

Juvenile Arthritis: A Teacher's Guide

HELP YOUR
STUDENT
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[arthritis.org](https://www.arthritis.org)



Understanding Juvenile Arthritis

If you're surprised that arthritis affects children, you're not alone. Arthritis is usually associated with old age. However, an estimated 300,000 children and teenagers in the U.S. have arthritis or a related condition. When a student has arthritis, it's important for you to know about the disease and how it affects their ability to learn and function at school. 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 change classes, providing an extra set of books to keep at home or helping with missed assignments.

This brochure will help you understand juvenile arthritis and give you advice on how you can help your student with arthritis.

What Is Juvenile Arthritis?

Arthritis is a term that refers to inflammation of the joint. More than 100 diseases and conditions fall in the "arthritis" category.

Juvenile arthritis (JA) is an umbrella term that refers to pediatric rheumatic diseases — including juvenile idiopathic arthritis and other musculoskeletal conditions — that can develop in children ages 16 and younger.

Juvenile idiopathic arthritis (JIA) is the most common type of arthritis in children. It, in turn, has seven subtypes: oligoarthritis, polyarticular RF-negative, polyarticular RF-positive, systemic arthritis, enthesitis-related arthritis, juvenile psoriatic arthritis and undifferentiated arthritis. While each subtype shares many of the same symptoms — namely pain, inflammation and fatigue — each subtype is distinct and also has its own special concerns and symptoms.

JIA has many other symptoms including pain, stiffness and swelling in one or more joints, spiking fevers and sometimes a rash. Some subtypes of JIA can interfere with growth, as well as affecting many other parts of the body, including the skin, eyes and internal organs.

Other Pediatric Rheumatic Diseases Related to JA

Juvenile myositis. Juvenile polymyositis is an inflammatory disease that causes muscle weakness. Juvenile dermatomyositis combines muscle weakness and a skin rash on the eyelids, cheeks and knuckles along with internal organs. It is the most common inflammatory muscle disease in children.

Juvenile lupus (juvenile systemic lupus erythematosus or SLE). Lupus is a systemic autoimmune disease that can affect joints, skin, kidneys, blood, brain and heart, as well as other organs and parts of the body. Both SLE and dermatomyositis can be triggered by UV light and these children need to be careful when outside.

Juvenile scleroderma. Scleroderma, which literally means “hard skin,” describes a group of conditions that causes the skin to tighten and harden on the fingers, hands, forearms and face. It can affect other parts of the body, such as the digestive system, lungs, kidneys, muscles, nerves and joints.

Juvenile Arthritis Facts

- Nearly 300,000 children in the U.S. have arthritis or a related disease.
- One in every 1,000 children worldwide has juvenile idiopathic arthritis.
- Children with JIA miss five times more school days than healthy children.
- Adolescents with JIA have poorer school functioning and school quality of life than their healthy peers.

Juvenile vasculitis. There are several forms of vasculitis, or inflammation of blood vessels. Joint symptoms may occur with each type. Other common symptoms include lung, kidney or skin involvement. Henoch-Schoenlein Purpura (HSP) is the most common of the pediatric vasculitides.

Mixed connective tissue disease. This disease may include features of arthritis, lupus, dermatomyositis and scleroderma.

Noninflammatory conditions in children.

Noninflammatory musculoskeletal conditions (e.g., fibromyalgia, amplified musculoskeletal pain syndrome, tendinitis, patellofemoral dysfunction, etc.) can cause chronic or recurrent muscle or joint pain in children. Signs of significant inflammation such as joint swelling are not present.

The Impact of Juvenile Arthritis

The primary impacts of inflammatory arthritis on daily life are pain and associated fatigue, which can cause distractions and lack of concentration. They may limp or otherwise change how they move to limit or avoid joint pain.

Arthritis is an unpredictable disease. Children with arthritis have good days and bad days, as well as good and bad times within the day. 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 their hand in class the next day. Sitting still for long periods of time may result in stiffness and further impair their abilities.

Increased disease activity is called a flare and can occur at any time. Children who are having a flare can be extremely fatigued, irritable, listless and may lose their appetite from the uncontrolled inflammation.



