's in pain and upset. It's hard to be positive then.'
Parent

'Being in pain is one of the hardest things. It's always there but I've learnt how to cope with it much better now.'
Teenager

'It was heartbreaking when my daughter was diagnosed at 13. A whole gamut of emotions would almost overwhelm me – anger, frustration, helplessness, sadness. I would have given anything to take the burden of pain away from her.'
Parent

control which uses electrical impulses to block the pain pathways to the brain, therefore reducing the level of pain experienced. It is more effective if used for one specific joint at a time.

- Splinting can help keep a joint immobilised or supported in a better position if it is causing a lot of pain. See page 20 for information about splints.
- Relaxation or distraction can divert the focus away from pain.

As well as these methods, many complementary therapies exist which help some people manage their pain. These include acupuncture, reflexology and homeopathy. See page 22 for information about complementary therapies.

If none of these techniques work for your son or daughter, they may consider attending a pain management clinic. A number of these exist around the UK, a few are aimed at adolescents. At these clinics, pain management techniques are taught by a range of health professionals who look at how pain is perceived by the individual and help them change the way they deal with it. Ask your doctor if there is a pain management clinic at your local hospital.

Further information

Arthritis Care produces a number of booklets: *Talk about Pain: how to deal with the pain of arthritis*, *The Balanced Approach: a guide to medicines and complementary therapies*, *Fit for Life: a guide to safe exercise for people with arthritis*. Available from Arthritis Care, 18 Stephenson Way, London NW1 2HD. Tel: 020 7380 6562.

Pain Society, 9 Bedford Square, London WC1B 3RA. Tel: 020 7636 2750. Produces free information booklet for people who live with pain.

PainWise UK, 33 Kingsdown Park, Whitstable, Kent CT5 2DT. Tel: 01227 277993 (after 2pm). Offers support to people with chronic pain via groups, a helpline and by post. Produces factsheets and a pain meditation tape.

***With thanks for her contribution to this section:*
*Sue Maillard, specialist physiotherapist in paediatric rheumatology, Great Ormond Street Hospital.***

Taking control

Although drug therapy is a key way of controlling the symptoms of arthritis, there is a lot your child can do to help themselves.

Exercise is important in managing arthritis. The facts about exercise are simple. Get enough and you'll feel better, be able to do more and may live longer.

Physiotherapy and regular exercise can be the furthest things from your child's mind if they live with pain on a daily basis. But exercise is all important for them – it helps limit pain, maintains mobility, boosts energy and keeps joints strong. It also helps prevent disability.

Most people exercise too little. Modern living does not encourage it as part of everyday activity. Finding the right sort of exercise is important for the self-management of arthritis.

Getting good advice, being careful about the way your son or daughter exercises and choosing something that suits them is essential in helping your child find a form of exercise they can stick to.

Exercise

For many parents taking their child for physiotherapy becomes a way of life. For others, it is a constant battle with their child to get them to do anything. And that's not forgetting parents who have totally given up the fight and resigned themselves to the fact that it's not going to happen.

If you fall into the first group, well done. If you fall into the latter two groups, don't worry. You are not alone – in fact you are probably in the majority.

Physiotherapists know – and understand – that most young people who have had arthritis for some years find exercises a real pain and don't do them.

Having said that, exercise is extremely important for people with arthritis and should be a life-long commitment.

The benefits of regular exercise include:

- better range of movement and joint mobility

- better pain management
- increased muscle strength
- stronger bones – which can help protect against osteoporosis
- weight control
- improved sleep patterns
- increased energy levels
- improved self-esteem.

If you find it difficult to get your son or daughter to exercise because they say it's boring, there are a number of things you can do. Try to convince them that exercise doesn't have to be boring.

There is a wide range of activities on offer these days that are fun and help people keep fit. It may be worth getting your child to contact your local leisure centre to see what's on offer. It could be anything from gentle activities such as swimming and yoga to more vigorous activities like aqua aerobics.

It is important to check with your child's physiotherapist or doctor that it is safe for them to participate in something new but, if their disease is well controlled, they should find something to suit them. Even if their disease is still active it should still be okay to participate in some activities.

Changing attitudes

Changing your child's attitude towards exercise may help. In the past, they may have associated exercise with their arthritis, but there are many forms of exercise which can be enjoyable and not in the least bit boring. Doing something new, particularly with a friend, may shed a whole new light on the exercise experience.

There are times, however, when a physiotherapist may feel it is necessary for them to do specific exercises, when the arthritis is flaring up or they are developing problems with specific joints for example.

When being given new exercises, encourage your son or daughter to ask appropriate questions such as: Why do I need to do these exercises? How long will I need to do them for? It may help to

'It has been very difficult to get my daughter to exercise other than in the hydrotherapy pool. To her, exercising is synonymous with pain. I try subtle subterfuge such as kneading bread, playing the piano and encouraging challenges with friends on the exercise bike.'

Parent

'I hate exercising. It's boring, dull and painful. Hydrotherapy is okay though as it's fun and the warm water is lovely.'

Teenager

motivate them if they know why they are doing them and that there is a goal to be reached. Encourage them to get involved in setting their own goals.

If your child has lots of joints affected by juvenile arthritis, they could try working on one or two joints for a few weeks and then swapping to work on a different joint for a few weeks. That way they won't have lots of exercises to do all at once, will probably work a little harder on the one or two joints and achieve more.

Rather than having to exercise every day, you could encourage your child to do it three or four times a week, or agree they can have weekends off. Find a compromise. There will be times when doing exercises may be difficult – such as during exams or holidays. At times like these allow your child some time off, but do make sure they start again on an agreed day.

Some hospitals may run therapy or hydrotherapy groups specifically for young people who need it. The sessions have the added benefit of allowing them to meet others and exercise in a more relaxed and fun environment.

Making their own decisions

If your teenager is adamant they are not going to do any exercise there is probably little you or the physiotherapist can do. As long as they understand the consequences of not doing exercise, in the end the decision should be theirs. It is virtually impossible to expect a young person to do physiotherapy every day over a period of years. They may find adolescence difficult enough without the added pressure of having to exercise.

