My Child has Arthritis

a practical guide for parents
## Contents

### About this booklet
- What is arthritis?  
  - Causes  
  - Symptoms  
  - Diagnosis

### Treatment
- Choosing the right treatment  
- Working with health and care professionals  
- Who’s who  
- Attending medical appointments  
- Tips for attending medical appointments  
- Medication  
- Managing pain  
- Exercise  
- Physiotherapy  
- Diet

### Managing your child’s arthritis
- Getting the support you need  
- Keeping positive  
- Applying for disability assistance

### Being organised

### Emotional responses

### Supporting your child

### Education
- Working with teachers
- Managing absences
- Challenges at school
- Who’s who
- Special educational needs

### Into adulthood
- Teenagers
- Managing their own healthcare
- Increasing involvement in appointments
- Transition to adult healthcare services

### Glossary

### Sources of further help and information

### Can you do something to help?
IF YOUR CHILD has been diagnosed as having arthritis, you probably have a great many concerns and questions. In this booklet we aim to provide the information you need to help you and your child understand and manage the condition, and to help you cope with both the practical and the emotional challenges involved in parenting a child of any age who has any form of arthritis.

Acknowledgements
Thanks to Lichfield Branch who are remembering their much loved member Jean, and to West Suffolk Hydro-Care for supporting the production of this publication.
What is arthritis?

Arthritis is a common condition that causes joint inflammation and pain. It is often thought of as a disease that affects older people, and it is most common in people aged 50 or over. But it can affect people of all ages, including children. It is estimated that around 15,000 children and young people in the UK are affected by the condition.

The word ‘arthritis’ literally means inflammation of the joints. Arthritis that affects children and young people is often referred to as juvenile idiopathic arthritis, or JIA (the word ‘idiopathic’ means ‘of unknown cause’). JIA covers a range of different types of the condition. In this booklet, we use the term ‘arthritis’ to cover all forms of arthritis in children.

Causes

It is not clear exactly what causes arthritis, and different types of arthritis may have different causes. Arthritis in children and young people is thought to stem from a combination of genetic factors and an immune system disorder. The immune system is the body’s defence mechanism, protecting us against injury or illness. Sometimes the body attempts to defend itself by generating inflammation or swelling, for example in order to fight bacteria. It is thought that arthritis in children and young people occurs when the body creates such inflammation in joints when it is not actually necessary; it is fighting itself, rather than any invasive threat. This is known as an autoimmune disorder. It is this inflammation that causes pain and difficulty in movement.

For a full glossary of terms, see pages 44–45.
**Symptoms**

There are various types of arthritis that affect children, but they all share a number of common symptoms, including persistent joint pain, inflammation, swelling, tenderness, and stiffness. Any joint might be affected but the joints most commonly affected are in the knees, hands and feet, and any number of joints might be affected, from just one or two to several.

Most people with arthritis will experience problems and pain in specific joints, while others might feel more generally unwell. Other symptoms might include a high temperature or a skin rash that might come and go.

Inflammation of an affected joint occurs when the joint lining thickens, the fluid that lubricates the joint (synovial fluid) increases, and toxins are released into the joint. These changes cause stiffness and pain, making movement of a joint difficult. If your child’s arthritis is affecting their knees, feet or hips, they may experience difficulty walking or climbing stairs. If it is affecting their hands, wrists or elbows, they might struggle with tasks such as writing, using a computer or dressing.

Arthritis affects different people in very different ways. And it is a fluctuating condition, meaning that its effects can vary from day to day, and from week to week. Typically, there will be times when the symptoms of arthritis improve or even disappear (referred to as going into remission), and times when they worsen (known as flare-ups). With the right treatment some people may find they are in remission for months or even years at a time. Others might experience more severe symptoms, perhaps as a result of changes in their general health, infection, or sometimes for no known reason.

Although there is no cure for arthritis, there are many effective treatments that can enable your child to live a happy and healthy life, and ongoing research is improving our understanding of the condition all the time.
‘With better drugs and a greater number of specialist centres across the UK, treatment of JIA has improved dramatically in the last 20 years, and keeps improving.’
Dr Janet McDonagh, expert in child and adolescent arthritis.

Diagnosis

There is no single test to diagnose arthritis. Your child’s doctor or specialist will examine your child, looking at the location of pain, swelling or tenderness, and ask questions, both about any restricted movement and about your child’s general health and medical history. Your child may be sent for blood tests, x-rays, and possibly other types of scans too, such as MRI (magnetic resonance imaging), CT (computerised tomography) or ultrasound, or a range of other types of test. The results of these tests will help confirm a diagnosis, as well as ruling out other possible causes of your child’s symptoms.

Arthritis is a long-term condition (also referred to as a ‘chronic’ condition), but the good news is that a diagnosis of arthritis is the first step towards effective treatment.

Sometimes, having a child diagnosed with arthritis might mean that the whole family has to make some adjustments. Following several months of anxiety, possibly confusing symptoms, medical appointments and tests, it is common for any parent to experience a mixture of emotions, including relief at receiving a diagnosis, disbelief that their child has a significant illness, and also frustration, denial or anger. There is no ‘right’ or ‘normal’ way to react to the diagnosis.

Be assured, you are not responsible for your child’s arthritis. And, if you have more than one child, know that it is very rare for more than one member of a family to be affected by childhood arthritis.
Choosing the right treatment

There is a wide range of treatment options available for arthritis, from medication to alternative therapies to various self-management techniques. Some children with arthritis may need specialist equipment (such as orthotics) or particular tests (such as eye tests). Surgery is relatively rare for children and young people with arthritis.

Your doctors will advise which treatment is best for your child, but you can play an active part in treatment decisions. As a parent, you know your child better than anyone else, and this knowledge is invaluable when planning any treatment.

Always remember that you have choices, and don’t be afraid to ask questions at every stage.
Working with health and care professionals

You and your child will come across numerous health and care professionals. Which specialists you meet and how they work together will depend on your child’s particular needs and circumstances, as well as on the way healthcare services are structured in your region. Some of the key ones are listed opposite.

You will meet some of these people regularly over several years, often acting as a link between them, sharing information and chasing up actions. Developing good, positive relationships with them can be hugely beneficial.

Before your child is given any treatment, you should have the opportunity to discuss with your doctor what the treatment is and how it is to be administered and any possible side effects. Once children reach 16 years of age, they are able to consent to their own treatment.
Who’s who

- **General Practitioner (GP)** – as well as being your first port of call for prescriptions or referrals, GPs are also useful for advice between specialist appointments, and for helping you to access specialist medical care.

