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Arthritis in Children

WHAT IS JUVENILE ARTHRITIS?

The word arthritis literally means joint inflammation (arth=joint; itis=inflammation). Joint inflammation causes joint pain, stiffness, swelling and decreased mobility. However, not all joint pain is arthritis. Arthralgia (arth=joint, algia=pain) or joint pain without inflammation, is common in many conditions. Arthritis can be a chronic illness, meaning that it may last for months or years. Juvenile arthritis refers to arthritis or an arthritis-related condition (rheumatic disease) that occurs before age 16.

Nearly 300,000 children in the United States have a form of juvenile arthritis. The most common form of arthritis in children is juvenile rheumatoid arthritis (JRA). Estimates vary on the number of children in the United States who have JRA; however, it is one of the most common chronic childhood illnesses, occurring nearly as often as insulin-dependent juvenile diabetes. Children also are affected by arthritis as a feature of many other diseases, including diseases that affect the spine, skin, gastrointestinal tract and other organs.

The cause of most forms of juvenile arthritis remains unknown. Juvenile arthritis is not contagious, and there is no evidence that foods, toxins, allergies or vitamin deficiencies play a role. Current research indicates that there may be a genetic predisposition to juvenile arthritis. In other words, the combination of genes your child inherited may contribute to the development of arthritis when combined with other undefined factors. Most of the symptoms of juvenile arthritis are due to inflammation as a result of imbalances in the immune system. Despite not knowing the exact cause or causes, there are many effective treatments available to help you and your child manage juvenile arthritis.

TYPES OF JUVENILE ARTHRITIS AND RELATED CONDITIONS

It is important to determine if your child has a type of arthritis or a related condition because treatments vary. Early diagnosis and treatment are keys to preventing or slowing joint damage.

Juvenile Rheumatoid Arthritis

Juvenile rheumatoid arthritis (JRA) is the most common form of arthritis in children. It is also referred to as juvenile idiopathic arthritis (JIA) and juvenile chronic arthritis (JCA). It often is a mild condition that causes few problems, but can produce serious complications in severe cases.

Symptoms of JRA include fatigue, joint swelling, stiffness or pain, which is often worse following sleep or inactivity. However, because JRA affects each child differently, your child may not experience all of these changes. Children also vary in the degree to which they are affected by any particular symptom.

Not only do the symptoms of JRA vary from child to child but they also vary from day to day and even throughout the same day. One day it might seem that your child has gone into remission, which is a period when arthritis symptoms and physical exam findings improve or even disappear. Other days your child might experience a flare, which is when arthritis is more active. However, only your child's doctor can determine when your child is in remission. Arthritis is considered active if even one joint is inflamed.

The diagnosis of JRA is based on physical examination findings. The diagnosis is made by the presence of active arthritis in one or more joints for at least six weeks, after other conditions have been ruled out. There is no laboratory test to diagnose JRA. Lab testing may assist in classification of arthritis or determining risk of more severe disease. Such testing may include rheumatoid factor (RF) and anti-nuclear antibody (ANA) tests. Your child's physician may refer you to a pediatric rheumatologist, a physician who specializes in treating children with arthritis, to help make

the diagnosis or after the diagnosis for management of treatment.

There are three major types of JRA: polyarticular JRA, which affects five or more joints; pauciarticular JRA, which affects four or fewer joints; and systemic onset JRA, which also includes a high fever and a characteristic rash. The common features for each of these types of arthritis are described below.

POLYARTICULAR ONSET JRA

Polyarticular means many joints. Polyarticular JRA affects five or more joints. Girls are affected by polyarticular JRA more frequently than boys. The onset of polyarticular JRA in some teenagers may more closely resemble adult rheumatoid arthritis (RA).

Polyarticular arthritis usually affects the small joints of the fingers and hands, but it also can affect weight-bearing joints, such as the knees, hips, ankles and feet. This subtype typically affects the same joints on both sides of the body. Additional findings may include low-grade fever, a positive blood test for rheumatoid factor (RF), rheumatoid nodules (bumps under the skin, most commonly on the elbow) and anemia (low red blood cell count).

Two locations of particular concern in children with polyarticular arthritis are the temporomandibular joint (TMJ) and the cervical spine (neck). TMJ arthritis can lead to limited jaw opening because of pain and discomfort when chewing. It may also cause abnormal growth of the jaw, resulting in a crooked mouth opening and smile. Neck arthritis can cause instability or bony fusion of the cervical spine, with the potential for spinal cord injury from relatively minor trauma. Your doctor will check for this by routine examination and X-rays when indicated.