Remember that your son or daughter's social and psychological development is just as important as their physical development. Sometimes people are so intent on getting those last few degrees of movement that they forget this.

Added to this, there is the effect that arguments has on you and the rest of the

family. It is vital to ensure that exercise, like arthritis, does not rule your lives and that your child is able to develop social interests. Stand back a little – you can still give them lots of encouragement and support, but without nagging them.

As they get older, you will find that their physiotherapist will take less responsibility for what they do or don't do. If you have been attending a paediatric unit, your child's care will be transferred to an adult unit where a physiotherapist will see them infrequently and probably only if they have a particular problem.

It is important to encourage your child to take responsibility for their disease and to begin looking after themselves.

Sports and activities

Everyone should maintain a level of general fitness to ensure that their heart, lungs, joints and muscles work to the best advantage. When someone develops arthritis it is essential they try to maintain their existing level of fitness.

Developing arthritis can mean having to change the way people exercise and sometimes it means that a person finds they are no longer able to take part in their usual sports or activities. Factors which may influence this are reduced range of movement, weakness of muscles, swelling, pain and lack of interest in activity.

Playing safe

Taking care and looking after joints is of prime concern when your son or daughter plays sport.

When playing games such as netball and tennis – which involve mainly the upper body – care should be taken when catching or hitting the ball because the impact during these movements may cause strain on the soft tissues around the joint.

When taking part in sports such as cross country running, football and hurdling – which involve the lower limbs – heavy impact, prolonged impact and twisting

actions may cause pain, swelling and damage to joints.

Contact sports should be avoided.

Adapting sport

If your child finds they cannot continue with their usual sport, they may choose to take up a new one. It is a good idea to encourage this as it will help them maintain their fitness levels. They may also be more inclined to take part in this form of exercise than in those prescribed by a physiotherapist.

Ideas of sports which put less strain on joints include yoga, dance, aqua aerobics, swimming or cycling.

Other, more adventurous activities your child might like to try include abseiling, climbing, skiing and canoeing. Many of these sports are taught at specialist centres under qualified supervision.

When participating in a sport, your son or daughter should always try to look after their joints and limit any accidents or falls.

Before beginning a new activity it is advisable to check with a doctor or physiotherapist. They will be able to tell your son or daughter of any moves that should be avoided.

Further information

Fit for Life: A guide to safe exercise for people with arthritis. A useful booklet giving the facts about arthritis and exercise as well as looking at the different types of exercise people with arthritis can do. Available from Arthritis Care, 18 Stephenson Way, London NW1 2HD. Tel: 020 7380 6562.

Disability Sports England, Unit 4G, 784-788 High Road, Tottenham, London N17 0DA. Tel: 020 8801 4466. www.britsport.com

Disability Sports Northern Ireland, Unit 10, Ormeau Business Park, 8 Cromac Avenue, Belfast BT7 2JA. Tel. 028 9050 8255. www.dsni.co.uk

Scottish Disability Sport, Caledonia House, South Gyle, Edinburgh EH12 9DQ. Tel: 0131 317 1130. www.scottishdisabilitysport.com

Federation of Sports Associations for the Disabled in Wales, Welsh Institute of Sport, Sophia Gardens, Cardiff, Glamorgan CF11 9SW. Tel: 029 2030 0525.



'I have to wear splints when my hands are bad. I don't really like to but they really help.'

Teenager

'I sleep in hand splints every night. We call them my badminton rackets.'

Teenager

Wearing splints

Most people with juvenile arthritis have to wear splints on some of their joints at some time or another. By the time they reach their teenage years, they will probably be sick of the sight of splints (as will you) and may not often wear them anymore.

At this stage in their life, they have a lot going on with schoolwork and their friends. It is important to work out what the priorities are as regards therapy and splinting and, again, a compromise has to be reached.

Splints are usually worn to support and rest a painful or swollen joint, keeping it in a correct position thus preventing or reducing contractures and deformities that may occur.

Usually, it is possible to plan which splints are very important. Holidays or breaks from splints can be planned. Alternating splints is another option so that some splints are worn some of the time instead of none being worn at all.

Here is a brief explanation of the types of splints that young people might need:

Resting splints – usually worn at night to support the joint in a corrective position while sleeping and relieve pain and early morning stiffness.

Functional splints – worn during the day and designed to support the joint (usually the wrist).

Collar – supports the neck when it is painful and has limited movement. Particularly helpful for long study periods and watching TV. Wearing a collar is not recommended for long-term use as it can decrease movement and ultimately cause more problems.

Ideally all splints should be individually made and fitted by an occupational therapist (OT) or a physiotherapist. They should be checked regularly so that they continue to fit properly and do what they are intended to do.



With thanks for their contribution to this section:

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Kerry Hebdon, senior occupational therapist, Middlesex adolescent unit, University College London Hospitals.

Bobby Jarvis, physiotherapist rehabilitation manager, Wexham Park Hospital.

Bernadette Johnson, senior physiotherapist, childhood arthritis unit, Birmingham Children's Hospital.

Elaine Murphy, superintendent physiotherapist, Wexham Park Hospital.

Yvonne Rogers, senior physiotherapist, Wexham Park Hospital.

Diet

The idea that diet may alter the symptoms of arthritis is enshrined deep in rheumatological folklore. People with arthritis always seem to be told to avoid this, that and the other. It can be a confusing issue, not helped by the array of books and articles about cooking and eating for arthritis.

Despite all the books and old wives tales, there is little scientifically-based evidence to support the case for diet or supplements improving arthritis.

That said, it is important to maintain a healthy, well-balanced diet. This means one higher in fruit, vegetables, pasta, fish and white meat, and lower in fatty foods such as red meat, cream and cheese.

Keeping to a healthy weight will also help the symptoms of arthritis. Extra weight means extra strain on painful joints. Obesity can increase the risk of developing osteoarthritis in the knee. Being overweight may also speed up wear and tear in joints.

Supplements

Diet doesn't just include food however, but also the many substances that can be bought to supplement the diet. People with arthritis take a huge range of supplements in the hope of finding that elusive cure.