- **Occupational therapist (OT)** – offers practical help in overcoming physical or other challenges through techniques, aids or equipment. May visit home or school to assess difficulties.

- **Ophthalmologist** – specialist in eye health.

- **Orthopaedic consultant** – senior doctor specialising in bone and joint surgery.

- **Paediatric rheumatologist** – specialises in providing care to children with arthritis and providing support and information to their families.

- **Paediatric rheumatology nurse** – nurse specialising in children’s arthritis.

- **Physiotherapist** – specialist in using exercise or physical treatment to overcome physical injuries or difficulties.

- **Play therapist/specialist** – hospital- or clinic-based expert in the behaviour of, and communicating with, young children.

- **Podiatrist (also called a chiropodist)** – specialist in treating foot problems, which may affect overall posture and other joints.

- **Psychologist/psychotherapist** – trained to enhance and promote wellbeing and to help people understand their condition, circumstances or difficulties, and help them find workable coping strategies.

- **Radiologist** – expert in using and interpreting x-rays, ultrasound and other medical scanning techniques.

- **Social worker** – helps to secure support for independent living, for example, through personal care or respite for carers; may be employed by a hospital or a local council.
Attending medical appointments

Appointments with any health and care professional can feel intimidating, and you and your child might find them exhausting. Learning about arthritis beforehand will help you to get more out of appointments, by helping you to understand better what doctors or other practitioners are saying, and being able to explain to your child what is going on.

A huge amount of information about arthritis is available via the Internet, but always be careful to double-check whether online information is correct, up-to-date, and relevant to the UK.

Some good sources of information are listed on pages 46–49.

Appointments with specialists can be infrequent and when you get there your time may feel all too brief. In order not to forget what you wanted to ask or discuss, or to risk overlooking what your child’s particular difficulties were a month or two before the appointment, it can be a good idea to take photographs or short videos of your child on bad days to show to doctors or specialists during appointments. Writing down in advance the questions you want to ask, and taking your notes with you, can also help you make the most of your appointment time. Similarly, making notes while you are there can help you to remember afterwards what the doctor or specialist has said.

You may want to ask a friend or family member to accompany you to an appointment for additional support. They could entertain or comfort your child (particularly if your child is very young) while you talk to the doctor, or perhaps take notes while you ask questions. Having support on the day can also help you feel more confident.
Your child is likely to have their own concerns, and these may well be different from your own. As far as possible, it is a good idea to include your child in all medical discussions. Children and young people need to have an active involvement in appointments, so they can explain exactly what symptoms feel like, and so they can gradually take responsibility for their own healthcare.

If your child has siblings, consider taking them along to some appointments too. This can help them understand what their brother or sister is experiencing, and help your child with arthritis not to feel singled out or isolated.

After an appointment, you might want to arrange a treat of some sort, to end the day on a positive note.

► See also ‘Managing their own healthcare’ on page 41.
Tips for attending medical appointments

1. **Prepare in advance** and take with you a list of questions or concerns, and discuss with your child what they might wish to talk about.

2. **Take a friend** or other family member with you if you can.

3. **Involve your child** as much as possible. With an older child or teenager, discuss with them afterwards what you all think went well and how they feel about what they learned.

4. **Take notes** during or immediately after the appointment or ask your doctor to write down anything that’s important in case you might forget. Note down the names of who you see, and ask for any notes.

5. Don’t be afraid to **ask questions** at any point, or to say if there’s anything you don’t fully understand. Medical professionals want to help and inform you; they will be happy to answer questions.
Medication

Your child is likely to be prescribed medication designed to help reduce the effects of their arthritis, as well as other medication to manage specific symptoms and to control pain.

It is a good idea always to be ready to ask questions about any proposed medication or procedures. For example:

- For how long has a particular medication been used?
- How effective is it, and are there any likely side effects?
- What alternatives could be available?
- Are there any recommended over-the-counter medications you could try, to help perhaps with specific flare-ups?
- Might physiotherapy also be helpful?
- Are there activities it can be especially helpful to encourage or to avoid?

Finding the right medication

It is not uncommon for people to have to try several types of medication before they find one that suits them. Your child may not be able to tell you how they feel about a particular treatment or whether it agrees with them, particularly if they are very young.

Always trust your instincts. If you have particular concerns about any treatment, you can always seek a second opinion. Speak to your GP in the first instance.

Taking medication

It is important that any prescribed medication is taken as directed. For example, some medicines need to be taken at a specific time of day, or before or after food, in order to be most effective.

If your child is very young it is likely that you will need to be fully responsible for administering their medication, while older children can benefit
from taking control themselves. For anyone, taking medication can be a tedious experience, and sometimes even unpleasant. Allowing children of any age to have a degree of control over the process, however small, can be beneficial.

There are a number of things you can try to help your child take their medication as prescribed. For example, a young child might choose what chair they like to sit in while they have an injection, which drink to wash their medicine down with, or which cup to drink from. Your child might be able to choose whether to take some drugs in tablet or liquid form. If you have a young child who has difficulty with accepting medication, a play specialist may be able to offer help.

While in the longer term your child will need to fully understand that they are taking medicine, and why, for younger children, it can be helpful to disguise medication by administering it in food or drink, such as mashed potato or hot chocolate.

Keeping calm and distracting or relaxing young children by cuddling them, singing a song or letting them hold a favourite toy while they take medication can be helpful. Or a numbing cream, an ice cube or a cold pack can help to reduce the pain of injections. Always avoid surprising your child with an injection or a mouthful of medicine, as this can lead to a lack of trust.

Post-medicine treats, such as daily stickers or a larger treat after a week of ticking off their medication on a chart can help some children to feel in control of their treatment.
If your child refuses to take medication

It is not uncommon for children and young people to refuse to take their medication at some point. If you are experiencing this, you are far from alone. To overcome the problem, it can help to know why exactly they are protesting. The following questions may help you to understand the reason.

- Are they frightened of needles?
- Does the medication make them feel unwell?
- Are they sensing your own anxiety?
- Are they seeking extra attention from you?
- Are they feeling uncomfortable having to take medication in front of others?
- Are they struggling with feeling different from other children?
- Are they trying to assert control over the situation?

It important that your child understands as far as possible what the medication is for and why it is important that they take it.

Encourage your child to take medication in a quiet place to avoid making a fuss. You could make your child feel less isolated by taking a dose of cod liver oil yourself when they take their medication (they may enjoy seeing you pull a face), or by giving your other children a vitamin pill at the same time.

Older children, while still requiring your encouragement, need to understand the impact of not taking medication. Instead of alarming them, calmly explain what the medication does. It can be harmful to suddenly stop taking certain medication, such as steroids, so discuss any problems with a doctor or nurse as soon as possible.

