



# **chat** 2 teachers

children have arthritis too

## A teacher's guide to juvenile arthritis

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**This booklet is produced by the Chat Alliance: Arthritis Care, the Children's Chronic Arthritis Association and the Lady Hoare Trust.**

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**Cover models:**  
Chris Loft and the pupils  
of Streatham Wells  
School, London

# Introduction

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What is juvenile arthritis? How might it affect a pupil? What does it mean on a day-to-day basis? How can a teacher make sure a pupil with arthritis gets the right support and enjoys a fair and equal education while they are at school?

If you are a teacher and already asking questions like these about a pupil who has arthritis, this is the right place to start.

Arthritis is a physical disability which causes pain and affects people's mobility. Most children with arthritis can and do attend local mainstream schools. Apart from the varying physical limitations brought about by their arthritis, they are usually able to enjoy and participate in all aspects of school life – and should be encouraged to do so. Children with arthritis usually turn out to be high achievers, and many often to do better academically at school than peers who don't have arthritis.

The symptoms of arthritis are not always visible. Most of the physical symptoms of juvenile arthritis can be treated with medication and other therapies. However, teachers need to be aware that the effects of the disease can vary greatly throughout the course of a school week, or even over the period of a day. By understanding the implications of arthritis, you will be able to help that child be confident, live school life to the maximum and develop the skills and confidence to equip them for life.

Teachers will benefit from developing a solid understanding of their pupil's individual needs and abilities. We hope the information contained in this guide will help you do just that.



# What is juvenile arthritis?

*'I didn't realise that my daughter's arthritis qualified her as having special needs. It wasn't until a teacher friend from another school pointed out that she qualified that we were able to take a major step forward. The school were then able to provide all the equipment she needed.'*

Juvenile arthritis, known medically as juvenile idiopathic arthritis or JIA, affects around one in 1,000 children of school age in the UK. There are many different types of juvenile arthritis. The main ones are listed on page 5.

Arthritis can be physically disabling, making a person's joints swollen, inflamed, stiff and painful. The joints may also appear to be larger or slightly misshapen. This is most likely to be most visible in the feet, knees and hands.

While some children will show these obvious signs of having arthritis, it may not always be possible to recognise arthritis by a pupil's physical appearance alone. Some children may go to great efforts in order to disguise any tell-tale signs, while others may not demonstrate any outwardly noticeable symptoms.

Whatever type of arthritis your pupil has, there may be times when they can enjoy school without any obvious difficulty or discomfort. However, arthritis is a variable disease and it can change rapidly throughout the course of a single day. It is also very painful. A teacher may need to learn to look for other signals to tell them

their pupil isn't feeling well. Walking more slowly than usual, being more inclined to be withdrawn or moody, looking miserable and being off food – all these signs, and many more, can show a teacher that their pupil is having a particularly bad day.

Some types of arthritis go into remission after a period of time, but others persist well into adulthood. When arthritis is left untreated, or when it is particularly severe, it can result in permanent joint damage. Even in a child of school age, arthritis can be significantly disabling. However, these cases are becoming less common due to advances in medical treatment.

The various symptoms of arthritis can be different in a very young child at primary school and a teenager at secondary. In addition, the issues and situations which can arise due to arthritis can be many and varied. A teacher's ability to understand each child's situation, combined with open communication with both the child and their parents, will be invaluable for school success.



# At-a-glance guide to juvenile arthritis

Just like everyone is an individual, every case of juvenile arthritis is different. There are many different types of the disease, and each has its own symptoms and methods of treatment. Please refer to this chart to learn more about the most common types of juvenile arthritis and to gain a better understanding of your pupil's condition.