The majority of people with arthritis rely on regular prescribed medication to relieve their symptoms, but many are willing to try anything to reduce pain. Products marketed at people with arthritis include herbal remedies, minerals, vitamins and dietary supplements.

Most supplements are regulated under food law, which means that, unless they have a licence, they have not been through the stringent tests drugs go through for safety and for efficacy.

Because supplements are often natural, many people assume they are safe, but this is not always the case. It is always advisable to check with a doctor before your son or

daughter takes supplements as many can react with prescribed medication.

Further information

***Food for Thought* is a useful booklet looking at the case for diet and arthritis as well as looking at some of the more common supplements taken by people with arthritis. Available from Arthritis Care, 18 Stephenson Way, London NW1 2HD. Tel: 020 7380 6562.**

With thanks for her contribution to this section:

Kate Llewelyn, publications manager, Arthritis Care.

'I must have bought every book on diet and arthritis there is. I can't get my daughter to try any type of exclusion diet though. She says she has to put up with enough as it is, so why should she deprive herself of something that gives her pleasure. I find it hard to argue with that.'

Parent

Complementary therapy

'My daughter was very wary of complementary therapies after a nasty experience with a homeopath when she was 15. She very much believes that the doctor's word is law but as she's grown older she's contemplated other therapies, including the Alexander technique, which have improved her posture and her general well-being.'

Parent

Many people with arthritis use complementary therapies in addition to conventional treatments and drugs prescribed by a doctor.

A wide range of complementary therapies are available throughout the UK. There are therapies which include touch and movement like acupuncture, massage, aromatherapy, Alexander technique, tai chi and yoga. There are medicine-based therapies like homeopathy and nutritional therapy, plus there are other therapies including meditation and counselling.

Not a cure

Like orthodox medicine, complementary therapies do not offer a cure for arthritis but they can help alleviate symptoms like pain and stiffness, and deal with some of the unwanted side effects of taking drugs. Complementary therapy practitioners tend to take a holistic approach to treatment, looking at the person as a whole and addressing issues like stress and mental well-being, rather than just focusing on physical symptoms.

Some alternative therapies and practitioners are regulated by statutory bodies. Others make wild claims about their healing powers with little or no supporting evidence or training. Make sure you check out a practitioner thoroughly before your child starts treatment. The Institute of Complementary Medicine can point you towards qualified practitioners (address at the end of this section).

Therapies can usually be used alongside conventional medication, although doctors' attitudes towards them vary. You should consult your son or daughter's GP or rheumatologist before they start a complementary therapy to make sure it will not interfere with any of their medication or treatment.

Keep up medication

Be cautious of practitioners who advise stopping prescribed medication. Tell the

therapist about the drugs your child is taking. Advise your child not to stop taking them without consulting their GP or rheumatologist.

Some complementary treatments are available on the NHS. You can ask your GP if he or she can refer your son or daughter. Some private health insurance companies will also pay for treatment. However, most people who receive complementary therapies in the UK pay for their own treatment. Check how much the treatment will cost and how long a course your son or daughter will need before starting.

Further information

The Balanced Approach. A useful booklet giving a full guide to both conventional medicine and complementary therapies. Available from Arthritis Care, 18 Stephenson Way, London NW1 2HD. Tel: 020 7380 6562.

The Institute for Complementary Medicine can send you a list of qualified practitioners. Send a large SAE and state which therapy you are interested in to: PO Box 194, Tavern Quay, London SE16 7QZ. Tel: 020 7237 5165. www.icmedicine.co.uk

***With thanks for her contribution to this section:
Josie Allen, publications editor, Arthritis Care.***

Education

Having arthritis doesn't mean having to give up education. Many young people with arthritis go through the education system with few problems, achieve exam success and move on to higher education and/or employment.

However, sometimes problems can arise to which solutions must be found to enable a young person with arthritis to stay in education. Schools, colleges and universities often have to be flexible – moving classes to more accessible parts of the school, giving extended deadlines for homework, providing notes when your son or daughter may find it painful to write and even arranging for extra time in exams.

Building a good relationship with the school or college and helping your child to communicate their needs will help both sides to find suitable solutions to problems that arise.

School

If your son or daughter is still at school and their needs are not being met by their school, you can try to get the local education authority (LEA) to give them an assessment. This assessment will determine their needs and may lead to a statement of special educational needs, usually known simply as a statement. This is a formal document which describes all a child's needs and the special help necessary to meet them.

Help is usually provided through additional support in a mainstream school though sometimes a pupil's needs are best met in a special school or unit.

If your child is statemented, the first annual review after their 14th birthday is important in preparing for a move to further education and adult life. It involves all those people and organisations who play a major role when your child leaves school – including you, your child, the careers service and the local social services department. This review produces a transition plan for the move to adult life.

The LEA will stop maintaining the statement – that is providing the support the statement obliges them to – if your son or daughter leaves school after their 16th birthday. If they stay at school, the LEA may keep the statement until they are 19 years.

Further education

Education for young people with special needs does not stop at 16. Depending on the interests and abilities of the young person, they can stay on at a mainstream or special school or can move to a college of further education.

If your child has a statement of special educational needs, further education will be considered when the transition plan is drawn up. Many disabled students attend ordinary courses at colleges with the help of special equipment or support.

Most places of further education have a disability liaison officer who can provide advice and information. Students whose needs cannot be met by a college of further education may be able to get a place at an independent specialist college.

If you have any questions about the choices open to your son or daughter after 16, the careers service provides help and advice to them.

Each careers service has a specialist careers advisor experienced in dealing with any area of special educational needs. Your child does not have to be statemented to access this help.

The DDA and education

Education was excluded from the main provisions of the Disability Discrimination Act (DDA) 1995 until the Special Educational Needs and Disability Act became law in May 2001.

Although the Act does not begin to come into effect until September 2002, it does mean that disabled children will now have the right to an education in mainstream schools and colleges.

It places new, anti-discrimination duties



'Schools are not disabled-friendly on the whole. Stairs, long corridors and constant classroom changing can be a big problem. When my daughter's mobility was limited, it was suggested she have home tuition. Supported by the school, I had to fight the education authority to get it. The home tutor helped my daughter keep up with her work but she was flexible and would work around her bad days.'