To learn more about juvenile arthritis and related diseases, visit [arthritis.org/juvenile-arthritis](https://www.arthritis.org/juvenile-arthritis).



Some children may experience a period of remission, which means their arthritis is not showing any symptoms or appears to be gone. With newer medications, this is becoming more and more common. However, it is also common for the disease to return at any time, even while on treatment.

Hidden Symptoms

Unless arthritis has caused joint damage and deformity, its effects can be invisible.

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

Students with arthritis may not complain, so be alert for clues that they're having problems such as a stiff walk, fatigue, irritability, difficulty raising their hand or writing/keyboarding, avoiding activities or becoming more isolated. Allow your student to adjust their level of activity as needed, but you can help by watching for warning signs as most students are not comfortable bringing attention to themselves.

Many children with arthritis may try to ignore or hide their stiffness and pain because they want to be like their classmates. You can ask your student to let you know when they're having a bad day and if there's anything you can do to help them on difficult days.

While arthritis may affect a student's physical abilities, it's important to remember that just like other students in your class, these students can also have other learning needs or challenges, such as learning disabilities or behavioral problems. For example, secondary depression from having a chronic illness is very common.

How Doctors Treat Juvenile Arthritis

Treating juvenile arthritis involves different types of medications, often in combination. Some children with arthritis may not have to take many, if any, medications during the school day. However, medications used to treat arthritis in children could have side effects that influence the way your student feels or performs at school. The treatments are designed to reduce an overactive immune response and therefore can also make your student more susceptible to catching other diseases.

Medications used to treat JA include nonsteroidal anti-inflammatory drugs (NSAIDs), corticosteroids, conventional disease-modifying antirheumatic drugs (cDMARDs), small molecules and biologic disease-modifying drugs (bDMARDs, aka biologics). These medications may be administered orally, by injection or through an infusion. Infusions are typically done in a doctor's office or hospital and can take several hours, thereby often resulting in absences from school.

NSAIDs (ibuprofen, naproxen, etc.) 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, bloating or nausea. It's important that these medications are taken at mealtimes or with a snack to avoid some of these side effects.

Corticosteroids (prednisone, etc.) are powerful anti-inflammatory drugs that can be taken orally

77% of parents reported pain moderately or severely interfered with their child's ability to sleep, pay attention, run, or walk one block.

Source: JA INSIGHTS Report

or by injection. While very effective, they also have numerous adverse effects. Mood swings, increased hunger and changes in appearance (moon face) are common.

cDMARDs (hydroxychloroquine, methotrexate, etc.), bDMARDs (etanercept, adalimumab, etc.) and small molecule medications work by slowing or stopping the overactive immune disease process as a means to prevent joint and other organ damage. Some of these medications are taken orally, while others are taken by injection or infusion. Because these medications modulate the immune system, students taking them may be more prone to infections, both mild and serious. Some medications can result in annoying mouth sores, nausea, fatigue or cause flu-like symptoms on the day after receiving a weekly dose.

Some children with JA may benefit from occupational or physical therapy to help improve their muscle strength, flexibility and function. These therapists may recommend the student wear splints or braces to improve function and limit pain. In some cases, children with severe arthritis may require surgery to relieve their pain 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 their hands are affected, they may find it difficult to hold a pencil, type on a keyboard, complete long writing assignments or carry their schoolbooks and computers. If their hips, knees and/or ankles are affected, they may have trouble walking to class quickly or participating in some activities during P.E.

Morning pain and stiffness may make it difficult to get to school on time or sit cross-legged on the floor during story time. Similarly, they may be stiff after sitting for a while or tire with prolonged standing. The following are a few of the common physical challenges faced by children with JA and advice on how you can help.

Morning Pain and Stiffness

Children with arthritis may develop severe stiffness overnight. Mornings may be particularly difficult, requiring a bath or shower and/or exercise to loosen stiff, sore joints and get going. These delays may cause your student to be late to school some days. Know that such tardiness is necessary and it may be necessary to adjust their schedule to allow for this common issue. 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 Inactivity

Prolonged sitting can cause joints to become stiff and painful. While you can't let your student run around and disrupt the class, look for ways to get them out of their seat and move around. For example, ask them 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 and it won't call attention to your student with arthritis!

