

## Handing Back Childhood – March is Childhood Arthritis Awareness Month

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Arthritis is often misinterpreted as a disease for older adults, a disease that causes stiffness and sore joints but that is a natural part of aging. However, arthritis is not just "aches and pains"; it is a debilitating disease that can alter the lives and lifestyles of people of all ages. one in four Nova Scotians live with arthritis, the highest prevalence in Canada, and 60 percent of those people are of working age or younger.

As many as 24,000 Canadian children and teens live with arthritis, or more than three in every 1,000 children. Many schools have at least one child with juvenile arthritis in their student body and it is The Arthritis Society's mission to advocate for those children and support greater understanding of their disease.

While the cause of arthritis remains a mystery, we do know that juvenile arthritis is an autoimmune disorder in which the body's own immune system attacks tissue in and around the joints. Fluid in the joints can cause pain and swelling and after time the inflammation can lead to permanent damage.

There are two main types of juvenile arthritis that can develop in children between the ages of 12 months and 16 years: oligoarticular arthritis and polyarticular arthritis. Oligoarticular arthritis affects up to four joints and usually involves the knees. Children living with oligoarticular arthritis also have an increased risk of developing uveitis, the chronic inflammation of the eyes which can be very serious. Polyarticular arthritis affects five or more joints and usually impacts the fingers and toes. Many joints can be affected by arthritis including ankles, knees, wrists, elbows, the jaw, fingers and toes. Stiffness and swelling in any of these joints can affect a child's life, taking it longer for them to do everyday tasks.

"Usually when I wake up, my fingers are really stiff. I take a hot shower and the heat helps me reduce stiffness. It takes about an hour and a half to exercise my fingers and go through my morning routine,"

– Veronika, 15.

Arthritis can create challenges in even the simplest tasks and often children and students struggle to talk about their disease, what it is like to live with pain, and how it affects their schooling and their relationships with their peers and teachers. Since juvenile arthritis affects each child differently, the signs and effects can be hard to recognize. Flare ups can last for weeks or months, and then go into remission, leaving the child symptom free. Pain can vary drastically, even within the same day, which is difficult to understand.

"In the morning it would hurt a lot and my friends could see it hurt a lot. But then after lunch I felt better and they would think I was lying," — Jack, 11.

Children living with arthritis move between the world of the well and the world of the disabled. This inconsistency often leaves teachers and other children less able to recognize and consider the real difficulties that face children living with arthritis.

"I have to remind my teachers that I can't do this, or have to remind them that I have arthritis and I'm hurting. Sometimes they just forget. It got to a point that I thought it was my fault that they can't remember that I have arthritis," — Cindy, 16.

The pain of arthritis can affect a child's ability to get out of bed, to get ready for school, or open their lunch pail and

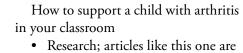
containers. If the arthritis affects their fingers and wrists, writing and holding a pen or pencil can be a struggle and affect their ability to get work done on time. Arthritis can also affect a child's learning experience due to the number of missed school days caused by pain or the numerous appointments and meetings with specialists.

"I have a lot of appointments, especially with my occupational therapist, and rheumatologist. I have to go to a clinic to do my pain medication because they do it through intravenous so I can't really do that at home or at school" — Veronika, 15.

Children with arthritis take antiinflammatory medication to control their disease and must undergo regular blood tests. Some medications put children at a higher risk of infection. Sometimes finding the right medication can be a challenge, and children have to face the adverse side effects until the right one can be found.

"Some of my medication affects my liver. Others lower my immune system, so I get sicker more quickly than other people do. I have a needle phobia that I go to a psychologist for. This makes it so I have trouble with bloodwork and treatments. I also get nosebleeds that are hard to stop because of the medicine I take"

-Rylund, 12.



- a great first step in open and effective communicationShow you care; recognize what
- the child is facing and talk about available accommodations

   Allow children with arthritis to
- have the same experiences, just differently from other children
  Listen, be patient with the child as they learn to explain the effects
- of arthritis on their bodyLet children take part in their own way, at their own pace
- Be a source of encouragement
- Show compassion

"I have special needs, but I am not a child with special needs. I just need tools to help me," — Veronika, 15.

The Arthritis Society is a charity that advocates on behalf of people living with arthritis. Since 1948, The Arthritis Society has been the largest nongovernment funder of basic and applied arthritis research in Canada, searching for underlying causes and the subsequent cures for arthritis. With so many people in Canada living with arthritis it is our priority to offer a wide range of programming to provide education, information, and services for those living with arthritis and their families. We advocate on behalf of Canadians living with arthritis, ensuring they have timely access to appropriate services and treatment options, while promoting greater understanding of the disease.

If you would like to learn more about arthritis or programming events in your area, visit our website www.arthritis.ca.

If you are interested in hosting an arthritis program in your school or classroom please contact Kim Slauenwhite, Community Education Coordinator, Nova Scotia Division at info@ns.arthritis.ca.









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