

Ways to Advocate for and Support your Child

Whether you're new to arthritis or a seasoned pro, it's important to remember that you play a vital role in advocating for and supporting your child. From pulling together your care team to helping your child cope, here are some practical tips to help you be at your best.



Assemble your care team

Regular follow-up appointments with healthcare providers are essential for effectively managing juvenile arthritis. Who should be on your care team list?

- **Primary care physician**—The ideal PCP will act as your quarterback, providing additional referrals and helping you manage your child's health.
- **Pediatric Rheumatologist**
- **Pain management**
- **Physical and/or occupational therapists.**
- **Ophthalmologist**—especially important if your child has uveitis or is at high risk of developing uveitis or is on certain treatments that may affect their vision.
- **Dentist**—Some children with arthritis will deal with temporomandibular joint (TMJ) or other dental issues. Make sure your dentist is aware of any diagnoses and medications.
- **Pharmacist**—to help catch potential prescription interactions, etc.
- **Mental Health Provider**—Dealing with any chronic illness can be difficult, leading to feelings of isolation, anxiety, and depression. Having a mental health provider can help your child process and handle these big feelings in a healthy way.

Make sure to check with a rheumatologist before you engage in complementary or alternative medicine practices.

Some questions your pediatric rheumatologist may ask you and your child:

- **Where does it hurt?** When does it hurt? How long has it hurt?
- **Are there activities** your child used to do easily that are now difficult?
- **Has there been an injury** to the joint from an accident, hobby, or sport?
- **Has anyone in your family** had similar problems?
- **What important events** in your child's life may affect their arthritis or the way they take care of themselves?
- **Is your child experiencing any unusual symptoms or side effects?** If so, what and when did these start?

Some questions you might want to ask your child's pediatric rheumatologist

- **What should we do** if we experience side effects?
- **What type of symptoms** or issues mean we should call in for help?
- **Are there limitations** on which vaccines my child can receive?



Consider tracking your child's symptoms regularly to share with providers when you see them. This could be on paper in a binder, using an app on a tablet, or using a spreadsheet on a computer. Some things you may want to consider tracking include:

- **A body outline** where they can color in or circle the painful areas (This can also be used to track psoriasis or rash!).
- **Pain levels** and locations.

If your child struggles with mobility, consider asking for an accessible parking placard if applicable. Eligibility for accessible parking placards will vary by state. Likewise, consider opting for wagons or electric scooters when you go out to places such as the zoo. These may help your child save their energy for fun things.

Think about accessibility changes you can make in your home to help your child spend less energy on tasks or be more independent. This might include a grabber to pick up toys or clothes from the floor, grab bars to get in and out of the tub, a shower seat to rest while showering, a loofah on a handle, adding motion sensor lighting into their closet and dresser, etc.



Some other assistive devices, mobility aids, and accessibility changes to consider can include: braces or splints to support affected joints, adaptive utensils to make eating easier, mobility aids like crutches or walkers, electric toothbrushes, water flossers, doorknob turners (if your doorknobs aren't lever-style), clothes that are easy to put on and take off, adding rings or other dangles to zippers for easier use, flexible straws, and voice-activated computer or assistant equipment (Dragon, Siri, Google Assistant, Alexa, etc.).

If you rent and your landlord isn't keen on certain changes to your living space, the [Fair Housing Act](#) covers you. Your local [Independent Living Center](#) can help you navigate any issues you run into here.