PAUCIARTICULAR ONSET JRA

Pauciarticular means few joints and is the most common form of JRA, particularly in young children. Pauciarticular JRA affects four or fewer joints, typically the large joints (knees, ankles or elbows) on one side of the body. Of the three JRA subtypes, pauciarticular has the highest risk for developing chronic eye inflammation called uveitis. Your child should have his or her eyes examined by an ophthalmologist (eye doctor) on a regular basis. For more information, see “Eye Care.”

SYSTEMIC ONSET JRA

Systemic means affecting the entire body. This is the least common form of JRA and may affect the child’s internal organs as well as joints. Boys and girls are equally likely to have systemic onset JRA. Symptoms of systemic onset JRA include:

- high, spiking fevers (103° or higher) that may last for weeks or even months;
- rash of pale red spots that appear on the child’s chest, thighs and sometimes other parts of the body (the rash often accompanies the fever and may come and go for many days in a row); and
- joint inflammation, which usually begins at the same time as the systemic symptoms (fever and rash) but may begin weeks or months later.

Other possible symptoms of systemic onset JRA include inflammation of the outer lining of the heart or lungs, inflammation of the heart or the lungs themselves, anemia, and enlarged lymph nodes, liver or spleen. In many children the systemic symptoms of the disease, including the fever, go away completely, but the arthritis remains. The arthritis in this form of JRA may come and go over weeks, but in most cases is chronic.

Along with thorough physical examinations, your child’s blood will be checked on a regular basis to help monitor his or her progress. Most children with systemic onset JRA are treated with medications to control both the systemic parts of the illness, such as fever and anemia, as well as the arthritis. Uveitis is uncommon in children with systemic onset JRA, but be sure your child’s eyes are examined annually.

Juvenile Spondyloarthropathies

The spondyloarthropathies are a group of diseases that may involve the spine or sacroiliac joints and the joints of the lower extremities, most commonly the hips and knees. There are several different forms of spondyloarthropathies, including juvenile ankylosing spondylitis, seronegative enthesopathy and arthropathy syndrome (SEA syndrome), arthritis associated with inflammatory bowel disease, and reactive arthritis.

Spondyloarthropathies occur more often in boys than in girls. Juvenile ankylosing spondylitis generally causes arthritis in the large joints of the lower extremities such as the hips and the axial skeleton. A blood test for a protein called HLA-B27 is frequently positive in children with ankylosing spondylitis.

Juvenile Psoriatic Arthritis

Juvenile psoriatic arthritis is a type of arthritis affecting both boys and girls that occurs in association with the skin condition psoriasis. However, the psoriasis may begin many years before or after the onset of arthritis. Symptoms of psoriasis include a scaling red rash commonly seen behind the ears, on the eyelids, elbows, and knees and at the scalp line or the belly button. There may be pitting or ridging of the fingernails. There may only be a family history of psoriasis rather than psoriasis in the child with arthritis.

Juvenile Dermatomyositis

Juvenile dermatomyositis (JDMS) is an inflammatory disease that causes muscle weakness and a characteristic skin rash on the eyelids and knuckles. About 20 percent of children with JDMS have arthritis. Treatment of the muscle and skin disease usually treats the arthritis as well. Your doctor may recommend additional treatment in special circumstances.

Juvenile dermatomyositis is more common in girls and occurs most often in children between the ages of 5 and 14. The muscle weakness most commonly affects the muscles of the trunk, shoulders and upper legs. This causes problems with activities like running, climbing stairs, or getting up from a chair and the floor. Muscle pain or tenderness is a frequent complaint of children with JDMS but is not usually severe.

Juvenile Vasculitis

Vasculitis means inflammation of the blood vessels. There are several distinct forms of vasculitis, each with unique clinical features that may include arthritis. In addition, vasculitis may be seen in children with JDMS or systemic lupus erythematosus.

Polyarteritis nodosa is a vasculitis of small and medium-sized blood vessels. It can affect any organ system, but most frequently involves the skin, kidneys, intestines, and joints. Other forms of juvenile vasculitis include cutaneous polyarteritis, Wegener's granulomatosis and Behçet's syndrome.

Juvenile Noninflammatory Disorders

Noninflammatory disorders are important causes of chronic or recurrent pain in children. They may be due to heredity, injury, or other unknown causes. They do not cause arthritis.

CHRONIC PAIN SYNDROMES

Widespread aching and stiffness characterize fibromyalgia, a chronic pain syndrome. Your child may have constant fatigue, disturbed sleep, anxiety and depression. Diagnosis is based on your child's medical history and the presence of tender points at specific locations on their body. Treatment consists of a combination of exercise, pain coping skills training, counseling, and medications. Fibromyalgia is much more common in females and rare before puberty.

