

Juvenile Arthritis: A Teacher's Guide



**How you can help your
student succeed**



**Arthritis
Foundation**SM

Understanding Juvenile Arthritis

If you're surprised that arthritis affects children, you're not alone. Most people think arthritis is a disease associated with old age. However, an estimated 300,000 children and teenagers in the U.S. have arthritis or a related condition. When one of your students has arthritis, it's important for you to know about the disease and how it affects your student. The severity of the disease and its impact are different for each child; however, many children will need some help at school, whether it's allowing extra time to take tests or changing classes, providing an extra set of books to keep at home or helping with missed assignments.

This brochure will provide you with general information about juvenile arthritis and advice on how you can help your student with arthritis. It will also briefly touch on educational rights and provide specific examples of challenges you and your student may encounter, as well as a summary of how you can help.

What Is Juvenile Arthritis?

Arthritis is a term that refers to inflammation of the joint. There are more than 100 diseases and conditions that affect the joints and the tissues surrounding the joints, such as muscles and tendons.

Juvenile arthritis (JA) is not a disease in itself. Also known as pediatric rheumatic disease, JA is an umbrella term used to describe the autoimmune and inflammatory conditions that can develop in children ages 16 and younger.

Although the various types of juvenile arthritis share many common symptoms, such as pain, joint swelling, redness and warmth, each type of

Arthritis Facts

- Nearly 53 million Americans have doctor-diagnosed arthritis.
- Two-thirds of people with arthritis are under the age of 65.
- Nearly 300,000 children have arthritis or a related disease. That's 1 in 250 kids.
- Arthritis accounts for nearly \$156 billion in lost wages and medical expenses each year.
- Children with arthritis make an estimated 621,000 visits to health care professionals each year.

JA is distinct and has its own special concerns and symptoms. The most common type of juvenile arthritis is juvenile idiopathic arthritis (JIA). JIA has also been referred to as juvenile rheumatoid arthritis. However, juvenile idiopathic arthritis is the term most preferred globally by medical professionals.

The major symptoms for most forms of arthritis are pain, fatigue and stiffness and swelling in one or more joints. Some types of juvenile arthritis can interfere with growth. In addition, some can affect other parts of the body as well, including the skin, eyes and internal organs.

Types of Juvenile Arthritis

Juvenile idiopathic arthritis (JIA). Considered the most common form of arthritis, JIA includes six subtypes: oligoarthritis, polyarthritis, systemic, enthesitis-related, juvenile psoriatic arthritis or undifferentiated arthritis.

Juvenile dermatomyositis. An inflammatory disease, juvenile dermatomyositis causes muscle weakness and a skin rash on the eyelids and knuckles.

Juvenile lupus. Lupus is an autoimmune disease. The most common form is systemic lupus erythematosus, or SLE. Lupus can affect the joints, skin, kidneys, blood and other areas of the body.

Juvenile scleroderma. Scleroderma, which literally means “hard skin,” describes a group of conditions that causes the skin to tighten and harden.

Kawasaki disease. This disease causes blood-vessel inflammation that can lead to heart complications.

Mixed connective tissue disease. This disease may include features of arthritis, lupus dermatomyositis and scleroderma, and is associated with very high levels of a particular antinuclear antibody called anti-RNP.

Fibromyalgia. This chronic pain syndrome is an arthritis-related condition, which can cause stiffness and aching, along with fatigue, disrupted sleep and other symptoms. More common in girls, fibromyalgia is seldom diagnosed before puberty.

The Impact of Juvenile Arthritis

The primary effect of arthritis on daily life is pain. Children experiencing pain can become fatigued and distracted. They may limp or otherwise change how they move in order to limit or avoid the pain of stiff joints.

Often one of the hardest things to understand about arthritis is its unpredictable nature. Children with arthritis have good days and bad days. A child who is able to run and play one day may find it hard to carry a lunch tray, walk to the restroom or even raise her hand in class the next day. Sitting still for long periods of time may make symptoms worse.

Bad periods of arthritis are called flares. Children who are having a flare of their arthritis or a related



Visit www.KidsGetArthritisToo.org to learn more about juvenile arthritis and related diseases.



condition may be irritable and listless and may lose their appetite. They also may have extreme fatigue, which can lead to inactivity or difficulty performing everyday tasks.

Alternately, some children may experience a period of remission which means that their arthritis is not showing any symptoms or appears to be gone.