Type	Explanation	Areas affected and symptoms	Treatment
<b>Oligo-articular JIA (including mono-articular JIA)</b>	Oligo-articular JIA is the most common type of juvenile arthritis. It affects four or fewer joints in the body, whereas mono-articular JIA affects only one. Young girls under five are most likely to develop oligo-articular JIA.	Large joints such as the knee, ankle or wrist are usually affected. The joints may be swollen and painful. Children may develop a limp or have trouble using an arm.	Corticosteroid injections into the affected joints and/or oral non-steroidal anti-inflammatory drugs (NSAIDs). A physiotherapy programme should be maintained.
<b>Polyarticular JIA (rheumatoid factor negative and rheumatoid factor positive polyarticular JIA)</b>  <b>Note: RhF stands for rheumatoid factor</b>	RhF negative and RhF positive polyarticular JIA can affect any joint in the body, and may result in related pain, swelling and stiffness. These types of juvenile arthritis can start at any age, and girls are more prone to developing it than boys. Both forms usually affect more than four joints in the first six months of juvenile arthritis being diagnosed.	Children may experience difficulties writing and using the hands. For example, carrying and lifting objects, as well as walking. They may also find it hard to join in many PE activities.	Steroids and NSAIDs treat joint pain and stiffness. Often additional drugs, known as second-line agents, may be used to help prevent joint damage. A physiotherapy programme should be maintained.
<b>Systemic onset arthritis (also known as systemic arthritis)</b>	Systemic arthritis may affect young boys or girls of any age, and affects both the joints and the internal organs. It begins with fever, rashes, poor appetite, lethargy and enlarged glands as well as swollen joints. This is the most difficult type of childhood arthritis to diagnose and children may be ill for some time before doctors make a definite diagnosis.	Young children with systemic arthritis may be generally miserable, irritable and off their food. Also, they are very often tired. Problems with the joints may appear in later life. Since systemic arthritis is difficult to detect, children are usually admitted to hospital for tests and treatment.	High-dose NSAIDs can control fevers. Often oral or intravenous corticosteroids may help control the disease. Additional drugs, known as second-line agents, will usually be required. A physiotherapy programme should be maintained.
<b>Enthesitis-related JIA</b>	Enthesitis-related arthritis usually affects boys over eight, but can occur in girls and in younger children as well. As well as arthritis in several joints, there is usually swelling at the point where the tendons are attached to the bones (called enthesitis).	This is often a very painful type of arthritis. It mainly affects the lower limbs, the hips, knees, ankles and sacroiliac joints (where the base of the spine joins the pelvis). Some people go on to develop ankylosing spondylitis.	Treatment is usually with NSAIDs and steroid injections into the affected joints. Additional drugs, known as second-line agents, may also be required. A physiotherapy programme should be maintained.
<b>Psoriatic JIA</b>	Psoriasis is a scaly skin rash which sometimes appears with childhood arthritis. Usually it affects the extensor surfaces of the knees and elbows. Signs of psoriasis can manifest in the fingernails and toenails. The arthritis associated with psoriasis can start before a child has ever had psoriasis of the skin.	This type of arthritis may only affect the fingers and toes, but it may affect other joints too.	Treatment and prognosis depend on which joints are affected. A physiotherapy programme should be maintained.

# Arthritis and school legislation

*'We were very fortunate to have had such a sympathetic and supportive headmaster. He went out of his way to provide as much help as possible to help our daughter in school. He had the foresight to get our daughter started on the statementing process while she was at middle school. He foresaw the difficulties, if she wasn't statemented, in moving on into secondary school. It was an incredibly difficult process and took a whole year to sort out. The entire statementing process seems to be aimed at people with learning difficulties. Trying to get someone statemented who has a purely physical disability was really difficult.'*

## Knowing what is expected

Arthritis qualifies as a special educational need (SEN), and pupils with arthritis may be classed as having SEN because of their physical disability. As a result, they are protected legally to ensure that their school meets their needs, and provides them with adequate learning tasks and support to enable them to learn effectively.

All mainstream schools are obliged by law to appoint a designated special educational needs co-ordinator or SENCO.

This person is responsible for making sure the school's SEN policy is put in practice, as well as communicating with the child's parents and other related staff.