Parent

'When I was looking for a university I looked for one which was campus based, had flat grounds and had halls of residence close to the campus, pubs and shops. I also made sure I could drive to campus whenever I liked.'

Teenager

'It was suggested many times that I should go to a special school that would be more adapted to my needs. But I was determined to stay where I was. I was worried about the standard of education and I had many great friends where I was. I wanted to be normal and not classed as special.'

Teenager

on schools, colleges, universities and providers of adult education. The Act strengthens the rights of children with special educational needs and it amends the DDA (1995) by placing new duties on providers of school and post-16 education.

Under the new Act, it is not permitted to treat disabled students less favourably and schools and colleges are obliged to make a reasonable amount of adjustment to improve accessibility to disabled students.

The DDA does not apply to schools in Northern Ireland.

Further information

***When a Young Person has Arthritis: A Guide for Teachers.* Available from ARC, Copeman House, St Mary's Court, St Mary's Gate, Chesterfield, Derbyshire S41 7TD. Tel: 01246 558033.**

www.arc.org.uk

***Bridging the Gap – A guide to the Disabled Students Allowances (DSAs) in further education is helpful in advising on grants.* The Department for Education and Employment (DfEE) publishes a wide variety of useful pamphlets and booklets. Phone the DfEE free information line on: 0800 731 9133. www.dfee.gov.uk/**

Skill: National Bureau for Students with Disabilities, Chapter House, 18-20 Crucifix Lane, London, SE1 3JW. voice/text: 020 7450 0620 Fax: 020 7450 0650. Information Service voice: 0800 328 5050 (freephone).

With thanks for their contribution to this section:

Dee Hanna, head of service, Brent Education Support Services, London. Alison Mascharenhas, former parents' and young people's programmes co-ordinator, Arthritis Care.

Careers

Young people with arthritis achieve significantly more qualifications on average, but are much less likely to find work, than their peers according to a recent UK study.

Many jobs are too physically demanding for some people with arthritis. Employers often lack understanding about arthritis. Then there are people's own barriers – will they be able to manage all the travelling? What if they need to take time off? Will their needs be accepted and understood?

Many people with arthritis do work. They work successfully and they manage to keep their jobs even though they have periods of flare up or operations.

Unfortunately, people are discriminated against and some competent people have lost their jobs purely because the firm didn't take the time to make reasonable adjustments.

Careers advice

Your son or daughter can do a number of things to help themselves build a rewarding career, despite all the barriers. Encouraging them to follow the advice listed below will help them greatly.

- **Get qualified.** Most young people with arthritis know they have to try hard at school just to stand a chance of getting anywhere. Your child will need at least basic literacy and computer skills. Even if your child isn't doing well at school all is not lost. Going to a college after leaving school is a way to catch up. Providing it is physically accessible, a local college is often a much more relaxed environment in which to learn.
- **Get skilled.** Finding a way to learn skills that are needed in work is very useful. This can be done through education, training or through voluntary work. If your child is studying a non-vocational course such as humanities or arts, suggest they think about trying a vocational course (or voluntary work) alongside.

- **Get careers advice.** Careers advice is available in a number of places including schools and universities. Information is available on all sorts of careers and opportunities that you and your child may not have thought of. They may also list the types of experience which are helpful to enter into a chosen field.
- **Get experience.** Encourage your child to look around for voluntary work opportunities or work placements – the more experience they get the better. Disability organisations often take on volunteers and are likely to be accessible and understand needs. Voluntary work can help give an idea whether working full time is realistic or whether part time work is more suitable.
- **Prepare a CV.** Having a good CV is essential when applying for jobs. Listing skills, experience and strengths will save time when applying and it can also help boost confidence when achievements are written down in such a concise way.
- **Start somewhere.** Your child may not know what they want to do yet, and only the most fortunate people leave school and enter the career of their choice. Even if they do have a good idea what they want, most vacancies are filled by people moving from one job to another rather than by school or university leavers or unemployed people. The experience gained in that first job will help your teenager move on in their preferred career.

The DDA and employment

The Disability Discrimination Act (DDA) 1995 aims to prevent discrimination against disabled people in the workplace – from the application stage through to carrying out a job.

Employers are required to make reasonable adjustments to the workplace and to the job description to allow a

'So many employers still look on disability as a hindrance so I have been worried about my child finding a suitable job. If an employer sees the job seeker's capabilities though, they would both benefit.'

Parent

'Establishing independence is important. With a bit of encouragement my child gained work experience in a newsagents, a solicitors and an auction gallery. This helped develop her social skills and built her CV up.'

Parent

'I used to want to be a doctor but I know I won't physically be able to do that. I'm sure there are ways around my mobility problems but I don't want to be worrying about it all the time. I haven't decided yet what I want to do instead.'

Teenager

disabled person to carry out their job to the best of their ability.

The Access to Work scheme, run through Jobcentres, can help. It provides practical support to enable a person to obtain or retain a job through the provision of specialist equipment, aids, adaptations to the workplace or even funding for travel to and from work. The scheme can help your employer with costs incurred while making reasonable adjustments as is law under the DDA. Ask the disability employment adviser at the Jobcentre for details of the scheme.

The DDA 1995 only covers employers of 15 or more people (although this is set to change in 2004 when the threshold will be reduced to 0). It does not cover the armed forces, the police, the fire-fighting and prison services.

Further information

Disability Rights Commission Helpline, Freepost MID 02164, Stratford-upon-Avon CV37 9BR. Tel: 08457 622 633. www.drc-gb.org/drc/

Working Horizons: employment information for people with arthritis. This booklet is full of essential information and personal experiences. Available from Arthritis Care, 18 Stephenson Way, London NW1 2HD. Tel: 020 7380 6562.

With thanks for his contribution to this section:

Barry Hayward, former Working Horizons project manager, Arthritis Care.

The road to independence

Independent living asserts that disabled people should have the right to determine their own lifestyle and participate fully in society without interference from others. In its broadest sense, the concept encompasses the full range of human and civil rights including the right of equal access to mainstream education, training, employment, welfare and support services, housing, transport, public buildings, leisure and information. It also means the right to personal and sexual relationships and parenthood.