Hidden Symptoms

Unless arthritis has caused joint damage and deformity, its effects can be invisible. Your student may show few outward signs of the disease.

Whether you see evidence of the disease or not, it's important to understand that your student's pain is genuine and the limitations are real.

Students with arthritis may not complain, so be alert for clues that they're in pain, such as a stiff walk or fatigue. Your only clue may be observing difficulty completing certain tasks. On "bad" days, your student may be slower, uncoordinated, irritable and barely able to walk or raise his or her hand. The student may avoid participating in class activities and feel isolated from classmates.

Many children with arthritis may try to ignore or hide their stiffness and pain because they want to be like their classmates. Children with arthritis should be allowed to adjust their level of activity, but you can help by watching for warning signs. You can also ask your student to let you know

when she's having a bad day and if there's anything you can do to help her on difficult days.

While arthritis often affects a student's physical abilities, it's important to remember that children with arthritis are just like other students in your class. Having arthritis does not exclude them from having other learning needs or challenges such as learning disabilities or behavioral problems, just like any other student.

How Do Doctors Treat Juvenile Arthritis?

Treating juvenile arthritis often involves different types of medications that suppress and control joint inflammation and pain. Thanks to medical advances in treating arthritis, some children with arthritis may not have to take many, if any, medications during the school day. While this is possible, you should be aware that medications used to treat arthritis in children could have side effects that influence the way your student feels or performs at school.

Medications used to treat types of juvenile arthritis include nonsteroidal anti-inflammatory drugs (NSAIDs), corticosteroids, disease-modifying antirheumatic drugs (DMARDs) and biologics. These medications may be taken orally or by injections. Some may be administered through an infusion, which is done in a doctor's office or hospital. Infusions may take several hours, often resulting in absences from school.

NSAIDs are commonly prescribed for children with arthritis to reduce inflammation and control pain. They are often taken at higher doses than those used to treat a headache or a fever. At these doses, children may experience stomach-related problems, such as heartburn, gas or bloating or nausea. It's important that they are taken at mealtimes or with a snack to avoid some of these side effects.

Corticosteroids are powerful anti-inflammatory drugs, which can be taken orally or by injection. When given at high doses, children can experience side effects, such as severe mood swings. They may develop appetite changes, often feeling hungry all the time. And they can have changes in their appearance (moon face), which could have an impact on their self-esteem.

DMARDs and biologics work by stopping the disease process in the immune system and preventing further damage to joints. Some of these medications are taken orally, while others are taken by injection or infusion. These medications suppress the immune system, so the children taking them are more prone to infections and colds. Some medications can result in annoying mouth sores or causing flu-like symptoms on the day after receiving a weekly dose.

In addition to medications, treatment for JIA may involve the student wearing splints or braces on their limbs to reduce pain, rest joints or keep those joints in proper position. Some children with JA may require occupational or physical therapy to help improve their muscle strength, flexibility and function. In rare cases, children with severe arthritis may require surgery to relieve their pain, correct joint deformity or repair damage to their joints and bones.



Physical Limitations and What You Can Do

Because arthritis affects each child differently, there are no cookie-cutter guidelines to follow for helping your student. If your student's hands are affected, she may find it difficult to hold a pencil, complete long writing assignments or carry her schoolbooks. If her knees are affected, she may have trouble walking to class quickly or participating in some activities during P.E. Problems, such as morning pain and stiffness may make it difficult to get to school on time or sit cross-legged on the floor during story time. Following are a few of the common physical challenges faced by children with JA and advice on how you can help.

Pain and Stiffness in the Early Morning

Children with arthritis may develop severe stiffness after long periods of inactivity. Mornings may be particularly difficult, requiring a bath and exercise to loosen stiff, sore joints and get going. Early morning pain and stiffness or doctor's appointments may cause your student to be late to school some days. Know that such tardiness or absence is necessary. Children with arthritis may be very sensitive about anything that calls attention to their condition and sets them apart from other children. You can help by being aware, patient and understanding. However, if tardiness or absences are excessive, check with the student's parents.

Pain and Stiffness Due to Prolonged Sitting

For younger children who stay in the same classroom all day, prolonged sitting can cause joints to become stiff and painful. While you can't let your student run around and disrupt the class,

you can look for ways to get him out of his seat and move around. For example, ask him to collect homework assignments. Children with arthritis should be encouraged to move around every 30 to 60 minutes. Have the whole class stand up and stretch periodically. Everyone will benefit!