Children and adolescents with localized musculoskeletal pain involving an extremity may have chronic regional pain syndrome (CRPS) (previously known as reflex sympathetic dystrophy or RSD). CRPS usually develops suddenly, often following injury to an extremity, such as a sprain or following casting of a broken bone. Once it starts, there is often constant pain and increasing disability. The pain can be worsened by even mild activity. The involved extremity may have swelling, tenderness, coolness and blotchy skin color. Even slight touch may cause severe discomfort and attempts to move the affected hand or foot are extremely painful. Treatment for CRPS is intense physical therapy of the affected limb. A psychologist may be needed to assist the child in pain control or desensitization.

For More Information

For more detailed information about these childhood rheumatic diseases or others as well as their treatments, visit the juvenile arthritis section of the Arthritis Foundation's Web site at www.arthritis.org.

DIAGNOSING JUVENILE ARTHRITIS

Your child's doctor may take many steps to find out if your child has a form of juvenile arthritis. While it can be frustrating, try to be patient. Ask questions about tests or procedures you don't understand. The main steps involved in making a diagnosis may include:

- A complete health history to help determine the length of time and character of symptoms that have been present, to rule out other possible causes such as trauma or viral infections, and to find out if other family members have had arthritis or related conditions.
- A physical examination to look for joint inflammation, rash, nodules and eye problems that may suggest the presence of juvenile arthritis or related conditions.
- Laboratory tests including erythrocyte sedimentation rate (sed rate or ESR), antinuclear antibody test (ANA), rheumatoid factor test (RF), HLA-B27 typing, complete blood count and urinalysis. Other tests may be ordered as determined by your doctor.
- X-rays of joints to check for signs of joint damage.

TREATING JUVENILE ARTHRITIS

Early diagnosis and treatment provides children with JRA the best possible opportunity for a good outcome. Your child's treatment will be based on the type of arthritis and his or her particular symptoms. The goals of any treatment program for juvenile arthritis are to control inflammation, relieve pain, prevent joint damage, and maximize function.

Your child's treatment program will include medication, exercise, eye care, dental care and proper nutrition. Rarely, other treatments, such

as surgery, may be necessary for special long-term problems.

Because so many different techniques are used to treat children with JRA, care is ideally provided by a team of health-care providers working together. Your child's health-care team may include specialists working together to offer your child a complete treatment program. These specialists may include a pediatric rheumatologist, nurse practitioner, physical and occupational therapist, dietitian, ophthalmologist, psychologist, nephrologist, neurologist, cardiologist, dentist, social worker or orthopaedic surgeon.

Pediatric rheumatology centers in many major medical centers offer this care in one location. If you do not live near a pediatric rheumatology center, your child's physician will refer you to the specialists your child needs.

Medication

The immediate goal of drug therapy is to reduce inflammation, relieve pain and swelling, and maximize functional abilities. Long-range goals are to prevent disease progress and destruction of bone, cartilage and soft tissues such as muscle, tendon and joint capsule. The following medications are used to treat children with arthritis and related conditions.

NONSTEROIDAL

ANTI-INFLAMMATORY DRUGS (NSAIDS)

NSAIDs (ibuprofen, naproxen and others) are the mainstay of initial therapy for juvenile arthritis. A particular NSAID should be taken for at least six to eight weeks to see if it helps control pain and inflammation. Not all children respond to each NSAID. Your child's doctor may try different NSAIDs to find one that works for your child. Laboratory tests may be conducted to

monitor medication toxicity from NSAIDs in your child. NSAIDs are available in liquid and pill form and are taken from one to three times per day, depending on the drug prescribed.

Possible side effects of NSAIDs include stomach pain, nausea and vomiting, anemia, headache, severe abdominal pain from stomach ulcers, fragility and scarring of the skin (especially with naproxen), decreased kidney function and difficulty concentrating.

Newer, related drugs are the selective COX-2 (cyclooxygenase-2) inhibitors – celecoxib (*Celebrex*), rofecoxib (*Vioxx*) and valdecoxib (*Bextra*) – which may be safer for the stomach. Even though COX-2 inhibitors have not received approval from the Food and Drug Administration (FDA) for use in JRA, they are used in children who do not tolerate standard NSAIDs.

DISEASE-MODIFYING

ANTI-INFLAMMATORY DRUGS (DMARDS)

DMARDs, or remittive agents, do not produce immediate pain relief or anti-inflammatory effect. Instead, they prevent joint damage, such as bony destruction and loss of joint space, weeks to months after therapy is begun. DMARDs are most often used in combination with NSAIDs. Children on these medications need to have regular laboratory testing to monitor for toxicity.

Methotrexate

Methotrexate (*Rheumatrex*, *Trexall*) is given weekly, either orally as a liquid or pill, or by injection. It is the most commonly prescribed DMARD in both children and adults with arthritis. Numerous studies in children with JRA have documented the benefit of methotrexate on long-term disease outcome.

