

Understanding Systemic Juvenile Idiopathic Arthritis

Social Effects

One of the most important skills for both parents and kids with juvenile arthritis (JA) to learn is how to communicate about their chronic disease with others. With systemic juvenile idiopathic arthritis (SJIA) especially, talking about this complex disease and its symptoms and side effects can be challenging.



Parents of Children With SJIA

Parents play a major role in advocating for their child with SJIA. For younger children with SJIA, a parent will primarily communicate with others and can guide their child in how to have these conversations as they get older.

When the topic comes up, whether it's a parent or child communicating, here's a conversation starter:
"You might not know it, but kids get arthritis, too. I have a form of arthritis that affects more than just my joints. It affects my whole body, including my immune system."

Family Members

- "SJIA is unpredictable. I love spending time with you, but sometimes I might cancel plans when I don't feel well. Since my immune system doesn't work right, it's really important that I avoid people who are sick. Even a mild cold can lead to a serious illness for me."
- "SJIA symptoms are often invisible, so I might look like I'm fine even when I have a lot of pain or fatigue."

Teachers & Coaches

- "Sometimes I'm really tired and I might need extra help at school, like help carrying my backpack or extra time to get to class or finish an assignment."
- "I'd like to participate in this sport as much as I can, but there might be times when I have to miss practice or a game. Is there something else I can do when I'm not up to playing?"



Child with SJIA



Friends With SJIA

- "I'm so glad I have friends like you who understand what I deal with because of JA."
- "Have you ever been to an Arthritis Foundation JA Camp or JA Conference? It's awesome to be around other kids like us who just get it."
- "My friends from JA Camp and I stay in touch and play games online together. It's nice having friends I can get ideas and learn from. I know I'm not alone on my arthritis journey."



Friends Without SJIA

- "Kids can get arthritis, and I have a form of it that affects my entire body. Even though I might not look sick, sometimes I don't feel well at all and I hurt."
- "Sometimes I can't play or do things everyone else is doing because of my arthritis, but it doesn't mean I don't want to, so even on my bad days, I hope we can find something we can do together."



Health Care Providers

- "I am taking my medicine and trying to move a lot, but sometimes I can't sleep well. What can I do to make it easier to sleep?"
- "I have a hard time because other kids don't understand why I miss school sometimes or why I have a hard time moving and walking."
- "It's frustrating to miss school for appointments. Can we have virtual appointments so I can stick to my schedule more?"

Find more details about SJIA here.