Difficulty Walking

If difficulty walking makes it hard to get to class on time, excuse your student early enough to get to his next class and avoid crowds in the hallways. If possible, make sure the student's classes are in the same area of the school to minimize the distance he has to walk between classes.

Difficulty Carrying Heavy Books

If arthritis in the upper extremities makes it difficult for your student to carry heavy books, try to arrange for her to have a locker on each floor or keep an extra set of books in the classroom. To avoid having her carry heavy books back and forth to school, provide an extra set to keep at home or, if possible, provide textbooks on DVD or post assignments online.

Problems Participating in P.E.

Physical activity is important for children with arthritis, but there are times they may not be able to do the same activities others do on the playground or in P.E. Your student shouldn't be forced to participate in any activities that cause pain or are prohibited by her health care provider. At the same time, she shouldn't be excluded from activities she's able to do. If her joints are painful or stiff, she should know to rest her joints and limit her activity. During these times, the student may be able to participate in another way, such as tossing a beach ball instead of a baseball, walking instead of jogging and dancing without jumping instead of jumping rope.

Missed School Due to Illness or Medical Appointments or Procedures

Getting the specialized care needed to treat childhood arthritis requires visits to the doctor and other healthcare providers. Due to a current national shortage of pediatric rheumatologists – doctors who specialize in the treatment of juvenile arthritis – some students may have to arrange to miss some school days to attend medical appointments hundreds of miles from home. Children may also miss school due to flares or surgical procedures.

During those times, you can help your student keep up with his assignments and allow him to make up missed tests. For long absences, make arrangements in advance with the hospital tutor or homebound teacher to help the student stay on track with his schoolwork.

Substitute Teachers

Be sure that all substitute teachers are aware of your student's needs and that the 504 plan – if one is in place – is shared and followed.



Emotional Challenges and How You Can Help

Living with a chronic illness like arthritis may also bring emotional challenges. A child with arthritis may struggle with feelings of isolation, frustration or fear for the future. Here are some of the more common emotional challenges children with arthritis experience and how you can help.

Whether and How to Tell Others About Her Arthritis

Some children don't mind classmates knowing about their arthritis, but others want to keep it to themselves. Be respectful of your student's wishes if she isn't ready to share her diagnosis. If she would like to share, you can help her. Perhaps you could have her write a paper to read to the class and then answer questions, or maybe you could invite a member of her health care team to speak to the class. This gives other students a chance to learn about arthritis. It can also foster respect for the student and enable classmates to provide appropriate support.

Wanting to Be Treated Like His Peers

While it's important to be sensitive to your student's special needs, it's also important not to coddle him or make him feel different. Treat your student as you treat other students. Don't give him unnecessary attention or lower your academic standards for him. Grade and discipline the student the same as you do other students, keeping in mind his physical limitations. Emphasize the student's strengths instead of weaknesses. The other students and the child will follow your lead.



Psychological Stress in the Family

Medical expenses, missed time from school and work and fears of future disability can cause stress within the child's family and affect your student's behavior and attitude at school. You can help your student by suggesting counseling as you would for any student experiencing stress. Provide support and references within the school.

Missing School Due to Illness or Hospitalization

For children, missing school due to illness means more than just missing schoolwork. It means missing important contact with friends and classmates. When your student must be out of school for more than a day or two, create a plan to help him maintain contact with school friends so he can continue to feel like part of the class. See if a friend or classmate in the student's neighborhood can deliver missed assignments or get well cards from the class. Consider creating an email message board so classmates can post news and stay in touch with each other.

Accommodations and the Law

In some cases, helping a child with arthritis will require some adaptations and equipment for the classroom. Simple devices such as a footstool, desktop book holder or floor pillow (especially for students through second grade) may make tasks easier and more comfortable. Some will need to use a computer, special pencil and pen grips, or have someone take notes for them because writing is difficult.

Helping students with the physical challenges of arthritis is not only part of being a good teacher, it's the law. Section 504 of the Rehabilitation Act of 1973 specifies that no one with a disability can be prevented from participating in federally funded programs – including elementary, secondary and post-secondary education. It also offers blanket protection for accommodations and support, such as extra time to go from one class to another, adaptive physical education or ramp access.

Working With the Student's Parents

Before or soon after the school year begins, parents should call a meeting with you to discuss their child's health. If you learn that a child in your classroom has arthritis and her parents haven't contacted you, take the initiative to schedule the meeting yourself. Ask the parents if they'd like to invite other school staff members who see the child on a regular basis. They can include the principal, P.E. teacher, school nurse, guidance counselor, care coordinator and/or bus driver.