## The law

The Disability Discrimination Act (DDA) was passed in 1995 to end the discrimination that many people face. Schools across England, Scotland and Wales are now required to abide by the Act, and may not discriminate against disabled pupils under it. Scotland also abides by the Additional Support for Learning Act 2004, and in Northern Ireland, separate secondary legislation and Codes of Practice are also required (set out in its Schedule 8). From 1 October 2004, the DDA requires schools in England, Scotland and Wales to provide suitable access to their facilities. There may be a need to make permanent physical adjustments to the school in order to meet the requirements set by the DDA.

## Statementing

Depending on the severity of a child's arthritis, they may require a statement of special educational needs (SEN) if they live in the UK. Scotland also has a similar procedure called a Record of Needs. These processes enable schools to receive government funding to provide the child with specialist equipment and support.

Statementing can be a positive step for a child with arthritis. The funding can be used where it is most needed, and could include provision for a learning support assistant

(LSA) who can support the pupil in class and around the school; it may pay for a laptop computer which the child can use in class and for homework; or it may enable suitable transport to and from school for the pupil. However, statementing can be a complicated process, and it can take families many months of paperwork and consultation to complete.

Some parents may not initially know that their child qualifies as SEN. But without setting the statementing process in motion, their child may not receive the extra support at school they are entitled to.

You can help. Teachers play a key role in getting statements implemented and are one of the few groups of people who can make the initial request for a statement. The child is then assessed through their local education authority (LEA) and decisions made as to their specific needs and requirements. It is vital that you make a point to discuss statementing with parents of a child with arthritis at an early stage. Together you can make sure the right action is taken to meet the pupil's needs.

## IEPs

Any child who has a statement of special needs will also have an individual education plan (IEP). This is a vital document which enables adults and teachers working with the child to focus on the child's learning activities. An IEP is a comprehensive, flexible written plan that details the pupil's specific needs. It is drawn up by the school's teaching staff and needs to be reviewed on an annual basis.

The IEP sets long and short-term objectives which the child needs to work towards. It details next-steps and how they are to be achieved; dates for when the plan is next to be reviewed; the specific nature of the pupil's barriers to learning; help from parents; medical requirements; and monitoring and assessment arrangements.

Your school's SENCO must make sure that appropriate IEPs are in place for those children who need them.

# School life for children with arthritis

All young people with arthritis have a right to enjoy all aspects of school life, and be included in activities and learning experiences on a par with their classmates. However, certain tasks and school routines may be harder to manage for a child with arthritis. An understanding teacher can help ensure they aren't struggling or excluded because of their physical condition.

There are many different aspects of school life which pose challenges to a youngster with arthritis. Here are some of the more common problems faced by a youngster with arthritis at school.

## Getting around

Arthritis tends to make joints stiff, especially first thing in the morning, and mobility can be limited as a result.

A child with arthritis will need plenty of time to get up and get mobile, and may need to do a physiotherapy stretching/exercise routine before even being able to get out of the house. Keeping up a programme of exercise is especially important in order to maintain mobility and fitness levels.

Many youngsters with arthritis will need a lift to school rather than taking public transport or the school bus to avoid

walking far, standing in queues, waiting in the cold or being pushed and shoved.

Teachers will also need to allow a child with arthritis more time to get from class to class, and possibly allow them to leave a few minutes before the end of the lesson so they can avoid the rush and get to their next lesson on time.

In addition, a child with arthritis will often feel tired or fatigued. Teachers should be aware that this is part of the disease – not necessarily because of a late night.

## Access and barriers

Getting up and down stairs with stiff, painful joints can be tricky. Couple this with carrying a heavy bag and trying to stay on two feet when the rest of the class is rushing past to get to the next lesson, and it can be a recipe for disaster.

Poor access can make school seem like an assault course. Lack of ramps and/or lifts, inaccessible toilet facilities and awkward doors can make it hard for wheelchair users and other ambulant people with mobility problems to get around.