If taking medication is an ongoing source of stress for you or your child, talk to your child’s doctors or the hospital pharmacist. They may be able to suggest alternative ways of taking medication, or alternative drugs. Your GP could also refer them to a psychologist (or a play specialist for younger children) to help overcome a fear of needles or break down negative associations with medicine.

‘When we’re giving medicine, we make up a song or rhyme to make it a bit jolly. When she used to go for steroid injections we bought her a little treat for being so brave.’

Sharon, whose 10-year-old daughter has oligoarticular JIA
Managing pain

Arthritis is a painful condition and pain is unpredictable, affecting everyone in different ways. It is always upsetting for you to see your child in pain, but there is a lot you can do to try to lessen its severity for your child.

Your child may need help describing their pain. With younger children, you could draw a range of facial expressions and ask them which one they feel like, or suggest they draw or point to where it hurts. This may be a useful way for shy children to communicate with doctors. Older children may be able to score the severity of their pain out of 10, or describe it as stiffness, a dull ache or a sharp feeling.

Although your child may not be able to tell you, or may not want to tell you about their pain, they will want you to understand, and you can learn to recognise the signs. You might notice that they seem unsettled, change their posture, become pale, quiet, angry or clingy. Comforting and reassuring your child by cuddling them, reading a story or watching a DVD or playing a game together can help to distract and calm them.

Administering painkillers can be an obvious and effective way to tackle pain, but here are some other options that can be very helpful in providing comfort and relief, and help restore a sense of being in control of one’s own pain management.

- **Hot and cold treatments.** Heat serves to open up the blood vessels and increase blood flow; it tends to be good for soothing stiff or tired joints. Cold slows down the blood flow to an area, helping to reduce swelling; it tends to be better for acute inflammation. Try, for example, warmth from a hot water bottle, a warm bath or a heat pack from a pharmacy, warming clothes on a radiator or wearing thermal layers; or cold from the application of a cold pack from a pharmacy or a pack of frozen peas. (Note: it is important to be careful when applying either hot or cold treatments: avoid scalding, and never apply a frozen pack without a barrier layer, for example a towel or tea towel between the pack and the skin, and limit the application of either to 10–15 minutes at a time before reapplying after a break.)
• **Massage** can be very beneficial for general relaxation and for soothing tired muscles and limbs. Ask your child’s physiotherapist to show you some techniques you can try at home.

• **Relaxation techniques**, such as visualisation, mindfulness or deep-breathing techniques, can help to alleviate some of the stress and fatigue that arthritis can cause. See our website for details (arthritis-care.org.uk). With practice, relaxation techniques can be very helpful not only for relieving muscle tension, but for reducing anxiety and promoting a general sense of calm and improved positive patterns of thinking.

• **TENS machines** (transcutaneous electrical nerve stimulation machines) use electrical pulses to interrupt pain signals to the brain and some people find they can help to alleviate the body’s response to pain. Speak to your child’s physiotherapist, who will be able to advise you about them and may be able to lend you one to try.

• **Complementary therapies**, such as aromatherapy or acupuncture, are therapies that can work alongside (i.e. complement) conventional medicines. They often involve making certain lifestyle changes, for example changes in diet or exercise. Some people find them very effective, while others remain sceptical about the medical benefits. It is a good idea to discuss new therapies with your doctor before trying them, as some may interfere with medication.

‘Having injections or taking tablets is quite a small sacrifice if they can help you to walk and run. My wanting to be able to do things overtook my fear of medication.’

Clare, now 23, who was diagnosed with polyarticular JIA at 13.
Exercise

Exercise has a positive impact on both physical and emotional wellbeing, and is good for everyone, including your child with arthritis, as it helps to:

- lessen stiffness
- improve joint mobility
- maintain strength in muscles that protect vulnerable joints
- improve bone strength
- combat stress
- improve mood, confidence and body image
- help to maintain a healthy weight.

Although exercising can be more challenging for a child or young person with arthritis, it is important that they remain as active as possible. Try to find a form of exercise that they enjoy and can manage without too much discomfort. Low-impact activities – such as swimming, water aerobics, canoeing, cycling, yoga or dancing – are all ways of exercising without putting too much strain on joints. Younger children can learn to be active through play – and sometimes not even realise that they are exercising.

At first, your child may associate exercise with increased pain (as is the case for many of us), but they may find it becomes easier over time and with practice, and this improvement can itself become an important motivating factor for them. Remember to tell any exercise instructors about your child’s condition so that they understand that some movements may be difficult, and can tailor any training to your child’s needs.

Always emphasise the importance of warming up before any exercise, and of keeping warm throughout, to help protect against joint or muscle strain and to improve overall mobility. And there is a wide range of support equipment – such as shock-absorbing shoes – that can help reduce the impact of exercise on their joints. A podiatrist will be able to advise you on this.
Physiotherapy

A physiotherapist is an expert in diagnosing and treating joint and muscle problems, using a range of exercise and physical treatments. Perhaps more than any other, a physiotherapist can play a key role in helping your child live as active and independent a life as possible.

You can request a referral from your GP to a specialist physiotherapist, who will carry out a full assessment of your child. They will examine your child’s particular movement difficulties, advise on ways to protect their joints, recommend forms of exercise best suited to your child’s individual needs, help set goals and monitor improvement, and provide a great deal of help and reassurance.

They are likely to suggest a programme of daily exercises that can be followed at home and will encourage you to understand these exercises too so that you can help monitor and encourage your child’s progress. Your child is likely to find it difficult to feel motivated, especially when in pain. Reward their efforts, and try to make the exercises as fun as possible, perhaps by joining in, playing motivating music or drawing up a tracker sheet to monitor and reward strength, mobility and stamina.
Diet

It is important to ensure that any child or young person eats a healthy diet. And while there is little conclusive evidence for any direct link between specific foods and flare-ups of arthritis, it is nevertheless important to stick to a well-balanced diet so the body receives the nutrition it needs to function as efficiently as possible.

Children and young people with arthritis can benefit especially from having plenty of calcium, vitamin D and iron-rich foods to assist bone strength and to help prevent anaemia. Doctors will advise you if this is the case for your child, and whether this can be managed through diet or by taking supplements.

Speak to your doctor about whether any particular drugs your child is taking might react with any particular foods or drink. The drug methotrexate, for example, can react with alcohol.