Occupational therapy – a guide to independent living

Gaining independence is vitally important to a developing young person and even more so for a young person with arthritis with restricted joint movement, weaker muscles and tiredness or fatigue. Not being independent can affect a person's dignity, privacy and self-respect.

Occupational therapy can play a vital role in enabling independence. It assesses people's ability to function within their own environment and provides advice, equipment and aids and adaptations to maximise their independence in all areas of their daily activities.

Occupational therapists (OTs) work with the individual to find solutions to problems they may be experiencing in their day-to-day life. An OT assessment may be carried out at the hospital or at home or school.

Common examples of problems people experience are difficulty getting in or out of the bath, writing, managing stairs or not being able to take part in their favourite sport or hobby.

It is not always possible to find a solution to every problem, but there are usually ways of working round them. It is useful to recognise that young people rarely want to accept aids or equipment especially at school or college as these can set them apart as different. The OT and your child

can work together to come to a compromise about this.

How to access occupational therapy

OTs are based in a variety of settings including hospitals, community and social services. As a general rule, OTs working in social services are able to assess the home environment and recommend equipment and adaptations to improve independence. OTs working in healthcare settings can usually provide assessment and therapy including splinting.

You may already have access to an OT. If not, a GP or consultant will be able to refer you. Alternatively, contact your local social services and ask for the occupational therapy department.

Further information

Arthritis & Equipment Guide, Disability Information Trust, Mary Marlborough Centre, Nuffield Orthopaedic Centre, Headington, Oxford OX3 7LD. Tel: 01865 227600.

Reaching Independence: a guide to living at home for people with arthritis. A booklet giving information about the services and support available to enable people to live independently. Available from Arthritis Care, 18 Stephenson Way, London NW1 2HD. Tel: 020 7380 6562.

Benefits

Your son or daughter may be entitled to a number of social security benefits paid by the government. Although no benefit is paid specifically for having arthritis, your child, or even you, the parents, may be entitled to a range of benefits to help cover the additional costs of the condition.

Disability living allowance

Disability living allowance (DLA) is paid to help towards the additional costs of disability. It is a tax free, non-means tested

'I was delighted my child had the confidence to move on and leave home. It established her independence. I was concerned though how she would cope in a strange environment.'
Parent

'Naturally, every parent worries about their child being away from home but I felt the extra worries about how she would cope, whether people would be kind to her and whether they would see beyond the disability.'
Parent

'We were all ignorant of the benefits that we are entitled to. There should be more advice given. It was five years before we realised we could have been claiming disability living allowance.'
Parent

'DLA has meant I can have my own car. It's amazing the independence this gives me – and my friends.'
Teenager

benefit. DLA has two parts: a mobility component and a care component. Your son or daughter may be eligible for one or both. Within each component there are different levels.

DLA mobility component is payable at one of two rates:

Higher: is payable for people unable, or virtually unable, to walk. For most people with arthritis it is the virtually unable to walk criteria that is applicable. Time, distance, speed, manner of walking and discomfort are all taken into account.

Lower: is generally not applicable to people with arthritis as it is payable to people who can walk but need someone guiding or assisting them.

DLA care component is payable at one of three rates:

Higher: is payable to people who satisfy both the daytime and the night-time disability tests.

Daytime: someone who needs help with personal care frequently throughout the day (during the middle of the day as well as in the morning and evening) or needs continual supervision to avoid substantial danger to themselves or others.

Night-time: someone who needs prolonged help (at least 20 minutes) or repeated help (two times or more); or needs someone to be awake at night to watch over them to avoid substantial danger (for at least 20 minutes, or three times or more).

Middle: is payable to someone satisfying either the daytime disability test or the night-time test.

Lower: is payable to someone needing help for at least an hour in the day, for example to help them get up in the morning, or for those over 16 who cannot prepare a cooked meal for themselves.

Other benefits

If your child is awarded DLA care component at either middle or higher rate, you may be entitled to claim invalid care

allowance if your earnings are less than £50 per week net of allowable expenses. Once your child reaches the age of 16, the allowance will be paid direct to them.

Parents who are receiving income support should claim invalid care allowance as they will then be eligible for various premiums on their benefit.

Once they reach 16, young disabled people who are unable to work can claim income support in their own right. Whether or not they qualify for these benefits depends on individual circumstances.

This is a very brief outline of the benefits relating to disability. It is advisable to contact a local disability organisation or welfare rights worker to get more advice and assistance in claiming. Your local Citizens Advice Bureau can give details of these organisations and there are organisations such as Disablement Information and Advice Lines (DIALs) who can also give advice.

Further information

Benefits Enquiry Line. Tel: 0800 882200.

Benefits for Beginners – a guide for people with arthritis. A useful booklet for people with arthritis detailing the benefits they or their carers may be entitled to.

Available from Arthritis Care, 18 Stephenson Way, London NW1 2HD. Tel: 020 7380 6562.

Citizens Advice Bureaux (National Association of), Myddleton House, 115-123 Pentonville Road, London N1 9LZ. Tel: 020 7833 2181.

DIAL UK, Park Lodge, St Catherine's Hospital, Tickhill Road, Doncaster DN4 8QN. Tel: 01302 310123.

Disability Alliance, Universal House, 88-94 Wentworth Street, London E1 7SA. Tel: 020 7247 8776.

**The Family Fund Trust, PO Box 50, York
YO1 9ZX. Tel: 01904 621115.
www.familyfundtrust.org.uk**

Grants

Having a child with arthritis can involve considerable additional expense to the family due to frequent visits to hospitals or physiotherapists, clothes wearing out because of splints and extra items needed to help with exercises. There are some sources of financial help available in addition to social security benefits.

A family with a child under the age of 16 severely affected by arthritis may be able to get grants from the Family Fund Trust, an organisation that makes grants to families who have a severely disabled child. These grants can be for everyday items like bedding and clothing but they also help with holidays, travel costs, driving lessons for the main carer and can provide washing machines and some other domestic items. They also publish a useful guide which is free to parents: *After 16 – what's new?* This covers information about benefits, education, finance, transport and many other useful topics.