If your pupil is unable to negotiate stairs, you may want to see if you can arrange for classes to be moved to a ground floor room in order to make access possible. You

*'The teachers used to allow our daughter to leave class a few minutes early, but the end of the lesson was when the homework was given out. It would have been helpful if they could have thought about this so she didn't miss out on work.'*



*'Communication is the key word. At the end of the day both the school and the parents want to help the child achieve. The main emphasis must come down initially to the parents to communicate with the school, but it's very much a learning process for both school and the parents. Everybody needs to work together for the benefit of the child.'*

may also wish to allow the pupil extra time to get around the school.

If your pupil is a wheelchair user, or has more severe mobility problems, they may need to use a lift to negotiate different levels. However, during a fire or a fire-drill, lifts are usually non-operational. It is against the law to carry a person up or down the stairs for health and safety reasons. Try to excuse the pupil from fire drills unless it is essential, and make sure you have a practical action plan in place should there be a real emergency.

### **Breaktimes**

Children with arthritis need to play and be part of the group as much as any others. However, standing around in a cold (or hot) playground can be uncomfortable and painful, and may do more harm than good. Teachers may wish to give their pupil the option of spending breaktimes in the library or classroom. Try to ensure, however, that they are not singled out as being loners.

Interaction is important for a child's social and emotional development, and you should encourage them to socialise whenever possible. Let their friends stay with them if they like. Joining in and being part of the crowd is an important part of

childhood, so only encourage them to branch off when they really need to.

### **Hospital schools and absence**

Missing out on school can be especially hard for a child with arthritis, as the general fatigue they experience can make catching-up so much more difficult.

Some LEAs may provide funding for tuition in hospitals, or at home if a child is too sick to physically attend their school. This may be an option for some children with more severe types of arthritis.

Although unlikely, if home tuition is necessary while a child is at secondary school, subject teachers must liaise with the parents and child to ensure the child is keeping up with their peers. It is important to stretch the child mentally, while also taking into account any bad days.

Reasons for absence may vary depending on the child's type of disease. Some children may need to go to hospital to have medical treatment or to have drugs administered. They may also require periods away from school for physiotherapy and/or occupational therapy.

Although rare in youngsters, some children may even need time off school for surgery in order to relieve pain and

### **TEACHER'S TIPS**

#### **Coping with absences**

- Stay in touch with the parents and keep a tab on the child's progress.
- Try to encourage your pupil to complete as much missed work as they can.
- Encourage other classmates to stay in touch too – a get-well card or a caring phone call can mean a lot.
- Find a classmate to pass on news about homework and lessons – and gossip.
- Forward homework and notes to the pupil while they are at home if they are well enough.
- Keep a check on what the child is missing, and photocopy notes taken in class to help them catch up when they feel better.





*'It's very difficult for parents because they have their child's best interests at heart, and while teachers attempt to have children's best interests at heart, they can't attempt to be experts on everything. Unless parents have got a very good relationship with their child's school, it's very difficult to be proactive.'*

improve mobility. The most common forms of surgery for arthritis are joint replacements (usually for the knees and/or hips), and other forms of operations which release the tension in muscles and tendons around the joints.

Should your pupil need to miss school for any reason, it is important that you maintain contact with the family and help the pupil catch up on missed work if they are well enough.

You should also recognise that children can find it hard to get back into the swing of things after absences as they may feel left out and different.

However mildly a pupil is affected by their arthritis, there are bound to be times when their arthritis causes them to miss school – even if it's for a check up, a blood test or physiotherapy.

## Medication

Taking various arrays of medication is all part and parcel of having arthritis. Although there is no known cure for the disease, prescribed medication can be effective in treating the symptoms and relieving the pain caused by it. Most medication needs to be taken several times a day at specific

times, and often with food.

However, there are a various issues surrounding medication for a young child. Your pupil may not want to be seen to be taking their medication in public and may appreciate a quiet place they can go to do so.