The symptoms both of arthritis itself and of some of the medication taken to treat it may change your child’s appetite and taste in foods. Fatigue or limited mobility can lead to weight gain, as can some drugs (notably steroids). Children who take steroids, for example, often feel hungry, so having a choice of healthy snacks available can help. Sometimes such changes in appetite and taste are unavoidable, but it is worth remembering that additional weight places extra strain on joints and in the longer-term can have a negative impact on self-esteem.

Children and young people might also use food to exercise a sense of control, making their own decisions about what they will or won’t eat. It can therefore become a point of conflict between their wishes and yours. If your child’s eating habits change suddenly or significantly, or if you are concerned about any issue relating to food, speak to your GP, who may be able to refer you to a nutritionist or other specialist for help and advice.
Managing your child’s arthritis

Getting the support you need

After receiving a diagnosis of arthritis, you may feel you must focus wholly on your child’s needs and put yourself last. But if you are to provide the support that your child needs, it is vital that you receive the support that you need too.

You may initially be supported and guided by various healthcare professionals, but in the longer-term you will need to develop a support network, for example involving other family members and friends. The symptoms or effects of arthritis can at first seem ‘invisible’ and you might feel that your child’s needs, and yours, seem to be invisible too, or are overlooked.

Some friends and family members might struggle to understand the impact that a diagnosis of arthritis has on your child and you, they might inadvertently make unhelpful comments, or simply not know how to help. They, like you, need to learn what the diagnosis means, and how they can best support you.

When people say they would like to help, don’t be afraid to tell them what you need – whether it’s a chat, a hug, an offer to accompany you to an appointment, or to arrange some diverting activities for your child.

You may find that chatting with others in a similar situation can be a source of great help and support. Arthritis Care runs a free helpline for young people and their families called ‘The Source’, which you can contact on 0808 808 2000 or email: TheSource@arthritiscare.org.uk (10am–4pm weekdays). We are also one of a number of organisations running social weekends, parents’ groups and online forums.

See pages 44–47 for further information on sources of support.
Keeping positive

1. **Be well-informed** – learning about arthritis and how it may affect your child will help you to feel prepared and more in control.

2. **Focus on what you can change** – you can’t cure your child’s arthritis, but you can lessen its impact, for example by managing their medication and helping them to remain active.

3. **Make goals** and recognise progress towards them – whether it’s taking your child swimming once a week, having an evening out with your partner or a friend once a month, or finding the best-shaped cushion to help your child to sit comfortably.

4. **Enjoy the good days** – difficult days may get you all down, but celebrating improvements, achievements or periods of remission can help lift everyone’s spirits.

5. **Make time for fun and friendships** – it is easy to become preoccupied with day-to-day management and appointments; remember to plan time for breaks and treats.
Making plans

One of the trickiest aspects of living with arthritis is that it is an unpredictable condition. In some ways you may need to plan ahead more in order to accommodate your child’s particular needs, sometimes you may have to cancel plans at the last minute if your child is having a bad day, and you will probably need to find time regularly to attend clinic appointments. It is undeniable that parenting becomes more complex when you have a child with arthritis.

Whatever your child’s form of arthritis, it is wise to try to keep family life as normal as possible by keeping up your family’s interests, activities and friendships. When your child is in pain or discomfort, it is of course natural to want to protect them as much as possible, and to indulge them by giving them their favourite meals, arranging their favourite activities or allowing them to duck out of activities that they may seem reluctant to attend. At times when their symptoms

There will almost certainly be times when you struggle with negative emotions and frustrations or feel overwhelmed by the responsibility of caring for your child with arthritis. This is not at all uncommon. If you feel that negative feelings are starting to interfere with daily life for you, or for any member of your family, there is help available. You can contact Arthritis Care for further information. Your GP should be able to refer you to a counsellor, a psychologist or a child psychologist. Or occupational therapists are a great source of advice on daily living, including home life, leisure, school and careers, as well as aids and equipment that can assist families affected by arthritis. If your child doesn’t have an occupational therapist, speak to your GP or rheumatology team.

It is important that you, your child, and other members of your family and your friends all feel able to discuss all your feelings and concerns, and to be listened to. There is a lot to take in – give yourselves time to adjust to the changes required, take time out as much as you can, and be sure to ask for support.
You may find that you increasingly need to take on the role of carer, perhaps by helping your child to get to the toilet, get washed or dressed, or by giving them lifts to school rather than letting them get the bus. Always try to work with health, care and education professionals to ensure your child gets the treatment and support they need, and ensure your child takes their medication, does their physiotherapy exercises and attends appointments.

Help your child to understand arthritis and to manage their own health, so that they can gradually take on more responsibility for decisions about their treatment and lifestyle as they grow up.

If your spouse or partner is unavailable to attend an appointment with you, ask a friend or other family member to accompany you in order to share the responsibility. If you can, update your spouse or partner on test results or new information. At any time, if you’re feeling left out, or perhaps overburdened by the responsibility of caring for your child, tell your partner, friend or other family member.
Taking time off work

Whether you go out to work, or are self-employed, working from home or part time, you are likely to need to take time off for your child’s appointments or when they are unwell, and some of this time may be unpaid.

Juggling work and caring for your child with arthritis can be a great source of stress, especially in the early days while you are still coming to terms with the changes you are having to make. However, it is generally advisable to avoid making any hasty decisions about giving up work or changing your job. Your child’s arthritis may settle down once their treatment is in place, or may even go into remission. As well as providing financial security, work can be a useful source of support and a distraction from challenges at home.

If you can, explain your situation to your manager and/or human resources team and ask what options might be available to you. You might want to carry on working but be worried that you now have additional demands on your time. Ask about your employer’s policies on parental leave, emergency leave or flexible working, such as varying your hours or working from home sometimes. Your doctor will be able to give you a letter confirming your child’s diagnosis if needed.

You can get advice about your rights from Citizens Advice or your union. The charity Contact a Family also has useful information on its website (www.cafamily.org.uk). All parents have rights at work, and parents of a disabled child have additional rights. Even if you don’t consider your child to be disabled it is worth checking whether they meet the legal definition of disability (see page 26).
Applying for disability assistance

Most children and young people with arthritis don’t consider themselves to be ‘disabled’, but they may meet the legal definition of disability. Under the 2010 Equality Act, which applies in England, Scotland and Wales, disability is ‘a mental or physical impairment that has a substantial and long-term adverse effect on the person’s ability to carry out normal day-to-day activities’. In Northern Ireland, equalities legislation is different (the Disability Discrimination Act applies), but the overall definition is similar.

If your child’s situation meets the legal definition of disability, you and they could be eligible for additional benefits, support, grants, discounts and legal rights in education, at work, and as transport users and consumers. (Many benefits are paid direct to a young person from the age of 16.) Discuss the issue with your doctors – you may need a letter from them stating that your child’s needs are different from those of their peers.