The Lady Hoare Trust's team of social workers across the country offers support to families whose children have arthritis or problems with their limbs. As part of the social work contact, small grants can be made to help with the extra costs related to the child's disability.

Whizz-kidz raises funds to provide wheelchairs, or other equipment, which will enable children to become independently mobile.

There are also many grant-making trusts which will assist with particular needs or items. Details of these can be got from local disability advice lines, Citizen's Advice Bureaux and other local resources.

Social services departments have a duty to assess disabled people's care needs and to provide funds to enable them to buy in

personal care so that they are able to live independently. See Employing a personal assistant below.

If a person's care needs are such that they need to pay more than £200 per week for their personal care, then the Independent Living Fund (ILF) can assist in funding these costs. The ILF administers a fund of money supplied by the government to help disabled people pay for care so that they can live independently.

As part of the social services assessment, the suitability of a disabled person's accommodation must also be considered and, if major alterations are required to provide the right facilities, various grants may be available to help with the cost.

Further information

**The Family Fund Trust, PO Box 50, York
YO1 9ZX. Tel: 01904 621115.
www.familyfundtrust.org.uk**

**Whizz-kidz, the movement for non-
mobile children, 1 Warwick Row, London
SW1E 5ER. Tel: 020 72336600.
www.whizz-kidz.org.uk**

Employing a personal assistant

An important aspect of independent living for a number of disabled people is employing a personal assistant to undertake tasks to enable them to live on a par with their non-disabled peers.

Financial support provided by social services departments enables disabled people to employ their own personal assistants to assist with essential personal and practical tasks to aid day-to-day living.

The direct payments give disabled people maximum choice over who helps them and is a significant advance on systems where disabled people are cared for in residential homes or receive help at home from staff employed by social services or health authorities.

However, receiving direct payments from local authorities is a complex process and the system may vary from area to area.

Further information

For information about direct payments in your area contact your local social services department or equivalent.

Controlling Your Own Personal Assistance Services. British Council of Organisations of Disabled People (BCODP) and the National Centre for Independent Living. Available from BCODP, Litchurch Plaza, Litchurch Lane, Derby DE24 8AA. Tel: 01332 295551. www.bcodp.org.uk

Direct payments information – a guide to receiving direct payments (1998). Available from Department of Health, PO Box 410, Wetherby, LS23 7LN, quote code DPG/E or at www.open.gov.uk

Independence: A guide to obtaining and funding personal assistants in post-16 education. SKILL: National Bureau for Students with Disabilities, 18-20 Crucifix Lane, London SE1 3JW Tel: 0800 328 5050. www.skill.org.uk

Driving

Learning to drive can be one of the greatest ways to achieve independence for young people with arthritis. It gives them freedom – the opportunity to get out by themselves, to go where they want, when they want and to travel to places which may have previously been inaccessible.

If your son or daughter receives the higher rate of the mobility component of the disability living allowance, they can be the envy of all their friends and learn to drive at 16.

Some young people, especially those more severely affected by arthritis, will benefit from going for an assessment at an approved centre. The Mobility Advice and Vehicle Information Service (MAVIS), set up

by the Department of Transport, Local Government and the Regions, provides this service and can recommend local centres.

Assessments aim to help disabled people make informed decisions about their mobility needs by providing a driving and passenger assessment, including the opportunity to drive a car round a specially constructed course, and advice on adaptations. An assessment also helps determine if the young person is legally able to drive a vehicle safely.

Your teenager may qualify for a blue (formerly orange) badge which allows disabled people special parking privileges. These vary from area to area. To qualify, people must have a disability which makes walking impossible or very difficult or be in receipt of the mobility component of the disability living allowance. To apply, contact your local social services.

Motability

Motability is a registered charity which runs a scheme to enable disabled people to lease or buy a car. To qualify for any of the Motability schemes, your son or daughter must receive the higher rate mobility component of DLA for a minimum of three years and eight weeks – the length of the agreement from the delivery date plus eight weeks processing time. If your child receives this, you may also be eligible for the scheme if they do not want their own car or they are too young to drive.

The scheme covers the cost of the car, insurance, servicing and membership with a recovery firm. It may also entitle people to free vehicle excise licence (road tax) as the car will be registered under a disabled driver. However, your child may also be entitled to free road tax if they receive the disability living allowance's mobility component (see page 27 for further information on this benefit).

There are three Motability schemes to choose from, all of which require you to commit all or part of the DLA benefit direct



to Motability Finance Ltd (MFL) for the length of the agreement.

If your child does not want to use any of the Motability schemes, or they do not qualify because their DLA award is less than the required term, they may experience some problems when trying to insure themselves aged sixteen.

Further information

***Driving with your Arthritis.* Available from the Arthritis Research Campaign, Copeman House, St Mary's Gate, Chesterfield, Derbyshire S41 7TD. Tel: 01246 558033. www.arc.org.uk**

For more information on Motability and the available schemes contact Motability, Customer Information Services, Goodman House, Station Approach, Harlow, Essex CM20 2ET. Tel: 01279 635666. www.motability.co.uk

Department of Transport, Local Government and the Regions, Eland House, Bressenden Place, London, SW1E 5DU. Tel: 020 7944 3000. www.mobility-unit.dtlr.gov.uk. Provides information on mobility and inclusion including transport and the blue badge scheme.

Fylde Benefits Directorate, Disability Living Allowance Unit, Warbreck House, Warbreck Hill, Blackpool FY2 0YE. Tel: 0345 123456. For information on exemption from vehicle excise duty.

MAVIS, Macadam Avenue, Old Wokingham Road, Crowthorne, Berkshire RG45 6XD. Tel: 01344 661000 (also on minicom). Information on all aspects of transport, both public and private, together with information on outdoor mobility needs, is available by letter or telephone. Details of other assessment centres in the UK are also available from MAVIS.

Social skills and confidence

Having arthritis doesn't mean your child has to give up their friends and social life. In fact, it is important to get out and about. It helps build confidence, helps interaction with peers and it can help keep people from concentrating too much on the effects of arthritis.