Speak to them and their parents to find out exactly what is required, as well as to discuss the implications of any side effects the treatment may bring on. In addition clearly outline, to both pupil and parents, the importance of being kept informed of any changes to the child's medication programme.

## Exercise and PE

Every child has the right to a good physical education, and children with arthritis will benefit in many ways from participating in exercise inclusively.

Taking part in team games is particularly important for developing comradeship and leadership skills, as well as being a great way to let off steam. However, a child's arthritis may prevent them from participating fully in games or PE. This may be because they find it too painful or it may be difficult because of reduced mobility or

***'Statementing gave our daughter access to a care assistant, who helped her get around physically. It made a huge difference. If she missed school, the care assistant helped her catch up with any work. When she made the transfer to secondary school, the care assistant's role merged into a that of a teaching assistant. She gave our daughter more independence and became a very good contact for us as parents, our child, and the school.'***

***'My pupil needs more energy to do simple tasks and is often exhausted by the end of the day. This can make participating in after-school activities and doing homework especially difficult. Arthritis is accumulative, and I find that she is often more tired by the end of the week.'***

it may be bad for their joints.

PE teachers may choose to use parallel activities – those with one strategy for including everyone, whatever their abilities – to ensure that the child is included in games. These lesson structures are invaluable for ensuring each pupil can accomplish tasks on a par with classmates.

Certain physical activities can be adapted in order to avoid over-straining the child's joints. Impact sports such as football and running may not be suitable for a child with arthritis, but shouldn't automatically be ruled out before you have consulted the child's parents (following medical advice).

Swimming is usually a safe bet for most children with arthritis – providing the pool and changing rooms are warm enough to prevent the child getting cold. Hydrotherapy in warm water is often used as part of physiotherapy treatment for arthritis, and can be an effective way to exercise comfortably while the joints are supported in the pool. However, teachers should ensure that the child is kept warm at all times, and has adequate support in getting in and out of the pool, showering,

drying and changing.

Getting dressed, knotting ties and pulling on tights or socks can be painful, time-consuming and downright awkward for a child with sore fingers. If this has to be done in public, it can also be humiliating. Make allowances for the child as you see fit and ask how you can help.

Whatever the sport, teachers should always take advice on the child's situation and abilities with parents, doctors and other healthcare professionals in order to make PE lessons as effective and beneficial as possible. Communicating with the child regularly will enable you to know the child's limits and recognise if they are not feeling well enough to continue the exercise.

You can find more information on PE for disabled children on a CD-ROM published by the DfES called *Success for All – an Inclusive Approach to PE and School Sport* (see Page 13 for contact details).

### **Physiotherapy**

A child's strength and stamina can be affected by juvenile arthritis. Physiotherapy can help develop both of these characteristics, which, in turn, can enable



the child to achieve better results in school activities. In addition, general flexibility and range of movement can be improved by regular physiotherapy sessions.

The child will have been shown how to do their exercises by a qualified physiotherapist and may need to carry out a range of recommended exercises, combined with periods of rest, while they are at school. Try to ensure that these periods are not spent in isolation; a friend to accompany the child can be a great help and can stop the child feeling alone.

If the child is becoming more tired and sore by the end of the day, it may be due to them having poor strength. In such cases the physiotherapy programme may need to be increased.

Teachers should discuss what is required in detail with the parents and relevant healthcare professionals. You should also make a point of being kept informed of the child's physiotherapy routine.

### **Aids to daily living**

Occupational therapy helps teach a child to accomplish a range of daily tasks, like washing and dressing, independently. A child with arthritis will be assessed by an occupational therapist (OT), and appropriate recommendations will be made. Although it is not a teacher's responsibility to provide adaptations, you should make sure you speak to the child to fully understand his or her requirements.

Occupational therapists can help provide all sorts of practical assistance for children with physical disabilities. The main aim is to enable the child to do things on their own – a vital part of their psychological education.