Few serious side effects have been reported with the low doses of methotrexate used to

treat JRA, but regular laboratory monitoring is still important. Side effects may include nausea, vomiting, mouth sores, diarrhea, low white blood cell count and liver irritation. Children on methotrexate may have reduced resistance to infection. For this reason they should not receive live vaccines such as mumps-measles-rubella (MMR) or chicken pox (varicella) while being treated with methotrexate.

Approximately 50 percent to 70 percent of children treated with methotrexate eventually improve; however, it takes at least four doses before improvement is evident and may take as long as three months for full effect. Dosages of methotrexate for children are calculated based on body weight and height, and are adjusted as the child grows. Treatment with methotrexate may make it easier for children with arthritis to attend school, participate in school functions, and reach age-appropriate developmental milestones.

Even though methotrexate does not have FDA approval for use in JRA, it is widely used to treat the disease and is the gold standard by which all other DMARDs are measured. Methotrexate has been used to treat JRA for more than 15 years and has an excellent safety profile.

Sulfasalazine

Sulfasalazine (*Azulfidine*, *Azulfidine EN-Tabs*) is available only in pill form, but may be made into a liquid by your pharmacist. Studies have shown it to be an effective treatment for juvenile arthritis. Side effects may include stomach upset, diarrhea, dizziness, headache, sunlight sensitivity, appetite loss, liver abnormalities, lowered blood count, nausea or vomiting, and rash.

Leflunomide

Leflunomide (*Arava*) also is taken in pill form. Although only FDA-approved for adults

with arthritis, leflunomide studies for use in children have shown significant benefits. Side effects may include diarrhea, skin rash, liver toxicity and hair loss.

Other agents

Cyclophosphamide (*Cytoxan*), thalidomide (*Thalomid*), and cyclosporin (*Neoral*) are sometimes used in juvenile arthritis when other agents have failed to control arthritis disease activity.

CORTICOSTEROIDS

Corticosteroids (prednisolone, prednisone, methylprednisolone, dexamethasone and others) are strong anti-inflammatory agents used when juvenile arthritis is severe or has not responded to other drugs. Because of many side effects, they are used with caution. If oral corticosteroids are prescribed, the lowest possible dose should be used for the shortest length of time. Often the drug is given by mouth as a pill or liquid. Corticosteroids also can be given as an injection into the joint itself or through a vein (I.V.). Corticosteroids given directly into the joint do not have the side effects associated with prolonged oral or intravenous administration.

Possible side effects of oral corticosteroids include high blood pressure, osteoporosis (thinning of the bones), Cushing's syndrome (weight gain, moon face, thin skin, muscle weakness and brittle bones), cataracts, slowed growth, reduced resistance to infection, sudden mood swings, increased appetite and increased risk for ulcers. All children taking corticosteroids should take calcium and vitamin D supplements to help prevent brittle bones. Children on corticosteroids should not receive live vaccines (MMR, Varicella).

A child taking corticosteroids should wear a medical alert bracelet or necklace. This will

alert emergency medical personnel to give supplemental medication if the child has surgery or is seriously injured.

HYDROXYCHLOROQUINE

Hydroxychloroquine (*Plaquenil*) is given in pill form (or a liquid specially prepared by your pharmacist) to control joint pain and swelling. While not a true DMARD and not helpful for extensive arthritis, it is often used in children with milder forms of arthritis or combined with methotrexate. It is standard therapy in many related conditions including systemic lupus erythematosus and juvenile dermatomyositis.

Side effects of hydroxychloroquine include upset stomach, diarrhea, skin rash, and rarely, eye changes that can alter color vision. Children taking this drug should have their eyes examined on a regular basis by an ophthalmologist. If eye changes are detected as part of routine screening, the medication can be stopped before clinically important changes in vision occur. Although the exact incidence of eye changes is not known, recent data suggest it is exceedingly rare at standard doses of hydroxychloroquine for less than five years.

BIOLOGIC AGENTS

Biologic agents, also called biologic response modifiers (BRMs), are a new class of drugs used to treat a number of diseases, including JRA. Four BRMs have been approved for the treatment of adult rheumatoid arthritis: etanercept (*Enbrel*), infliximab (*Remicade*), adalimumab (*Humira*) and anakinra (*Kineret*). Etanercept, infliximab, and adalimumab all block the action of a protein known to contribute to inflammation called tumor necrosis factor or TNF.

Etanercept is the only BRM that is FDA-approved for use in children and teenagers (ages

4-17) with polyarticular JRA. It has been shown to be effective in children with JRA who do not improve on methotrexate alone. Etanercept may also be beneficial in the treatment of systemic JRA and the uveitis associated with JRA.