► For further information about disability assistance, and about financial, emotional and practical support, contact Arthritis Care.
Being organised

To help keep on top of the practical challenges of organising the best care for your child, some of the following tips might be useful:

- Keep copies of all correspondence to and from doctors, teachers, benefits agencies, etc., for future reference.

- Make notes of important telephone calls with medical and educational staff, including their name and their department, and request written confirmation of key decisions.

- Keep an up-to-date record of your child’s medication and doses, to help with repeat prescriptions and so that others can supervise medication if necessary.

- Try keeping a diary of your child’s symptoms for a few weeks, noting any changes in moods, energy levels and any side effects from medication, to help you to track how effective treatment is.

- Prepare notes and questions before appointments. Some hospital websites have forms you can print, complete and take to appointments.

- Prepare for flare-ups – keep a stock of things that comfort your child, or prepare and freeze some meals for days when you might not have time to cook.
Emotional responses

Living with arthritis can trigger a whole range of emotions, including those listed below. There is no ‘right’ or ‘normal’ way to react. However you and your family members feel, you are not alone.

A child or young person with arthritis may:

- be frustrated or angry
- want to be normal
- feel isolated from friends, especially if they cannot participate in activities
- be stoical, and seem to handle the situation better than you
- become withdrawn or clingy, because of pain or a lack of confidence
- regress, by acting more childish, babyish or naughty than before
- experience strong and sudden mood swings
- be embarrassed by signs of their arthritis – for example, apparent clumsiness or a limp
- carry on pretty much as before, bar the occasional bad day.

Parents of a child or young person with arthritis may:

- be angry and question why their child has arthritis
- feel guilty and wonder if they could have done anything differently to improve their child’s symptoms
- feel helpless
- be emotionally drained
- experience relationship difficulties, especially if each parent has a very different caring role.

Siblings of a child or young person with arthritis may:

- worry that they will ‘catch’ arthritis
- be frightened that their sibling with arthritis may die (death from arthritis is exceptionally rare)
- be jealous of any extra attention that the child with arthritis receives
- be confused by changes in family routine, or their sibling’s health or behaviour
- be very protective of their sibling with arthritis
- regress, by acting more childish, babyish or naughty than before
- carry on pretty much as before, bar the occasional upset.
‘My other children help Kayleigh with her exercises, and make it fun. They encourage her to go out and walk to strengthen her muscles, otherwise she’d sit on the sofa.’

Michelle, whose 5-year-old daughter has polyarticular JIA.

Supporting your child

How you engage with your child about their diagnosis can greatly affect how positive they are able to be in managing their own condition, their treatment and their day-to-day life. Your child is likely to have all kinds of questions, concerns and fears, even if they might struggle to articulate them.

Having an understanding of any condition is the best way to learn how to deal with it most effectively. Even if your child is very young, try to explain to them what arthritis is, and how a specific treatment is designed to help them. As soon as your child is old enough, introduce proper medical terms so that doctors’ language begins to sound familiar rather than frightening. Be sensitive to what you know they can understand. Always be honest with them about what to expect during medical procedures, but avoid frightening them by going into detail that they might not be able or want to hear. With younger children, in particular, try to focus on what will happen this morning or this afternoon, today or tomorrow, rather than too far in the future. This will help keep things manageable for them.

Try to provide regular opportunities for your child with arthritis, and their siblings, to talk openly about the condition, and listen to how much they understand. Sometimes it’s easier for your child to open up about their thoughts and emotions in a one-on-one situation, perhaps when you’re sharing an activity. Younger children can sometimes be comfortable expressing their emotions through art, creative play or making music, while teenagers may benefit from airing their thoughts and feelings in a diary. Encourage whatever form of expression suits them best.

Younger children may have fears that they think you will find ‘silly’, or older children or teenagers may feel embarrassed talking about their vulnerabilities. By providing opportunities for them to open up, you can encourage them to feel they can talk openly. And by listening and being informed and ready to respond to their concerns, you can nip in the bud any misconceptions or unfounded fears they might have, and provide the explanations and reassurance they need.
**Encouraging independence**

A degree of independence is important for any child, enabling them to explore life’s possibilities with freedom and confidence, and to develop their sense of self worth and forge their individual identity. It can be particularly hard for a child, therefore, to learn that they have a condition that threatens those youthful energy levels or restricts their mobility.

Your child may not be able to pursue a full range of sports or physical activities, and may find formerly simple daily tasks sometimes extremely difficult. But you can encourage them to set and attain new goals, even if they are relatively small tasks. This will give them a sense of achievement and new ways to develop their self belief.

Your child is likely to need a careful balance of activity and rest. You might have to keep a close eye on things for them at first, but as they get older they will start to assess for themselves how much they can manage before needing a break.

Always try to involve your child in discussions and decisions about the treatment and management of their arthritis from a young age. This will help them to feel that they are in charge of their arthritis, instead of the other way round.

Encourage your child to adopt good posture, protect their joints and remain as active as possible, to develop and retain strength, stamina and flexibility. In turn, this may reduce pain. Your child’s physiotherapist or occupational therapist will show them how to use strong muscle groups and joints to reduce the strain on weaker ones, when doing such things as getting up out of a chair or carrying bags. They can also show very young children different ways of moving and explore ways to avoid pain.

Over time, you can help your child to pace themselves to maintain a full and active life while reducing flare-ups and fatigue. Many parents find that they need to push their children to do more, rather than stop them doing lots of things.
Working with teachers

Ensuring that your child’s teachers understand their arthritis and its effects is the first step towards enabling your child to participate as fully as possible in all educational activities. Ask for a meeting to discuss your child’s needs. Providing copies of doctors’ letters that outline your child’s diagnosis and treatment can be a simple and direct way to communicate the exact nature of their condition (note that doctors require your permission before contacting a nursery or school directly). When your child is older or wants more assurance of confidentiality, you could ask their doctor to write a specific letter to their school or college, focusing on information relevant to their educational needs.

Discuss with your child’s teachers what they can expect from your child on good and bad days. For example, fatigue might some days be overwhelming for your child but unnoticeable to others. Children and young people often hide their symptoms to appear ‘normal’ at school, so tell teachers about the signs that show your child is in discomfort so that they can look out for them.

Most teachers are very sympathetic when they know what the problem is, and will be keen to tailor their attention and support to your child’s needs.
Managing absences

Almost all children and young people with arthritis manage well in mainstream education but will need time off from time to time for medical tests and appointments, or because of fatigue or flare-ups. Nurseries, schools and colleges are strict about absences, so it is important to try to schedule tests and appointments so as to limit your child’s time off as much as possible.

