DAD HAS ANKYLOSING SPONDYLITIS

Two short graphic stories to explain spondyloarthritis to children
A Message from the Canadian Spondylitis Association

The Canadian Spondylitis Association (CSA) is a national non-profit organization run by patients living with Spondyloarthritis which include:

• Ankylosing Spondylitis
• Psoriatic Arthritis
• Undifferentiated Spondyloarthritis
• Enteropathic Arthritis
• Reactive Arthritis
• Juvenile Onset Arthritis

The mission of the CSA is to create awareness of Spondyloarthritis in order to ease the path to diagnosis. Our vision is to be the primary resource for people diagnosed and living with Spondyloarthritis in Canada. We achieve this through awareness, research, support and advocacy across Canada.

I am the President of the CSA and I live with both Ankylosing Spondylitis and Psoriatic Arthritis. Like many of you I have had my fair share of challenges over the years. When I became a father I realized how difficult it was to explain my illness to my daughter. Trying to explain my condition, symptoms and therefore my daily limitations to a 6 year old seemed impossible. I found this book to be very helpful for me and my daughter. She started pointing to the pictures of the swollen joints and understood clearly why Daddy couldn’t do everything other Dads were able to do. We sit together quite often to read this book and she even shows her friends.

For those of you living with Spondyloarthritis I hope that you find this book of value and encourage you to join the Canadian Spondylitis Association (www.spondylitis.ca) for continued support and education.

Gerald & Tessa Major
Cat to the rescue!

Dad! Help, I'm going to fall!...

Don't panic, hang in there, I can't come and get you!

But why?

You know why, it's my ankylosing spondylitis...

I'm in pain today and I can't move as I'd like to.

Ankylosing spondylitis mainly causes the joints to become inflamed.

The joints are the junctions between the bones (in this case the vertebrae). They swell and become painful.

The disease attacks the spine, which is the series of small bones that run down the back...

... but sometimes also the pelvis, hips, knees, ankles...

Inflammation is the body's response to an injury or burn. It's painful, warm, red and swollen.
That’s why my back’s a bit stiff and I can’t catch you.

Concentrate hard so you won’t be afraid.

What would a superhero do?

Concentrate hard so you won’t be afraid.

He’s going to save you! Follow him!

Hey! How did that cat get there?

Yaaaaay, I did it!

Mamma, mamma, I got caught in the ropes at the playground and a cat showed us what to do...
Just like tai chi

Wakey-wakey, shower time!

Mam? Why is dad not having breakfast with us?

Because he needs time to get up. His back hurts a lot...

... The joints in his back and sometimes in his knees and elbows are swollen when they don't move, and it hurts...

... You know, he'd love to be with us, but he can't, it's his disease, called spondyloarthritis.

... After a night's sleep, he needs to move them gently to "unfreeze" them.
Hey, Daaad

I'm OK today, not too much pain...

... I can even take you to school.

Hey, Daaad

It is good for me to move, you know I can walk, but I don't find it easy to run!

Look at their slow moves. Do they have a similar disease as you?

No, that's Tai Chi, a martial art. What I have is an-ky-lo-sing spon-dy-li-tis!

Mam, mam, I saw people practicing Tai Chi and because of that I can remember the name of Dad's disease: ankylosing spondylitis!

That evening...
Andy is ten years old and his father has ankylosing spondylitis, a painful condition that affects the back. This disease can impact family life, as shown in the two graphic stories in this booklet.

**Ankylosing spondylitis, a disease that affects family life**

Ankylosing spondylitis mainly affects the joints of the pelvis and back but can also affect the main joints of the limbs (hips, knees, ankles, elbows, wrists) and often the Achilles' tendon.

The main symptoms of the disease are pain, stiffness and fatigue. It develops in flare-ups followed by remissions. In the long term, the inflammation can cause the joints to ossify, causing loss of mobility and disabling spinal deformities. It may be accompanied by inflammation of the eyes, skin and intestines.

The first symptoms most commonly appear between the ages of 20 and 35. Although its intensity and development vary from one patient to the next, its symptoms and the restrictions and limitations it causes do affect family life in most cases.

It is important to tell your family and friends about this disease. The purpose of this booklet is to help explain the disease to children and enable you and them to talk about it.

For further information visit:
www.spondylitis.ca