Everyone has to work hard at relationships and people with arthritis are no different. However, many teenagers with arthritis may well have to invest more time and energy into making relationships work whether they are platonic or sexual.

Adjusting to life as a teenager

Arthritis can make young people less outgoing, less inclined to involve themselves and even embarrassed in case their friends see them as a burden because of any physical limitations.

Having arthritis during teenage years puts added pressures on relationships. Adolescence is where teenagers assert their personality and become sexually aware.

Having arthritis can affect a person's self-image, lowering their confidence and self-esteem. Anxieties about oneself can be at their highest during teenage years, as people try to establish themselves. Having a condition that is often only associated with older people can be especially difficult for younger people.

Overcoming feelings of inadequacy is not easy but many people with arthritis do have successful relationships. Your child can

'Getting out and about was a real problem before I learnt to drive. I had to rely on people for lifts. Driving, however, can be a problem, with steering and gear changing becoming a strain.'

Teenager

'Driving a car has brought my son great independence. It has loosened his dependence on us and put him on a par with his friends. It has also made him realise he can cope in the big world and do his own thing in his own time.'

Parent

'Being able to drive is fantastic. Two of us have a car so the whole lot of us can go and do what we want, when we want.'

Teenager

'I never look on my son as being any different to his peers, there are just times when he may take a bit longer to do a specific task or he may tire easily. He is accepted and treated the same as his peers by his peers. It is sometimes adults that may have a problem with this.'

Parent

'Sometimes I feel that there is too much to cope with and that I have to be strong for everybody and deal with problems that arise. This is as well as trying to hold down a full time job and family life in general.'

Parent

'My friends and arthritis have never really been a problem. There have been times when I couldn't go out, but they always come back and fill me in on the gossip. When my flare up lasts a long time I get depressed but my friends never fail to come around.'

Teenager

do things to keep their social life going, even when their arthritis is at its worst.

Arthritis Care publishes a booklet called *Our Relationships, Our Sexuality: a guide for people with arthritis* which explores issues surrounding relationships (both platonic and sexual), sexuality and arthritis.

The booklet is for anyone who thinks arthritis prevents him or her from forming or sustaining relationships. It is also for anyone who thinks arthritis prevents them from having a satisfying sex life. It looks at communication and maintaining a good social life, as well as the practical side of lovemaking.

Further information

Our Relationships, Our Sexuality: a guide for people with arthritis is available from Arthritis Care, 18 Stephenson Way, London NW1 2HD. Tel: 020 7380 6562.

Out and about

Disabled people have more rights of access since the introduction of the DDA (1995).

This has an implication in a number of areas of life.

Under the access to goods, facilities and services section of the act, all service providers, whether the service be free or

paid for, have a duty not to treat disabled customers less favourably than other customers. This applies to shops, hotels, pubs, doctors' surgeries, courts – anything that provides a service.

It is illegal to refuse to serve a disabled person, to offer a disabled person a lower standard of service, to offer a disabled person less favourable terms and to fail to make any of the reasonable adjustments listed below.

Service providers are now required to make reasonable adjustments where access is difficult or impossible in regard to:

- their policies, procedures or practices
- making available auxiliary aids and services (for example electric scooters, adapted trolleys)
- providing alternatives where a physical feature prevents access.

However, service providers do not have to make any permanent adjustments to physical barriers until 2004.

Further information

www.disability.gov.uk has a lot of information about the Disability Discrimination Act. Tel: 0345 622 633 for printed leaflets (including the useful DX19).



Holidays

Having arthritis doesn't mean being unable to go on holiday, whether as a family or with friends. However, people with arthritis experience a number of barriers to travel that non-disabled people don't.

Whether holidaying in the UK or abroad, booking a holiday involving your son or daughter may need a lot of careful planning to make sure you get the holiday you all want.

Things are easier now for travellers with mobility problems. Airports run special assistance schemes which provide, amongst other things, a wheelchair or motorised buggy for those who cannot walk distances. Public transport is becoming more accessible and disabled people have been given new rights under the DDA 1995 Access to Goods, Facilities and Services.

Going abroad

Travel agents can look into the suitability of resorts and hotels and can make arrangements with a tour operator or airline for special assistance.

Pre-existing conditions such as arthritis are often not covered in the small print of insurance cover. Check this out before buying insurance. Some holiday companies provide cover for a small extra charge. Specialist insurance can prove quite costly.

In the UK

Holidays are available at Arthritis Care's four hotels, based in Blackpool, Largs, Nairn and Poole. They offer a high standard of accommodation, are fully accessible and include walk-in showers in the bathroom. Entertainment is laid on most evenings and there are plenty of games and books.

There are special rates for children at certain times of the year and those under 14 are accommodated at half price when sharing a room with one or more adults. Contact details for the hotels are at the end of this section.

Rail travel

If holidaying in the UK, a number of trains now have more space and an accessible toilet for travellers with mobility problems including wheelchair users. Special assistance is available at stations but at least 24 hours notice must be given.

Your son or daughter may be entitled to a disabled person's railcard which gives a disabled person and their adult travelling companion discounts on ticket prices.

Wheelchairs or other equipment can be borrowed from the Red Cross near to your UK holiday destination. No fee is charged for use of any equipment hired out, but the Red Cross does ask for a donation.

Breaks for parents

Parent carers of a disabled child may be entitled to respite care from their local social services. This ranges from short breaks of a few hours per week or month, to longer periods for a holiday.

Local activity groups give parents a few hours break whilst their child is occupied elsewhere. Your local social services department can give information about these services. The Government has recently recognised that parents need breaks. Funding is now available to social services departments for this purpose.

Further information

For an Arthritis Care hotels brochure and/or bookings:

The New Mayfair Hotel, Blackpool, Lancs.

Tel: 01253 347543.

Burnlea Hotel, Largs, West Scotland.

Tel: 01475 687235.

Lovat Lodge Hotel, Nairn, Scottish Highlands. Tel: 01667 453298.

Orton Rigg Hotel, Poole, Dorset.

Tel: 01202 707946.

www.arthritiscare.org.uk

Carers National Association, Ruth Pitter House, 20-25 Glasshouse Yard, LONDON, EC1A 4JS. Tel: 020 7490 8818.