Tell teachers if alternative arrangements would help to increase your child’s attendance. The box on the opposite page gives a few ideas. If your child needs time off because of ill health, tell their school or college what the problem is and send copies of doctors’ notes.

During periods of absence, keep in touch with teachers and classmates through visits, calls or emails. Your child may be able to study at home or attend key events such as performances and sports days. This should help them to feel less isolated, and will ease the return to class when they are well enough.
## Challenges at school

<table>
<thead>
<tr>
<th>My child...</th>
<th>Possible solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>has an invisible condition</td>
<td>Talk to staff to explain your child’s condition.</td>
</tr>
<tr>
<td>has difficulty sitting with legs crossed or getting up from the floor</td>
<td>Try sitting on a chair in circle time and assemblies.</td>
</tr>
<tr>
<td>gets tired out during playtime, or stiffens up in cold weather</td>
<td>Enjoy quiet, indoor activities with friends at playtime.</td>
</tr>
<tr>
<td>cannot sit in the same position for long</td>
<td>Take stretch breaks in lessons or exams.</td>
</tr>
<tr>
<td>cannot walk quickly, or finds that being jostled causes pain</td>
<td>Have lessons in the same room or close by, leave early to get to the next lesson, or get a ‘lift pass’.</td>
</tr>
<tr>
<td>struggles to get dressed and undressed</td>
<td>Get extra time or help to change for PE.</td>
</tr>
<tr>
<td>cannot carry heavy things</td>
<td>Have a set of textbooks at home as well as school, or ask a friend to carry their bag or have more than one locker around the school.</td>
</tr>
<tr>
<td>finds school furniture and equipment awkward or uncomfortable</td>
<td>Get specially designed equipment such as an angled desk, cushion, chunky pens or a laptop.</td>
</tr>
<tr>
<td>struggles to manage a full school day</td>
<td>Have a reduced timetable or extra breaks.</td>
</tr>
<tr>
<td>cannot write quickly or for long periods</td>
<td>Get additional time, or a scribe to help write answers, in coursework, tests or exams.</td>
</tr>
<tr>
<td>is moving from primary to secondary school, or from secondary school to</td>
<td>Contact the Disability Officer to arrange pre-transfer visits to identify possible challenges, and send written information about specific needs to new institution before first term.</td>
</tr>
<tr>
<td>college or university</td>
<td></td>
</tr>
</tbody>
</table>
Who’s who

• **School or college nurse** – a specialist nurse employed by your local health authority/trust or your child’s educational institution.

• **Special educational needs co-ordinator (SENCO)** – a teacher in charge of co-ordinating additional support for individual children who require it, including children with arthritis.

• **Family support worker** – a school or local authority/council employee who works with families to resolve practical problems. Sometimes accessed by referral from a social worker.

• **Education welfare officer** – an official who works with schools and families to improve school attendance.
‘School has been great with Rhys. He’s not had to have much time off. His appointments are every six months now, and the community nurse does his blood tests before school.’

Emma, whose 7-year-old son has oligoarticular JIA.

Special educational needs

When your child has genuine reasons for missing school or college (such as unavoidable appointments or severe flare-ups), any meeting with an education welfare officer should be just a formality. Even so, it may be useful to demonstrate that you have done whatever you can to maximise your child’s attendance and to show officials a record of appointments with healthcare professionals.

Arthritis is considered a special educational need because children and young people may need special arrangements to get the most out of their education. Getting an education, health and care plan (EHC) is often the key to getting the right support for your child at school, nursery or college. Talk to the SENCO about how to put this in place for your child. Note that this process can be a lengthy one so it is advisable to get it underway soon after your child’s diagnosis, even if their needs don’t seem great at the outset. Having an EHC plan is a good way to ensure that your child receives ongoing support when they change schools, or progress to higher education.

▶ The box on page 33 gives examples of how to tackle some common problems in school.
Into adulthood

Around one third of children and young people with arthritis will have some form of arthritis in adulthood – depending on the type of arthritis and whether or not it goes into remission.

Teenagers

Having arthritis presents additional challenges to teenagers. Some behaviour that is not uncommon in all teenagers, such as wanting to stay out late or refusing to do what parents say, can cause additional anxieties for parents if their daughter or son has arthritis.

Getting to know others in a similar situation is particularly beneficial for teenagers – to help them feel less isolated, give each other support or exchange information. Arthritis Care has a specific online forum for young people.

For details of this and other resources aimed at young people with arthritis, see pages 46–49.

Young people with arthritis can be acutely aware of any visible signs of their condition, such as swollen joints, a limp, mobility aids or supports. Sometimes arthritis causes reduced or delayed growth, for example, boys going through puberty
may experience only slow growth of facial hair or their voice won’t break until much later, which can be particularly embarrassing for them. Some medication can also affect things such as hair growth or weight gain, but reinforce the positive effects of their medication, and remember that the effects of steroids, for example, usually reverse when the course of treatment finishes.

Do what you can to boost their confidence – encouraging their friendships and participation in social activities, hobbies and clubs is a great way to do this. It is worth reassuring them that every young person feels awkward in some way about how they look. Try to have honest discussions with their doctors about what to expect. If their anxieties about their physical appearance are severe or prolonged, your GP may be able to offer a referral for specialist support, for example to a counsellor or psychotherapist.

Your child may deliberately avoid wearing splints or ‘sensible’ shoes to try look more like their friends. Try to get them to discuss any embarrassment with
their occupational therapist, to work out acceptable compromises. Perhaps supports could be worn at night rather than during the day, or it may be OK to go without orthotics on Saturdays.

All young people value privacy, particularly from their parents. This can be difficult if their arthritis limits their ability to wash, dress or care for themselves. If you can, invite them to tell you what they think might help them to be more independent, for example, installing a downstairs toilet or shower that’s more accessible; fitting a shower or taps with easy-to-use controls; wearing clothes with fabrics and fastenings that make it easier to get dressed and undressed; or wearing a vest and shorts to appointments to avoid having to get undressed. Your child’s occupational therapist can advise you on useful aids and adaptations, many of which may be subsidised by your local council or health authority.

If your teenager is preparing to leave home, get in touch with social services to find out about local support that might be available to assist independent living. If they are planning to enter higher education, encourage them to contact universities before applying, to discuss what support they offer for students with health conditions. Their school or college careers service and SENCO may have useful information and advice.