During the meeting, ask your student's parents about any special accommodations the student needs. Also ask about any issues you should be

aware of or procedures you should follow. These might include:

- **The type of arthritis your student has.** This will enable you to learn more about the disease and how it affects your student.
- **Medications.** If their child needs medicine at school, have the parents provide you with a medication schedule. Ask if the child will need help taking medications or being reminded to go to the clinic.
- **Upcoming absences.** Will the child need to miss school due to physical therapy sessions, doctor's appointments, or a scheduled surgical procedure?
- **Emergency information.** Who should you call in cases of an emergency? What constitutes an emergency that would require a call to a parent or other point person?
- **Activity limitations.** Are there any activities their child shouldn't do or can't safely do?

This meeting is also the time to speak with your student's parents about developing a 504 plan. The 504 plan is a living document that can accompany a child from kindergarten to college. It can be adapted to meet her needs as they change on a yearly – or more frequent – basis.

Section 504 does not require the student to be enrolled in special education to receive related services. If parents feel that their child's rights have been violated, they have a right to appeal to the courts.



For additional information about 504 plans, sample accommodations and more, visit kgat.org/education

Strengthening the Parent-Teacher Partnership

Parents of children with arthritis generally are eager to work with you and other school staff to ensure that their child achieves maximum potential, both academically and socially. Try the following tips to make the most of the parent-teacher partnership.

Schedule a meeting. A meeting at the start of the school year is essential, but let your student's parents know you are available to meet throughout the school year if you or they feel the need.

Keep lines of communication open. Throughout the school year, inform parents of changes in their child's physical and emotional health and urge them to communicate regularly with you, too. Ask them how they prefer to receive communication – notes, phone calls, email – and let them know what works best for you.

Designate a point person. Help your student's parents select a point person who will be sure to communicate information from the parents to the other staff.

Make an emergency plan. Know who to call and when you should call them. Ask your student's parents about what would cause you to put the plan in motion. Scenarios may include your student missing her medication, experiencing a fall or another child in the class coming down with the chicken pox. The last example is important because children with arthritis often take medications that weaken their immune systems.

Educational Rights Information and Resources

The following sites offer tips, tools and guides to help you understand and ensure your student's educational rights.

- **GreatSchools** is a national nonprofit whose mission is to inspire and guide parents to become effective champions of their children's education. The site includes a large section on legal rights and advocacy for special education (www.greatschools.org).
- The **U.S. Department of Education** website has information about the Individuals with Disabilities Education Act (<http://idea.ed.gov>).
- **Center for Parent Information and Resources** is a national information center that provides parents and educators information about disabilities, legal protections and effective educational practices (www.parentcenterhub.org). CPIR also houses links to Parent Training and Information Centers (PTIs) throughout the country. Each state has at least one. And many also have Community Parent Resource Centers (CPRCs). To find a PTI or CPRC near you, visit www.parentcenterhub.org/find-your-center.
- The **Office for Civil Rights** ensures equal access to education and nationally promotes educational excellence through vigorous enforcement of civil rights. This is the site to file a formal complaint for violation of federal education protections (www.ed.gov/about/offices/list/ocr/index.html).

The Outlook for Children With Arthritis

While scientists don't know what causes most forms of childhood arthritis, research is providing clues. Ongoing Arthritis Foundation-funded studies are aimed at learning more about its causes and finding better ways to control juvenile arthritis to improve the quality of life for those affected by it. With specialized care, most children with arthritis reach adulthood without severe joint damage or physical disability. However, there remains a minority of children with severe unremitting disease despite the best medical care available.

The school years greatly influence a child's emotional development. If students are treated as – and see themselves as – equals to others, they can live happily through their school years with a positive outlook for the future.

You can help ensure those hopes and dreams with your encouragement and guidance.





The Arthritis Foundation is the Champion of Yes.

We lead the fight for the arthritis community and help you conquer your everyday battles through life-changing information and resources, access to optimal care, advancements in science and community connections.

**Go to www.arthritis.org
or call 800-283-7800.**

Acknowledgements

The Arthritis Foundation appreciates the contributions of and reviews by the following:

Harry Gewanter, MD, FAAP, FACR, Pediatric and Adolescent Health Partners, Richmond, VA

Lisa Shelton, MSN, Rheumatology Nurse Practitioner and Clinical Trials Manager, Centers for Disease Control, Atlanta



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