Etanercept is given as once- or twice-weekly injections and can be used alone or in combination with methotrexate. The most common side effect of etanercept is a mild skin reaction at the site of the shot. Since etanercept was recently developed, there is no information available about its long-term safety. It should not be used in children with chronic infections. Your child's doctor should be informed if your child develops signs of significant infection requiring antibiotics while on etanercept, to decide if the medication should be stopped temporarily.

Infliximab works similarly to etanercept and is given as an I.V. infusion in a clinic or hospital. It has not been FDA-approved for use in children with JRA. Infliximab has an increased risk of serious allergic reaction and your child will be monitored closely during infusions.

Adalimumab and anakinra are additional BRMs currently under investigation for use in children. Adalimumab is another TNF-blocking agent that is given as a subcutaneous injection once every two weeks. Anakinra works by blocking another inflammatory protein called interleukin-1. It is administered by daily injections. These medications are both available for use by prescription as they have FDA approval to treat adult rheumatoid arthritis.

It is important that your child be screened for tuberculosis infection (TB) prior to starting any anti-TNF drug, including infliximab, etanercept or adalimumab.

Another BRM, intravenous immunoglobulin (IVIG), has been used to treat a number of

childhood rheumatic diseases. It is usually given intravenously once a month. Side effects include the risk of a severe allergic reaction and headache.

Researchers currently are developing other biologic therapies. These include monoclonal antibodies, receptor inhibitors and peptide vaccines, all of which are designed to modify the immune response in a precise manner.

ANALGESICS

Analgesics (acetaminophen, tramadol) do not decrease inflammation, but provide pain relief. Children with continued pain despite acetaminophen and tramadol may be treated with opioid pain medications. These include oxycodone, morphine and methadone. Side effects may include dizziness, nausea, constipation, headache and sleepiness. They should be taken only under a physician's advice in conjunction with other medications.

Adequate pain treatment is important not just for comfort, but is vital for continued use of affected joints. It is through regular use that muscles, bones, and joints maintain strength and mobility.

Exercise

Exercise is an important part of juvenile arthritis treatment. For children with arthritis, exercise helps keep joints mobile and muscles strong, while regaining lost motion or strength and making everyday activities like walking or dressing easier. General fitness and endurance also are improved by regular exercise.

THERAPEUTIC EXERCISE

While medications reduce pain and inflammation, only therapeutic exercise can restore lost motion in a joint. These exercises can make

it easier for children to walk and perform other activities of daily living such as eating, writing, dressing, etc.

Range-of-motion exercises keep joints flexible. They are especially important for children with decreased motion in a joint or whose joints have become fixed in a bent position. Strengthening exercises build muscle, strength and endurance. Doing these exercises on a regular basis is challenging, and your child will need a lot of family support.

A physical or occupational therapist will teach you and your child how to perform therapeutic exercises at home. Most exercises must be done daily. The therapist will show your child how to use hot baths, hot packs, hot wax and/or cold treatments before exercise to make the therapy easier.

SPORTS AND RECREATIONAL ACTIVITIES

Recreational activities help your child exercise joints and muscles, develop important social skills, and have fun. But remember that recreational activities do not take the place of therapeutic exercise.

Participating in sports and recreational activities helps children with arthritis develop confidence in their physical abilities. Encourage activities that exercise the joints and muscles without putting weight-bearing stress on the joints, such as swimming and bike riding.

Strong muscles, joint protection and stretching are the keys to participating in sports. Even aggressive sports like soccer and basketball may not be off limits for your child if their arthritis is well controlled. Special exercises and protective equipment can further reduce the risk of injury and help your child play sports. Activities such as trampoline and jogging are not recommended.

Splints

Splints help keep joints in the correct position and relieve pain. If a joint is becoming deformed (bent in the wrong position) or at risk for developing a deformity, a splint may help position or stretch the joint gradually back to its normal position or keep it in a normal position. Commonly used splints include knee extension splints, wrist extension splints, and ring splints for the fingers.

An occupational or physical therapist usually makes the splint. Splints are made from different firm materials including plastic and casting material. The therapist customizes the splint for your child and will adjust the splint as your child grows or as the joint position changes. It is important for maximum benefit that the splints fit correctly. It is a good habit to bring your child's splints to all clinic appointments to be checked.

Morning Stiffness Relief

Many children experience stiffness when they get up in the morning or after a nap. Morning stiffness is one of the best measures of arthritis activity: the longer the stiffness lasts, the more active the arthritis. Taking a hot bath or shower, sleeping in a sleeping bag or a sweat suit, sleeping on a heated waterbed, doing range-of-motion exercises and using a hot or cold pack can help relieve stiffness. Although most children do better with warmth, there are a few who respond to cold treatments (a plastic bag filled with ice or frozen vegetables works well).