**Social challenges of having arthritis**

Knowing how to pace themselves is a challenge for people of any age with arthritis, but can be particularly tough for young people because of peer pressure, exams, and the desire to fit in and appear ‘normal’. Your child will need help working out whether using aids, such as splints
Although it’s challenging to juggle school or college, a social life and dealing with arthritis, it is worth encouraging your child to build up work experience through weekend or holiday jobs or work placements as much as possible. This experience will widen their social circle, build their confidence, and broaden their CV. It will also help them to find out what kind of work suits their personality and skills, and what is manageable for them.
Transport

Being able to travel around on their own or with friends is important to young people as it gives them a sense of independence. The painful effects of arthritis can make travelling on public transport exhausting or stressful. Using buses or trains in peak hours is best avoided, as having to wait for long periods can cause stiffness, especially when cold, or being jostled in crowds can be painful. Try to work out compromises – for example, if you’re able to give them a lift, it may enable them to stay out for longer than if they travelled by public transport.

Note that some teenagers who receive benefits because of severely reduced mobility can learn to drive at the age of 16, a year ahead of their peers. This can be a great boost to their confidence and independence. They may also receive help towards the cost of driving lessons.
Managing their own healthcare

Helping your child to gradually take on more responsibility for their own healthcare will help them in the longer-term. As they gradually develop self-awareness and knowledge about arthritis, this will enhance their confidence in working with healthcare professionals. Every young person is different, but by the start of secondary school they should have a fair understanding of their condition and medication. You could start by letting them fill their medication dispenser under your supervision, and gradually progress to taking medication without you around. Encourage them to read clinic letters and keep a list of questions for the doctor, as well as a medication diary from a fairly early age, to help them understand their condition and needs.

By taking increasing responsibility for their medication or physiotherapy exercises they will learn the benefits, and by making the occasional inevitable mistake, they will learn the consequences of not keeping up with their routine. Many young people go through phases of not wanting to comply, but this is part of growing up and asserting their independence. Learning from these experiences will help them to make confident and informed decisions in the future.

‘When Carys has appointments, I let her answer questions. She will still look to me for confirmation but I say: “You tell the doctor how it feels.” Things have come up in those conversations that haven’t come up at home.’

Fiona, whose 12-year-old daughter has oligoarticular JIA.

A pill dispenser like this can be an invaluable aid for remembering what medication needs to be taken when.
**Increasing involvement in appointments**

- Encourage medical staff to talk to your child, rather than you; let your child sit slightly closer to the doctor.

- Ensure that your child understands what is being said. If in doubt, ask doctors to repeat themselves or to explain complex language (even better, encourage your child to say if they don’t understand something).

- Encourage your child to ask their own questions. Some may feel too shy about doing this, so you could perhaps ask questions that they have prepared in advance.

- When they are happy to, get your child into the habit of seeing medical staff alone at the beginning of appointments so they can discuss issues in confidence, and then to invite you in to join them a little later. At this stage, encourage them to summarise the plan of management that they and medical staff have agreed.

- Encourage your child to manage a diary of appointments and to request repeat prescriptions.

- Support older children in contacting the hospital themselves with any queries.
Transition to adult healthcare services

Health professionals may discuss ‘transition’ with you and your child when they are around 13 or 14 years old. This is shorthand for the process of moving from paediatric to adult health services at 16–18 years old. If healthcare professionals don’t initiate this discussion, ask them yourself about this transition and how transferring to adult services will take place.

The process will vary depending on where you live – some regions have specific adolescent healthcare programmes and others switch from paediatric to adult services almost overnight. This transition can be quite a leap, because adult healthcare usually involves seeing different doctors and nurses, often in different hospitals, or the focus might shift from overseeing the general wellbeing of a person to addressing specific health problems.

Confidentiality

Although young people are increasingly responsible for their own healthcare decisions, there is nothing to stop them choosing to still involve you if you are both comfortable with that. It is important to realise that young people have the right to medical confidentiality, irrespective of age. (This is a legal right except where there is risk of serious harm to themselves or another person.)
Anaemia
A lack of iron in the body leading to a reduced number of red blood cells. Supplements may be needed to boost iron levels.

Autoimmune
Describes the process where the body attacks its own cells.

Biologic drugs
May be used if methotrexate does not work by itself. These include anti-TNF drugs such as etanercept (Enbrel) and adalimumab (Humira). The biologic drug tocilizumab (RoActemra) may also be given. The availability of these drugs will vary across the UK.

Disease-modifying anti-rheumatic drugs (DMARDs)
Medication, such as methotrexate (see below), taken as a pill, liquid or injection to stop JIA progressing.

Education, health and care plan (EHC)
A plan of care for children and young people up to the age of 25. (EHCs have replaced Statements of Special Educational Needs.)

Flare-up
A temporary worsening of JIA symptoms, which may last days, weeks or months.

Inflammation
A defence reaction of the body which destroys invading bacteria or viruses.

Juvenile idiopathic arthritis (JIA)
General term to describe several different forms of arthritis in children and young people before their sixteenth birthday.

Methotrexate
A drug commonly used to treat arthritis in children and adults. It is the most effective drug for many people with JIA.
Non-steroidal anti-inflammatory drugs (NSAIDs)
A group of drugs such as ibuprofen and diclofenac that may be used to reduce pain and inflammation associated with JIA. They may be taken in tablet or liquid form.

Orthotics
Orthotic devices are designed to support, relieve or correct problems with movement. Examples include specialist insoles, splints or braces.

Pacing
Managing activity levels to avoid unnecessary pain and fatigue. Pacing is a key technique in managing JIA and other forms of arthritis.

Side effects
Unwanted effects of medicines.

Steroids
Medication taken by mouth, injection or drip to reduce inflammation. Steroidal eye drops are used for children who have uveitis (see below).

Transition
The process of transferring from children’s or adolescents’ healthcare services to adult services. It is a gradual process of planning, preparation and support for young people as they develop the skills and knowledge to manage their own healthcare while coping with key changes in their lives.

Uveitis
An inflammatory eye condition associated with JIA. It is more common with some forms of JIA – such as oligoarticular JIA – than others. Uveitis has no outwardly visible symptoms so regular eye checks are important, and it can be easily treated.
Sources of further help and information

*Here at Arthritis Care we believe there is always something you can do to reduce the impact of arthritis, whether it’s finding out more about the type of arthritis your child has, meeting up with others at a parent group or by encouraging your child to attend one of our social weekends.*

**Talk to us**

The Source is our free helpline for young people and their families. Talking about arthritis, sharing your concerns and how you feel can really help. The Source is run by people with experience of arthritis who are here to listen and help you find answers to your questions. You can call them on 0808 808 2000 or email: TheSource@arthritiscare.org.uk (10am–4pm weekdays)

The Source can:
- help you with any questions you have about arthritis
- be there to listen if you need someone to talk to
- tell you more about the young people’s forum
- tell you about services, courses and support that can help you in your area.