Some children with arthritis may need to use adapted pens, pencils, paintbrushes and scissors which are easier to grip. Others may benefit from using a laptop computer so they can do their work at home or in the library. Desks may be adapted. Tools may be provided to turn on taps and open lunchboxes, and so on.

In some cases, children with arthritis may need to use mobility aids, like crutches or splints. Wrist and leg splints can offer support to tired joints, as well as help straighten out the limbs and improve movement range.

However, some youngsters may feel embarrassed to use such equipment, or wear their splints in public for fear of standing out from the crowd. The same applies to any noticeable special treatment by the teacher, or obvious segregation from the rest of the class. Youngsters are especially vulnerable to peer pressure, and teachers must stay sharp to any issues or concerns the child and his or her parents have.

Taking the opportunity to discuss any problems or concerns with the child and the parents at the earliest opportunity can help ensure the child is correctly supported and encouraged throughout those more difficult times.

### **Exams**

Sitting for hours at a time and writing for long periods can be extremely difficult if you have arthritis. However, examination boards are very approachable when there is a genuine problem. Providing the application is supported by a consultant or doctor's letter, and made well in advance, allowances and adaptations can be made accordingly.

Pupils with arthritis may be allowed to use a computer to type up their answers, or be allowed extra time which includes periods of rest. Some boards will allow the pupil to dictate their exam answers – but this may only be in more severe cases and will require much practice by the pupil and their scribe in order to feel comfortable with the approach.

Teachers should discuss exams with the pupil and their parents to make sure any necessary allowances can be made in plenty of time.



# Teachers and parents

*'You can hand a teacher as many bits of paper as you like, but you have to remember how many other bits of paper they get given. Meeting them face-to-face highlights the situation, and makes it personal.'*

*'Parents need to take responsibility and get involved. Those that don't may find their child gets left behind.'*

*'Many teachers are parents themselves. As parents, their child's health is of paramount importance and, therefore, schools often aren't very pushy on children who aren't well. Teachers need guidance from parents as to how much they might expect from the child over the course of the day.'*

## Working with parents

Most parents enjoy being pro-active with their school and their child's teachers. Having an open communication channel between all parties creates a free flow of information and a real understanding of all the issues which affect a child with arthritis and their family. Effective communication ultimately allows the child to be treated appropriately at school by teachers, other members of staff and classmates alike.

However, although many assertive parents are keen and able to be actively involved, others may find it less straightforward, and may benefit from a teacher's support and understanding.

For some parents, school can seem like a daunting, complicated place. A teacher who can help such parents understand the rules, procedures and structures will unlock the mystery and help them feel more confident about approaching and communicating with the school when they need to.

Some parents may not know who to speak to, or not want to appear to be making a fuss. They may still be dealing with the shock of finding out their child's diagnosis, or struggling to cope with the additional pressures and responsibilities resulting from their child's arthritis.

It is vital that you encourage parents to speak up about the issues that affect them and their child. This is the only way you and other school personnel can develop a solid understanding of the child's needs and abilities, and offer the right support.

Make sure the parents know who they can contact at school, and how and when they can do so. Gaining the trust of the child, from both teacher's and parent's perspective, is key, and will help the child feel valued and respected as an individual. Careful judgement may be necessary at times if the delicate balance between you, the parent and child is to be maintained.

The best teachers don't penalise the child for their impairment. Instead, they take the time and effort to learn as much as possible about their pupil's condition, and

how it affects aspects of their life. It is only then that they can properly identify with the parental concerns, and build up a caring relationship with all concerned.

### **TEACHER'S TIP** **How arthritis affects your pupil**

As a starting point, try using the chart on page 15 to help you build up a deeper level of understanding between you and your pupil.