Eye Care

Eye inflammation is associated with various forms of juvenile arthritis. However, frequent eye exams can identify inflammatory problems

early and reduce the potential for permanent loss of vision.

Children with pauciarticular JRA are at the highest risk of developing chronic eye inflammation (uveitis). Chronic uveitis occurs most commonly in young girls with pauciarticular JRA whose blood contains a protein known as antinuclear antibody (ANA). It most often occurs in the first three to five years after diagnosis, but has been reported as much as 30 years after diagnosis of arthritis. It also can occur in children with other types of JRA and in children who do not have a positive ANA. This inflammation of the eyes most often occurs without eye symptoms or changes in the appearance of the eye. The degree of arthritis activity has no impact on the development of uveitis. Therefore, it is extremely important for all children with JRA to have their eyes checked by an ophthalmologist at diagnosis and regularly thereafter. Since the risk of uveitis remains elevated even after five years, regular eye exams should continue throughout the remainder of the child's life. This allows the eye doctor to detect problems early and begin proper treatment quickly, preventing long-term difficulties.

The ophthalmologist will give your child a complete medical eye evaluation, including a slit lamp exam. This simple and painless procedure can spot problems before symptoms are present. The frequency of eye exams will depend on your child's risk for developing eye problems as determined by your child's pediatric rheumatologist according to published guidelines.

Dental Care

Children with arthritis may have limited jaw opening, which can make brushing and flossing their teeth difficult. Your child's dentist may suggest various toothbrush handles, elec-

tric toothbrushes, floss holders, toothpicks, and rinses that will help your child maintain healthy teeth and gums.

Medications also may affect your child's oral health and development. Always inform your dentist about the status of your child's arthritis and medications. The dentist will consider these when planning treatment. Older children who have had joint replacements may require an antibiotic before dental work.

The joint in front of the ears, where the lower jaw connects to the base of the skull, is called the temporomandibular joint (TMJ). Arthritis may affect this joint in the same way it does others, causing pain, stiffness and altered growth. Jaw exercises and therapy may be recommended for the pain and stiffness. If the lower jaw does not develop properly, it may create an overbite. Your doctor may utilize X-ray, CT (CAT scan) or MRI scans to detect TMJ arthritis. Your child's dentist may recommend early consultation with an orthodontist if this occurs. Surgery is sometimes necessary for this condition.

A child with active arthritis may not be able to keep their mouth open long enough for routine dental work. Consider this when scheduling appointments and work with your dentist to make dental care as easy as possible. Sometimes more frequent, shorter visits are helpful.

Diet

Children with arthritis may have a poor appetite, leading to weight loss and poor growth, while a side effect of corticosteroid use is excessive weight gain secondary to an increased appetite.

Arthritis places increased demands on a child's body and may create the need for additional caloric intake. Children may have little appetite when they feel ill or have a difficult time eating with painful joints or limited

mobility. Some children with arthritis feel too sick or tired to eat and those with TMJ arthritis may have too much pain with chewing. Encourage your child to eat a well-balanced diet at regular intervals and include planned snacks even when he or she may not feel like eating. Try to reduce the amount of food he or she needs to eat by increasing the nutrient content of each bite of food or drink. For example, add melted cheese, gravies, margarine and dips to foods, and offer whole milk. This can help prevent weight loss and poor growth. Most children with arthritis need additional calcium and vitamin D to help strengthen their bones.

On the other hand, children with arthritis may gain too much weight due to corticosteroid side effects or limited activity. Excess weight puts extra stress on joints such as knees, hips and ankles. Appropriate exercise combined with eating a well-balanced diet based on the basic four food groups can help your child maintain a normal body weight. A registered dietitian can teach you ways to improve your child's diet.

Surgery

Surgery is rarely used to treat juvenile arthritis early in the course of the disease. However, surgery can be used to relieve pain, straighten out a bent or deformed joint, or replace a damaged joint.

In joint replacement surgery, the entire joint is replaced with an artificial joint. This procedure is used mainly in teenagers whose growth is complete. The most common reason for joint replacement is severe pain in a badly damaged joint. The most commonly replaced joints are the hips, knees and less often, wrists. When used appropriately, joint replacement surgery can significantly reduce pain and improve function.

Soft tissue release may help improve the position of a joint that has been pulled out of line. During soft tissue release surgery the surgeon cuts and repairs tight tissues that cause a contracture, allowing the joint to return to a more normal position.

