

# Juvenile Idiopathic Arthritis

## Emma's Story

Juvenile Idiopathic Arthritis (JIA) is a general name for several kinds of arthritis. "Juvenile" means that it affects young people, "idiopathic" means that we don't know what the cause is; and "arthritis" means inflammation of the joints. JIA is chronic arthritis that begins in children under 16 years of age. It causes inflammation in one or more joints for six weeks or longer. JIA can appear in many different ways and can range in severity. It mostly affects the joints and the surrounding tissues, although it can affect other organs like the eyes. Some of the symptoms and signs of an inflamed joint include joint swelling, pain, stiffness (especially in the morning), and warmth around the joint. Your child may not have all of these in every joint that is inflamed. Less commonly your child may also have other symptoms such as fever, rash, loss of appetite and loss of weight.

When 5 year old Emma Pearce was diagnosed with JIA, her parents Peter and Leanne didn't even realise that this condition existed.



Dr Adib, Emma Pearce & Dr McCrossin

Peter and Leanne thought arthritis was a condition of older people and didn't know children could get arthritis. Since Emma's diagnosis it has been a steep learning curve for the family. Peter and Leanne do things like break up car trips every hour or so, this way Emma can move around and doesn't have to sit in the one place for too long. Emma's parents were suddenly thrown into a world of hospital visits and injections and figuring out the best way to give

these to Emma without causing distress and creating anxiety. This was difficult in the beginning and they have now worked out a strategy that works well for them which includes injecting Emma while she is asleep. "In hindsight, we can see that Emma had symptoms for a while. She had what we now know is a "flare-up" on Queens Birthday holiday 2008", Peter said. Emma's tolerance to pain was normally very high, we could see that she was tired and lethargic and obviously in pain.

JIA affects each child differently, and treatments are tailored to suit each child. The main ways of treating arthritis in children are to give medications to control the inflammation and exercise to keep the joints moving and muscles strong. Also, in some cases splints are used to support the joints, injections into the affected joint are given to reduce inflammation and pain management strategies are used to manage the pain. The goals of treatment is to reduce inflammation and pain, prevent or slow down joint damage and to get the child back into mainstream life as soon as possible.

As soon as Emma was diagnosed, Peter and Leanne were able to get help very quickly. "Dr Adib referred us to Arthritis Queensland, and Kellie sent us up heaps of information straight away. She also referred us on to Montrose Access", Peter advised. Emma's diagnosis has affected the family in a number of small ways. "We have had to change her lifestyle a bit, but not too much as we want her to have a normal childhood" said Peter. There have also been small changes in the daily routine, such as having a warm shower in the mornings to ease her joints.

When asked what arthritis is Emma replied; "I think it is sore bones." She went on to say that "Sometimes I get sore bones, I get sore knees and hands and



shoulders in the morning, but not this morning." Emma doesn't let her condition hold her back, refusing to let her sore joints stop her from playing with her friends. Emma says that she likes having arthritis "because I get to sit on a chair during carpet time". Everyone else has to sit on the floor. Peter says that they have been very lucky because Emma's teacher has a child with a joint condition and is very understanding of Emma's needs.

"The backup from Arthritis Queensland and Montrose Access has been unbelievable. I have been able to get information straight away via email. The Arthritis Queensland and Montrose Access visit has been a god-send to us. It saves us the long trip to Brisbane, and these visits educate local doctors and even teachers" said Peter. Arthritis Queensland together with Montrose Access and Dr Adib conducted outreach clinics earlier this year in both Gladstone and Mackay.



Emma Pearce and Lynne Borgert