# Useful contacts

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## ■ Arthritis organisations

### Arthritis Care

Switchboard: 020 7380 6500

(Helpline Mon-Fri 12pm-4pm)

Tel: 0808 800 4050

Helplines@arthritiscare.org.uk

(The Source helpline for young people under 26, Mon-Fri 10am-2pm)

Tel: 0808 808 2000

TheSource@arthritiscare.org.uk

www.arthritiscare.org.uk

### arc (Arthritis Research Campaign)

Tel: 0870 850 5000

www.arc.org.uk

### Children's Chronic Arthritis Association

Tel: 01905 745595

www.ccaa.org.uk

### Choices – for families of children with arthritis

www.kidswitharthritis.org

### The Lady Hoare Trust for physically disabled children

Tel: 020 7820 9989

www.ladyhoaretrust.org.uk

## ■ Educational organisations

### Advisory Centre for Education (ACE)

Tel: 020 7354 8318 (Mon-Fri 2pm-5pm)

www.ace-ed.org.uk

### Connexions Direct

Tel: 0808 001 3219 (main helpline)

Text: 07766 413219

www.connexions.gov.uk

### Council for Disabled Children

Tel: 020 7843 6000

www.ncb.org.uk

### Department for Education, Northern Ireland

Tel: 028 9127 9279

www.deni.gov.uk

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

Tel: 0870 000 2288

www.dfes.gov.uk

### Enquire

(a national advice service on SEN)

Tel: 0845 123 2303

www.childrenscotland.org.uk/enquire

### National Association for Special Educational Needs

Tel: 01827 311500 (UK)

www.nasen.org.uk

### The Scottish Executive Education Department (SEED)

Tel: 0131 244 2544

www.scotland.gov.uk

### SKILL – National Bureau for Students with Disabilities

Tel: 0800 328 5050 (UK)

www.skill.org.uk



# Understanding the effects of arthritis

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*Please fill out these pages for each pupil you teach who has arthritis. The forms have been designed to be photocopied – please feel free to do so as often as you require.*

*The form opposite is meant for you to complete with your pupil. It is designed to help you increase your understanding of the disease and the aspects of school life that affect your pupil.*

**Pupil's name:** \_\_\_\_\_

**School:** \_\_\_\_\_

**Class/Year:** \_\_\_\_\_

**Type of arthritis:** \_\_\_\_\_

**Date last updated:** \_\_\_\_\_

**Date for next review:** \_\_\_\_\_



children have arthritis too

<b>NAME</b> _____				<b>TEACHER'S NOTES</b>
<b>Issue</b>	<b>Always</b>	<b>Sometimes</b>	<b>Never</b>	
It takes me a long time to get up and dressed in the mornings				
I need a lift to school as it is awkward for me to use other forms of transport				
It is hard for me to get up and down steps and stairs				
I need to be excused from fire drills				
Sitting on the floor (eg, during assembly) is painful				
I cannot get up very quickly				
I need help taking off my coat/boots/hat				
I need help getting changed for PE				
I need to rest and lie down if I get tired				
It helps if I can leave class early to avoid the rush				
I need someone to help me catch up on things if I've been off school				
I am unable to stand in line for a long time				
It is important that I keep warm				
My joints are painful and it hurts if people bump into me				
I need to wear splints or use mobility aids at school				
I need to take medication at school				
I need to be reminded to take my medication				
I need help taking my medication				
My medication can make me feel drowsy/sick				
I need time to do physiotherapy exercises at school				
I can't write quickly enough in class and need extra time to complete certain tasks				
I need to rest when I get home				
I need help writing up my homework				
I need help turning taps and handles (eg, doors, toilets)				
I find it awkward to write on the blackboard				
I find it hard to use a pen, pencil and paintbrush				
Raising my hand in class is difficult				
It is difficult to carry things (eg, lunchtrays, school books, bags)				
Because I get stiff, I need to get up and walk around during class				
I need more time to get from class to class				



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

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

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

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

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



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

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

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

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

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

THE LADY HOARE  
**trust**

for physically disabled children

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

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

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

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

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

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

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

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