'After my daughter developed RA we continued to go on holidays but their nature changed. Beach holidays were out for a number of years but the car took us around Europe.'

Parent

'We always use airport assistance when travelling by air. Going on a buggy car with the lights flashing is an adventure.'

Parent

Contact a Family, 170 Tottenham Court Road, London, W1T 7HO. Tel: 020 7383 3555. www.cafamily.org.uk

Disabled Person's Railcard. Application form available from local train stations or by writing to Disabled Person's Railcard Office, PO Box 1YT Newcastle-upon-Tyne NE99 1YT.

The Family Holiday Association, 16 Mortimer Street, London W1T 3JL . Tel: 002 7436 3304. www.fhaonline.org.uk

Holiday Care Service, 2nd Floor Imperial Buildings, Victoria Road, Horley, Surrey RH6 7PZ. Tel: 01293 774535. Provides information and advice to people who, because of disability or age, find it difficult both to find and arrange a holiday for themselves. www.holidaycare.org.uk

Tripscope, The Vassall Centre, Gill Avenue, Bristol, BS16 2QQ. Tel: 08457 58 56 41. Travel information and advice for people with mobility problems.

With thanks for their contribution to this section:

Sue Crawford, assistant social work co-ordinator, Lady Hoare Trust.

Sharon Fraine of the CCAA.

Eileen Francis, training development officer, Arthritis Care.

Tim Gardiner, general manager – hotels, Arthritis Care.

Janine Hackett, senior occupational therapist, paediatric rheumatology unit, Birmingham Children's Hospital.

Kerry Hebdon, senior occupational therapist, Middlesex adolescent unit, University College London Hospitals.

Kate Llewelyn, publications manager, Arthritis Care.

Mira Marcetic, area family contact, CCAA.

JCA to JIA

Juvenile idiopathic arthritis – why change?

Juvenile chronic arthritis (JCA) changed its name in 1999 to juvenile idiopathic arthritis (JIA) to ensure the same naming system is used throughout the world. Previously, in the UK and some other countries, JCA was used as the name for a group of different types of childhood arthritis, with juvenile rheumatoid arthritis (JRA) referring to only one specific type of JCA. In other countries, JRA was used in the way that we in the UK used JCA. Difficulty occurred when trying to make sense of which type of JCA/JRA was being referred to. To cut out the confusion, an internationally-agreed diagnostic naming system was decided on

to encourage international collaborations and to more accurately describe the groups. The sub-classifications have also been altered slightly to ensure in each group the same type of disease is more easily understood.

Below is a list of some of the sub-groups of JIA. Their old names are printed alongside in case you do not recognise the new names.

With thanks for her contribution to this section:

Sue Maillard, specialist physiotherapist in paediatric rheumatology, Great Ormond Street Hospital.

Juvenile means under 16. Idiopathic means of unknown cause. Arthritis means inflamed joint.

JIA is only diagnosed if a joint has been swollen for more than six weeks.

New Name

Systemic onset JIA

(Spiking fever, rash and arthritis in the first six months)

Old Name

Systemic onset JCA

Oligo-articular JIA

(Four or less joints in the first six months)

Pauci-articular JCA

Extended oligo-articular JIA

(More than four joints developing after six months)

Extended Pauci-articular JCA

Rheumatoid factor negative polyarticular JIA

(More than four joints in the first six months – no rheumatoid factor)

Seronegative polyarticular JCA

Rheumatoid factor positive polyarticular JIA

(More than five joints in the first six months – with rheumatoid factor)

Juvenile rheumatoid arthritis

Psoriatic JIA

Psoriatic JCA

Enthesitis related JIA

Spondyloarthropathy JCA

Other (have features of 2 or more groups)



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 national voluntary organisation working with all people with arthritis. It operates:

- over 600 local branches and groups
- It provides a wide range of services including:
- a helpline, by letter and by telephone
 - The Source, a helpline for young people with arthritis
 - four hotels
 - *Arthritis News*, a bi-monthly magazine
 - *No Limits*, a magazine for 15-20 year olds
 - information booklets on a range of topics including exercise and benefits
 - a range of self-management and personal development training programmes.

Young Arthritis Care is run for all young people with arthritis. It has a nationwide network of contacts consisting of young people with arthritis or parents of children with arthritis who help, support and advise others in similar situations to their own. There are local groups around the country which allow members to get together, share information and give each other support. Publications on subjects including diet, exercise, medication and complementary therapies are available.

Arthritis Care 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.

All Arthritis Care and Young Arthritis Care's work is aimed at promoting independence and empowering people with arthritis to live positive lives.



Children's Chronic Arthritis Association
Ground floor office,
Amber Gate,
City Walls Road,
Worcester WR1 2AH
Tel: 01905 745595
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.



for physically disabled children

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

Lady Hoare Trust
1st Floor, 89 Albert Embankment,
London SE1 7TP
Tel: 020 7820 9989
Fax: 020 7582 8251
www.ladyhoaretrust.org.uk
Registered charity No.1067492

The Lady Hoare Trust helps children with arthritis or severe limb disabilities by providing them and their families with practical and financial support.

The Trust, founded in 1962 to help children disabled by the drug thalidomide, now encompasses all children under the age of 18 who have joint and limb disabilities. It provides practical help to these children and their families via a network of specially trained fieldworkers as well as financial help in the form of small grants.

The Trust also offers advice and information to meet the very diverse needs of families with children affected by arthritis and severe limb disabilities, and works to raise public awareness of the needs of children who live with these conditions.

Our experience has shown the importance of helping the whole family cope with the extra practical and emotional demands of having a child with a physical disability. Parents may need help with practical issues such as treatment, benefits or education and extra support may be needed through times of stress.

Fieldworkers, usually qualified social workers, use their skills and experience to help children and their families cope, responding quickly to requests for help and visiting families at home. They provide assistance in whatever form is appropriate to the individual family. They can often become the family's first contact point when they need help and can provide continuity so that over time they become someone the family knows well and can depend upon.

Edited by Kate Llewelyn. Thanks to the sub-group of the CHAT Alliance for their hard work in getting this booklet together.

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