Difficulty Walking

If difficulty walking makes it hard to get to class on time, excuse your student early enough to get to their next class and avoid crowds in the hallways. If possible, try to cluster your student's classes in the same area of the school to minimize the distance they have to walk between classes. If they have problems with stairs, give them an elevator pass.

Trouble Carrying Heavy Books

If arthritis in the upper extremities makes it challenging for your student to carry heavy items, try to arrange for them to have a locker on each floor or keep an extra set of books in the classroom. To avoid having them carry heavy books back and forth to school, provide an extra set to keep at home or ensure access to online textbooks and notes.

Problems During P.E. and Recess

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 their health care provider. Some students have difficulties dressing and excusing them from dressing for PE may be necessary.

At the same time, physical activity is important and they shouldn't be excluded from activities they're able to do. If their joints are painful or stiff, activities and/or the intensity of the activity can be modified. Have your student toss a beach ball instead of a baseball, walk instead of jog or dance instead of jumping rope. Your student could perform their physical therapy exercises in lieu of whatever the class is doing. If your student with arthritis is isolated during recess, help set up group games they can participate in. Be alert for signs of bullying or purposeful exclusion.

School Absences

The specialized care required to treat childhood arthritis requires frequent visits to doctors and other health care providers. Depending upon your location, some students may have to miss school to attend medical appointments hundreds of miles from home given the lack of appropriate pediatric subspecialists.



Children may also miss school due to flares, therapy appointments or surgical procedures. Some students may become too fatigued to complete a full day of school. During those times, they will need your help in order to keep up with their assignments and allow them to make up missed tests. Post assignments on the class blog or portal. For long absences, work with the family, hospital tutor or homebound teacher to help the student stay on track with their schoolwork.

Emotional Challenges

Living with a chronic illness like arthritis brings with it emotional challenges for both the child as well as the rest of the family. 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.

Telling Others About Their 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 they would like to share, you can help. Perhaps you could have them write a paper to read to the class and then answer questions, or maybe you could invite a member of their 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.

 To learn more about how JA affects the mental and emotional health of students, watch the webinars at arthritis.org/events/webinars.

Wanting Equal Treatment

While it's important to be sensitive to your student's special needs, it's also important not to coddle them or make them feel different.

Children with arthritis may be very sensitive about anything that calls attention to their condition and sets them apart from other students. Don't give them unnecessary attention or lower your academic standards for them. Grade and discipline the student the same as you do other students, keeping in mind their physical limitations, including their potential fatigue. Emphasize the student's strengths instead of weaknesses. The other students and the child will follow your lead.

Family Stressors

Medical expenses, missed time from school and work, and fears of future disability can cause additional stress within the child's family. This may 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. Reach out to the family for ways you can be helpful.

Feeling Left Out

For children, missing school due to illness means more than just missing schoolwork. It means missing important contact with friends and classmates. Be proactive so that when your student must be out of school for more than a day or two, a plan is in place to ensure they 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 online message board so classmates can post news and stay in touch with each other.

Accommodations and the Law

Students with arthritis may require a variety of modifications or accommodations within school. These could include physical devices such as a footstool, desktop book holder or floor pillow (especially for younger students). Some will need to use a computer, special pencil and pen grips, or have someone take notes for them because writing is difficult. Other students may need to have voice recognition or other software to accommodate their limitations. Similarly, adjustments to their schedules, allowing extra time for tests or assignments or permitting rest time during the school day may be necessary.

Helping students with the physical, social and/or emotional challenges of arthritis is not only part of being a good teacher, it's also the law. Section 504 of the Rehabilitation Act of 1973 specifies that no one with a chronic illness or disability can be prevented from having equal access to participate in federally funded programs — including public elementary, secondary and post-secondary education. It also offers blanket protection for accommodations and supports, such as extra time to go from one class to another, adaptive physical education or ramp access for students up to age 22. Accommodations, modifications and supports include equal access to social or other school activities and not just physical accommodations.

