MENTAL HEALTH AND JSPA:

OUR KIDS' WELLNESS, AND OUR OWN

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Parents and caregivers who care for a child with a chronic illness like juvenile spondyloarthritis (JSpA) know it impacts the whole family. It can alter the family equilibrium and affect the family socially, psychologically, and in everyday interactions—inside the home and with others.

This is a subject on which I could write an entire book. But for this article, I would like to focus on one important facet: The child diagnosed with the chronic illness and how we as parents and caregivers can support their mental health. (I hope this article can serve as a helpful overview, but please note that it should not replace medical guidance from your healthcare provider or mental health professional.)

Children already face a variety of challenges: academic pressures from school, the need to fit in socially, and the development of a self-identity in a complicated world, to name a few. A chronic illness adds additional pressure that manages to percolate into every area of a child's life.

To best address childhood and adolescent mental health, it helps to have a general understanding of child development. By understanding this, we can determine what is relatively normal for our child and what is not.

How children express, process, and understand pain and other symptoms may look very different depending on the age group. For example, a five-year-old may have difficulty expressing their pain because they don't have the vocabulary necessary to describe the nature of the pain. As a result, the child may act out in other ways.

Cognitive development related to age also plays a significant role in how children understand their illness. Younger children can understand what is happening to them, but they may not fully understand why. Meanwhile, older children and adolescents might think about their illness in more abstract terms, such as its implications for their lives and impact on their life purpose. This is critical for addressing any symptoms of anxiety and depression that may surface.

Finally, an understanding of child development can empower us to support our children in the best possible way. We can understand what is typical for their age range and quickly address any issues indicating that they might be struggling.

JSpA is a systemic disease, meaning it can affect the whole body. Flare-ups in any part of the body complicate and can limit activities and pursuits our children enjoy. Social interactions, enriching activities, and the ability to play are all crucial components of their emotional development. These pursuits teach our children appropriate social behavior with their peers, collaboration, and how to entertain themselves. Unfortunately, these are also the activities that can get disrupted when a child isn't feeling well. As caregivers, we can be vigilant and keep an eye out for signs of behavioral problems resulting from a lack of development in this area. If issues arise, we can work with healthcare providers and professionals to support our children to help them stay on track.

One of the best things we can do for our kids is teach them how to regulate their emotions. This is especially critical for young children who (regardless of having a chronic illness) are learning which emotions they can manage and what constitutes a healthy response to that emotion.

Children look to their parents for guidance on what to do in a novel situation. This is why babies or young children often look at their parents when they are unsure how to respond to a problem. This behavior is present throughout all of childhood. A chronic illness is an unknown situation—and a complicated one, with many open-ended questions that we must learn to navigate alongside our children. But how can we reassure our children if we are overwhelmed with questions, ourselves?

We as parents and caregivers must manage our own emotions because our children are watching us and will eventually emulate our behavior. It's a challenge that we fail more often than we want to admit. It's okay to feel what we feel throughout this challenging journey. After all, we're entitled to our feelings, too.

We must examine our behavior and determine if our response to our emotions is healthy and appropriate. It's often helpful to ask yourself, "Would I want my child to react the way I did in front of them?" With solid role models, our children will learn that they can process extremely unpleasant feelings like sadness, fear, and anger in healthy ways. The roller coaster of emotions we experience when dealing with a chronic illness like JSpA is an unexpected call to improve our own emotional regulation skills.

Being able to process emotions in healthy ways can help children better manage their challenges. Many mental health issues such as anxiety, depression, and behavior problems can stem from a lack of emotional regulation. To put it simply, not knowing what to do with painful emotions puts one at risk of self-destructive behavior in adulthood.

If you've ever been to counseling yourself, you might know that a big part of psychotherapy is learning how to process difficult emotions in beneficial ways. Why not empower our children from an early age with these skills?

Additional Resources:

Emotional Intelligence and other books by Daniel Goleman

Conquering Your Child's Chronic Pain: A Pediatrician's Guide for Reclaiming a Normal Childhood by Lonnie K. Zeltzer, MD, and Christina Blackett Schlank

Children with Chronic Conditions: Perspectives on Condition Management (nih.gov)

Chronic Illness and Children (aacap.org)