Arthritis Care has services all across the UK for young people and families. Northern Ireland and Scotland have well-established services, including activity weekends, personal-development courses, family events, parent seminars and Facebook pages, and England and Wales are also developing services. Please contact the young people and families’ team in your region for more information about what is available.

**Arthritis Care contact numbers:**
- England Office: 020 7380 6512
- Northern Ireland Office: 028 9078 2940
- Scotland Office: 0141 954 7776
- Wales Office: 029 2044 4155

We’re here with free, up-to-date information about arthritis. You can download leaflets on childhood arthritis including:

- *My Child has Oligoarticular JIA – a guide to the condition and its treatment*
- *My Child has Polyarticular JIA – a guide to the condition and its treatment*
- *My Child has Systemic JIA – a guide to the condition and its treatment*

There is also *Kids with Arthritis – a guide for families* by Carrie Britton PhD (4th edn, 2006), which is available by contacting The Source helpline. A bilingual version in Welsh and English is also available.
Other ways we can help you

We are also one of a number of organisations running social weekends, parents’ groups and an online forum. To find out more contact The Source or go to arthritiscare.org.uk

List of other organisations and websites for families

Children’s Chronic Arthritis Association (CCAA)
Founded in 1985, The Children’s Chronic Arthritis Association is the leading charity run by parents and professionals to provide a support network for children with arthritis and their families.
www.ccaa.org.uk

Arthritis Research UK
Everything we do is driven by knowledge to positively impact on what matters to people with arthritis. Our long-term commitment is to prevent the onset of arthritis, develop a cure for arthritis and transform the lives of those with arthritis.
www.arthritisresearchuk.org

JIA @ National Rheumatoid Arthritis Society (NRAS)
We aim to provide information and support for people affected by juvenile idiopathic arthritis (JIA) and rheumatoid arthritis (RA), their families, friends and carers, as well as health professionals.
www.jia.org.uk

Contact a Family
Contact a Family is a national charity that provides information, advice and support. We bring families together so they can support each other. We campaign to improve their circumstances, and for their right to be included and equal in society.
www.cafamily.org.uk/medical-information/conditions/a/arthritis-(juvenile-idiopathic)/
Making Contact
Being the parent of a disabled child can be very isolating and lead to stresses and strains on individuals within a family. Here you can share your experiences with others and get support too.
www.makingcontact.org

G.R.A.C.E Support
Founded in 1997 by the parents of a child who was diagnosed with juvenile arthritis at only fifteen months old. They decided to create the G.R.A.C.E Support charity to offer information and advice to other people with arthritis and their families.
www.gracecharity.org.uk

Olivia’s Vision
OV was established in 2010 to provide information, support and advice for anyone affected by uveitis.
www.oliviasvision.org

Scotland

Scottish Network for Arthritis in Children
SNAC was set up by parents of kids with JIA to provide support and information for families affected by the condition.
www.snac.uk.com

Uveitis Information Group (Scotland)
A patient-led charity, based in Scotland, run by volunteers who suffer from uveitis. We work closely with medical professionals in the UK and internationally, and with other uveitis patient groups.
www.uveitis.net/uig/index.php

West Midlands

Kids Like Us
A local charity that supports children with arthritis and their families in the West Midlands. Their aim is to raise funds to help those who have JIA, as well as awareness so that children are diagnosed quickly and families find help and support as soon as possible.
www.kidslikeus.info
List of useful organisations and websites for young people

Arthritis Research UK: Centre for adolescent rheumatology
The mission of the Centre is to improve the health and wellbeing of adolescents and young adults with arthritis and other rheumatic diseases through cutting-edge research.
www.centre-for-adolescent-rheumatology.org

JIA @ National Rheumatoid Arthritis Society (NRAS)
We aim to provide information and support for people affected by juvenile idiopathic arthritis (JIA) and rheumatoid arthritis (RA), their families, friends and carers, as well as health professionals.
www.jia.org.uk

Arthur’s Place
At Arthur’s Place you’ll find a mix of life hacks (helpful tips for dealing with everyday life, from relationships to coping at work), facts about arthritis, great videos and apps, and a network of people sharing their stories and helping each other.
www.arthursplace.co.uk

Youth health talks
healthtalk.org provides free, reliable information about health issues, by sharing people’s real-life experiences.
www.healthtalk.org/young-peoples-experiences/arthritis/topics

Arthritis In Young People
Arthritis In Young People (AIYP) was created by someone with arthritis. Thinking the awareness of arthritis in younger people was lower than it should be and feeling alone, Arthritis In Young People was born.
www.arthritisinyoungpeople.com

Psoriasis Association
A UK charity, dedicated to raising awareness of psoriasis and supporting those with it.
www.psoteen.org.uk
We hope this booklet has been useful to you. It’s just one of our many publications that are free to anyone who is affected by arthritis. Every year over 1000 people under 16 will develop inflammatory arthritis in the UK. The challenges of living with arthritis are too often overlooked and underestimated. We’re here to change that. Now more than ever we need people like you to lend their time, experience and voice to help others.

Help us improve our information

We know that the people who use our information are the real experts. That’s why we involve them in our work. If you are a parent of a child who has arthritis you can help us improve our information.

You can comment on a variety of information, including booklets and factsheets. If you’d like to know more about becoming a reviewer, email reviewing@arthritiscare.org.uk You can get involved from home whenever you like. You don’t need any special skills, just an interest in our information.

Share your experience

Would you be willing to share your story, to help others to manage the challenges of being a parent of a child with arthritis? Contact The Source to speak to someone about getting your story online or in the media.
Can you do something to help?

The challenges of living with arthritis are too often overlooked and underestimated. We’re here to change that. But we can only do this with your help. Please help make sure we are there for every child who needs us by making a donation today.

To make a donation all you need to do is visit arthritiscare.org.uk/donate or call us on 020 7380 6540

Thank you
We believe there is always something you can do to reduce the impact of arthritis. The Source is our free helpline for young people and their families. Talking about arthritis, sharing your concerns and how you feel, can really help.

There are free publications that you can find on our website or order by post. Or you may prefer to visit our online community where you can chat to others about the things that matter to you.

To find out more about Arthritis Care call our free helpline dedicated to young people and their families.

The Source: 0808 808 2000
(open weekdays 10am–4pm)

TheSource@arthritiscare.org.uk