Fusion surgery is indicated when the joint becomes so severely damaged that pain relief or return to function can not be attained with other modalities. Fusion is when the surgeon permanently fixes the joint in a functional position, thus relieving movement that contributes to pain. Examples include the wrist or ankles. If the cervical spine (neck) is unstable from arthritis, fusion may be required to stabilize the spine and prevent serious injury.

EMOTIONAL ISSUES

Your child may feel angry or sad about having arthritis. In addition, parents, siblings and other family members also have emotional reactions to the disease and its effect on the family. Learning to cope with arthritis will benefit everyone. It is important to realize that emotional and social impairment may do more long-term harm to your child than the disease itself if not addressed early and appropriately.

When you are first told your child has arthritis, you might feel shock or disbelief. You also may feel guilty and ask yourself if something you did or didn't do caused your child's arthritis. While these thoughts are common for parents whose children are ill, you are not to blame. Remember, you are not the cause of your child's arthritis.

The child with arthritis may feel many different emotions. Children can feel hurt by an illness that isn't their fault, blame parents for the illness, and engage in self-pity or become angry because of restrictions on activities, unwanted

medications and therapeutic exercises. They may also resent other children who do not have the disease, including their brothers and sisters.

Siblings may feel left out and resentful because of the amount of time and attention given to the child with arthritis. Or they may feel guilty, as if they somehow caused the illness. Some siblings may feel pressure to achieve or make up for what their sibling with arthritis can no longer do. Others want to involve themselves in caregiving to the point that they give up their own activities. In these cases, try to help siblings find other ways to deal with their feelings. Let brothers and sisters settle their own differences. Whenever possible, encourage siblings to talk with peers who live in homes with similar concerns. Parents should also set aside special time to be with their other children.

How You Can Help

The key to dealing with emotions is to talk about them with one another. Your attitude toward arthritis will affect the way your child feels about arthritis. Talk to your child about how she or he feels about the illness. Allow your child to express his or her anger about having arthritis. Talk to your other children about arthritis. Let them express their feelings about the disease. Encourage the family to treat the child with arthritis as they did before he or she became ill as much as possible, remembering that he or she will need some extra attention.

Expect your child with arthritis to behave as well as your other children and share household responsibilities. Avoid making arthritis or a related condition the center of attention. Avoid giving your child special privileges. Assigning chores that he or she is capable of doing and keeping your child active teaches them how to adapt and increases their self-assurance. Being

consistent will help your child learn what is expected. When your child first becomes ill, you may set aside relationships with other family members. It is important, however, to continue to talk and spend time with others. Special times should be planned to spend alone with your spouse or with the entire family.

Encourage your child to learn as much as possible about arthritis and the treatment program. Older children can be responsible for taking medications on time, reporting medication side effects to you, and following an exercise program. These responsibilities will help prepare them for the transition to adult health care.

Adolescence can be an especially challenging time for children with chronic illness. Peer acceptance, including the need to look and act like everyone else, will be important to your child. In addition, it is developmentally appropriate for your child to desire to separate from the family and begin the transition to independence from parents.

Chronic illness can impede this natural transition and make attainment of normal developmental milestones more difficult. Encourage and support them in asking questions of providers about their treatment program, future health implications and social issues. Try not to overprotect your child. While this is a natural reaction, it can interfere with your child's emotional development and independence. Encourage your child to complete tasks that he or she is capable of doing. Don't be manipulated into allowing activities that are harmful, but compromise when possible.

SCHOOL ATTENDANCE

Children with arthritis should attend school regularly and not be isolated from other children of the same age. However, your child may need

special materials and services to help him or her get along in school. Regular attendance should be expected despite morning stiffness or pain.

It is important to educate your child's teachers, the school nurse, and the principal about arthritis and its effects on your child. A member of your child's health-care team may be able to help educate these professionals about arthritis. This is a process that should be repeated at least annually as your child interacts with new teachers or starts at a new school.

ADDITIONAL RESOURCES

Arthritis education is very important for you, your child and the rest of your family. Helping children and their families cope with a chronic, often unpredictable, and frequently painful illness of uncertain outcome presents a great challenge. The American Juvenile Arthritis Organization (AJAO) provides families with networking and educational opportunities through participation in regional and national juvenile arthritis family conferences. AJAO also assists with educating teachers and school administrators to ensure that the child's educational needs are met.

Many local Arthritis Foundation chapters and pediatric rheumatology centers have family support groups that provide resources, avenues for sharing ideas and feelings, and a place to meet and learn from other families who truly understand what your child is experiencing. They also may offer opportunities for families to learn about many aspects of managing juvenile arthritis from experts.

If emotional stress becomes great, it may be helpful to seek professional counseling. Your child's doctor, nurse or medical social worker may be able to help you, or may be able to refer you to other sources of help.