It is important to ensure that all substitute teachers are aware of your student's needs and that the 504 plan or IEP is shared and followed. The

65% of kids with arthritis have moderate to severe depressive symptoms.

Source: JA INSIGHTS Report

law states that all school personnel are required to implement these plans.

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 condition and abilities. If you learn that a child in your classroom has arthritis and their 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, after school care coordinator or bus driver.

504 Versus an IEP

Any child with a chronic or disabling condition that interferes with their "activities of daily living" is eligible for a 504 plan, a blueprint for how the school will provide supports and remove barriers for a student with a disability. If their condition also affects their ability to "make appropriate educational progress," they are eligible for an Individualized Educational Plan (IEP), a special education plan for students who qualify with disabilities laid out in the Individuals with Disability Education Act (IDEA). Schools are legally required to perform "Child Find" activities, meaning they must actively identify and evaluate students who may need supports, modifications and/or accommodations within school. If a student has an IEP, they may not also need a 504 plan.



For additional information about 504 plans, sample accommodations, sample recommendation letters and more, visit arthritis.org/juvenile-arthritis/school-and-college.

Strengthening the Parent-Teacher Partnership

Parents of all children, including those 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.

Be accessible. 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. It may help to set up regular meetings or other methods of communication to ensure no problems arise.

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. Scenarios requiring a call may include your student missing their medication or 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.

During the meeting, ask the parents about any special accommodations the student needs. Have them describe your student's strengths and how they or previous educators have helped your student. Also ask about any issues you should be aware of or procedures you should follow, including:

- **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 your student needs medicine at school, get a medication schedule. Ask if the child will need help taking medications or to be reminded to go to the clinic. Ask about pertinent side effects.
- **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, accommodations, modifications or supports you should know about? Are there individuals, peers or adults — in or out of the school — who could help you better serve your student?

This meeting is also the time to speak with your student's parents about developing a 504 plan.

32% of parents reported that their child often or almost always tired easily.

Source: JA INSIGHTS Report

The 504 plan is a living document that accompanies a student from kindergarten to college.

It is to be adapted as necessary to meet their needs as they change on a yearly — or more frequent — basis. Section 504 does not require the student to be enrolled in special educational classes to receive appropriate accommodations and supports. If parents feel that their child's rights have been violated, they have a legal right to appeal within the local, state or federal educational systems and, if necessary, to state or federal courts.

Educational Rights 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 ([greatschools.org](https://www.greatschools.org)).
- The **U.S. Department of Education** has information about the Individuals with Disabilities Education Act (sites.ed.gov/idea/), as well as contact information for your state's Department of Education (www2.ed.gov/about/contacts/state/index.html).
- **Center for Parent Information and Resources** (CPIR) is a national information center that provides parents and educators information about disabilities, legal protections and effective educational practices (parentcenterhub.org). CPIR also houses links to Parent Training and Information Centers and Community Parent Resource Centers around the country.



- 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 where you would file a formal complaint for violation of federal education protections (www2.ed.gov/about/offices/list/ocr/index.html).



As a teacher, you have an amazing opportunity to help shape future generations. The **Arthritis Foundation is a special place where you'll find strength, support and solutions to help you best prepare your students with juvenile arthritis. Here are a few ways to start your journey:**

I WANT TO CONNECT with people going through a similar experience. **Go to connectgroups.arthritis.org.**

I WANT TO LEARN more about juvenile arthritis. **Go to arthritis.org/about-juvenile-arthritis.**

I WANT TIPS and tools to improve my everyday life. **Go to arthritis.org/juvenile-arthritis.**

NEED HELP NOW? Call our Helpline 24/7 at **800-283-7800** or visit **arthritis.org**.



Acknowledgements

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

Harry L. Gewanter, MD, FAAP, MACR, Medical Director, Medical Home Plus, Inc., Richmond, Virginia

Deborah Durkee, APRN, Family Nurse Practitioner, Department of Pediatrics, Division of Allergy, Immunology and Rheumatology, University of Utah Health, Salt Lake City

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