

Life with Arthritis and Rheumatic Diseases

Different Challenges and What Can Help

There are many challenges that children with juvenile arthritis and rheumatic conditions face, from explaining their condition to friends to navigating through the school system. However, there are many ways that parents can help their children.

Have a Relationship with Your Child's Care Team

When your child is diagnosed with a rheumatic disease, they will begin to see a pediatric rheumatologist. This means that they will have an expanded health care team. Instead of seeing only a pediatrician, they will also be seeing a pediatric rheumatologist, medical specialists, and allied health professionals. You should be familiar with everyone on the team, so that you can help coordinate care and services for your child. These people will help you make important medical and health decisions, so it is important that you are comfortable working with them. Asking questions and sharing insights with your child's medical team will help enhance care for your child.

Keep Thorough Medical Records

Staying organized is essential to managing your child's medical care. This means that you should maintain detailed medical records at home. It is much easier to keep medical records organized when they are all in one place. Your family should keep a binder for important medical information, such as notes from your child's medical team and a chart of medications. You should also keep lab reports, immunization records, X-rays, imaging reports, therapy reports, and surgical records. Another section in your binder should contain insurance information. If you would prefer, there are many sites online that offer excellent ways to organize and view your child's medical information. If you choose to use an internet site, investigate the site to make sure it is extremely secure.

Get Your Child's School Involved

Children with arthritis and rheumatic conditions may need special accommodations at school. Just as education is important for your child and family, it is also very important for you to educate your child's teachers, the school nurse, and the principal about your child's condition and its effects. Parents should schedule a meeting with school staff members who see the child on a regular basis and discuss special needs, procedures to be aware of, medications, upcoming absences, activity limitations, emergency information. A member of your child's healthcare team may be able to help. The Arthritis Foundation also has many resources on navigating the school system.

Be Active

When joints are sore or painful to move, it is natural to want to rest. However, it is very important to maintain a regular exercise program. Strong and healthy muscles can help support and protect affected joints. Exercise also helps to maintain range of motion in the joints. Physical therapy and occupational therapy is very important in treating conditions that affect the joints, and will help in creating exercises for your child. If your child sees a physical therapist, the physical therapist will help your child to improve their mobility. If your child sees an occupational therapist, the occupational therapist will help your child with activities of daily living. Both types of therapists will give your child therapeutic exercises. These exercises are critical for your child to routinely practice. In addition to therapeutic exercise, sports and recreational activities are important for your child. Recreational activities help the joints and muscles, build social skills, and are fun! Work your child's pediatric rheumatologist, physical and occupational therapists, and sports coaches to find safe activities for your child.

Stay Educated

Education on your child's condition is important for you, your family, and your child. You should become an expert on your child's condition. When you are knowledgeable about your child's disease, you are better equipped to treat it! Being educated on your child's conditions can also help in learning to cope with the emotional aspects of the disease. However, patients must be selective when accessing medical information from the Internet. While the Internet is becoming a major source of healthcare information, there is a lot of misleading and dangerous information on diseases. For guidance on using Web resources, ask your doctor for suggestions and visit the Medical Library Association's *Guide to Finding and Evaluating Health Information on the Web*, at <http://www.mlanet.org/resources/userguide.html>.