Federal Laws that Can Help

Several federal laws give your child rights by barring discrimination against children with disabilities in public schools and requiring private schools to be accessible. These include:

Public Law 101-476 Formerly the Education for All Handicapped Children Act PL 94-142: Says that every child has a right to a free, appropriate public education, whether or not the child has a disability;

Part H of the Individual with Disabilities Education Act (IDEA): Provides money to states to identify infants and toddlers with developmental disabilities, and offer them and their families early intervention services until the age of three;

The Americans with Disabilities Act: Requires private schools, day-care centers, and nurseries to be accessible to children with disabilities and bans discrimination in hiring and employment;

Section 504 of The Rehabilitation Act of 1973: Bans discrimination against disabled persons in programs that receive federal funds and allows for accommodations to be made in school programs.

Financial Assistance

As it may sometimes be difficult to get affordable private health insurance that covers all aspects of arthritis care, you should be aware of available financial assistance and health insurance programs. Some public programs that can help are listed below. Your medical social worker will be of great assistance in determining which program is right for you and in the application process.

Supplemental Security Income (SSI): This is a monthly payment from the federal Social Security Administration (SSA) to people of any age that are disabled, blind or aged if they have limited income and resources. In most states, children who receive SSI automatically qualify for Medicaid. Contact your local social security administration for more details.

Medicaid: Even if your income is too high for SSI, you may still qualify for Medicaid. In certain states, families with large medical bills may be classified as medically needy if medical expenses substantially reduce their income. Some states also separate the child's assets from those of the parents, enabling a child to qualify for Medicaid. Contact your local health and human services department for more information.

State Children's Health Insurance Program (SCHIP): The Balanced Budget Act of 1997 created a new child's health insurance program called the State Children's Health Insurance Program. This program gives each state permission to offer health insurance for children up to age 19, who are not already insured. SCHIP is a state-administered program and each state sets its own guidelines regarding eligibility and services. Families who earn too much to qualify for Medicaid may qualify for SCHIP. To get information regarding SCHIP in your state, contact your local health and human services department.

State high-risk insurance pools: Some states have created programs to provide health insurance to people who cannot get health insurance anywhere else. Coverage may be expensive and may not cover preexisting conditions like arthritis.

Social Security Disability Insurance (SSDI): A disabled child under age 22 can receive SSDI benefits based on a parent's work history and Social Security record if the parent is retired, disabled, or deceased. A child who has received SSDI benefits for 24 months becomes eligible for Medicare. Contact your local social security administration for more details.

State programs: Under the federal Title V program, states receive funds to provide rehabilitation and other services for disabled children under age 16 who qualify. States may also have other funds to cover care and services for families and children. Contact your local Health and Human Services Department for more information.

FOR MORE INFORMATION

The following publications from the Arthritis Foundation may be helpful as you and your child learn to manage juvenile arthritis.

Kids Get Arthritis Too – A bimonthly newsletter filled with the information your family needs to live successfully with arthritis. Call (800) 283-7800 for ordering information.

Raising A Child with Arthritis: A Parent's Guide – This book is an essential guide to understanding and coping with the challenges of caring for a child with arthritis. It includes reliable advice and information from top pediatric health professionals.

When Your Student Has Arthritis – An overview of arthritis, including juvenile rheumatoid arthritis and treatment. Also includes a school activity checklist for students, education rights and how teachers can help.

THE ARTHRITIS FOUNDATION

The mission of the Arthritis Foundation is to improve lives through leadership in the prevention, control and cure of arthritis and related diseases.

The Arthritis Foundation supports research with the greatest potential for advances and has invested more than \$320 million in these efforts since its inception in 1948. Additionally, the Arthritis Foundation supports key public policy and advocacy efforts at a local and national level in order to make a difference on behalf of 70 million people living with arthritis.

As your partner in taking greater control of arthritis, the Arthritis Foundation also offers a large number of programs and services nation-

wide to make life with arthritis easier and less painful and to help you become an active partner in your own health care.

Contact us at (800) 283-7800 or visit us on the Web at www.arthritis.org to become an Arthritis Advocate or to find out how you can become involved.

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For more information: The Arthritis Foundation offers a wide variety of books, brochures and videos about different forms of arthritis, treatment and self-management techniques to help you take control of your arthritis. To order any of these products, become an Arthritis Foundation member or to subscribe to the Arthritis Foundation's award-winning consumer health magazine, *Arthritis Today*, call (800) 283-7800. Call or visit our Web site (www.arthritis.org) to find out how you can take control of your arthritis and start living better today!

MISSION STATEMENT:

The mission of the Arthritis Foundation is to improve lives through leadership in the prevention, control and cure of arthritis and related diseases.

This brochure has been reviewed by the
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