



October 23, 2008

Childhood arthritis is a different story – hidden problem revealed

New report shows that children with arthritis suffer enormously and that there are significant numbers of adult Australians whose arthritis started in childhood.

“People simply don’t understand that arthritis in children is very different from adults and don’t take it seriously,” says Robin Grindrod, mother of a 15 year old who has had arthritis since the age of eight. “She misses about a third of her schooling through pain and disability and I even struggled to have the education system make provision for her to use a laptop because she has difficulty holding a pen.”

“This new report from the Australian Institute of Health and Welfare (AIHW) is excellent and most welcome,” says Ainslie Cahill, Chief Executive of Arthritis Australia. “It documents – probably for the first time – how wrong it is to think of childhood arthritis as similar to what adults’ experience.

“Arthritis doesn’t discriminate and, no matter what age, severe forms can make everyday living a challenge. For children living with arthritis, school, sport, playing and partying aren’t much fun when mobility is compromised and painful flare-ups take so much enjoyment away. Sometimes participation is not even possible.”

“We are not talking about osteoarthritis, the wear and tear form of arthritis that adults are mostly effected by. In children, arthritis – juvenile arthritis is the commonly used term – is an inflammatory disease. It is often characterised as one of the auto immune diseases with the inflammation predominantly effecting the joints’ explains Dr Jeffrey Chaitow, a Paediatric rheumatologist and Head Department of Rheumatology at The Children’s Hospital at Westmead. “The persistent inflammation potentially damages the joints causing long-term problems. Pain and stiffness affects most of these children and can certainly have a dampening effect on their overall enjoyment of life.

“But I would say the secondary effects – and this is confirmed by this report – is that severe juvenile arthritis can markedly affect the child’s growth, their muscular development, their bone mineral density and even change how the child looks and feels, particularly their self esteem” says Dr Chaitow.

Adults whose arthritis began early in childhood tend to be more severely affected and in poor general health.

Treatment is improving markedly with new medications coming onto the market and currently being trialed in Australia as part of world wide multicentre trials.

The AIHW report has found that there are at least 4600 children with arthritis and 22,000 adults whose arthritis started in childhood. The vast majority of these children find it hard to mix socially because of their pain and disability; more than half cannot sit properly in class; more than two thirds are limited in what they can do physically and about one in two have trouble doing everyday tasks like tying shoe laces or holding a cup.

“From what I’ve experienced, these kids just want to belong but their joint problems don’t make that easy. Juvenile arthritis gets in the way of their lives and it can break your heart to see it,” says Robin Grindrod. “I want my daughter to grow into a happy, healthy and independent adult. Nurturing that independence is very difficult when there are very few support systems for these children living with arthritis to reach their full potential.”

An early and proper diagnosis is critical for ensuring proper treatment to arrest joint damage and control pain as is access to support services for the child and family.

Understanding is vital, too. Like all kids, those with juvenile arthritis don’t like being singled out or thought of as different. Schools and teachers can make all the difference - with accurate knowledge and a discreet helping hand the child’s path can be made easier so they too get the most from everything school has to offer.

Contact Arthritis Australia 1800 011 041 or www.arthritisaustralia.com.au for all juvenile arthritis information, including a copy of **Juvenile Arthritis, A Teacher’s Guide**.

Background

Juvenile Arthritis in Australia is a report prepared by the National Centre for Monitoring Arthritis and Musculoskeletal Conditions at the Australian Institute of Health and Welfare and is available from their website: www.aihw.gov.au

Juvenile Arthritis

This is defined in the report as arthritis in children aged under 16 which lasted at least six weeks. Often there are only one or two joints affected but it can spread to many and the sorts of conditions that produce arthritis in children can affect other parts of the body causing skin rashes, inflammation in the eyes and even kidney failure.

Treatment

Unlike adults with osteoarthritis where anti inflammatory drugs have only a limited affect, inflammation and immune system dampening medications are often at the heart of treating children with arthritis. These can have major side effects although newer (but more expensive) drugs appear to be safer. The trouble is that they often have not been tested properly in children or that they come in formulations which make it hard for children to take them. Access by children to suitable anti-arthritis medications is a significant issue and they sometimes rely on hospital pharmacists to provide the drugs.

Awareness

Juvenile Idiopathic Arthritis or JIA – generally known as juvenile arthritis – refers to all types of arthritis that affect young people less than 16 years of age. JIA is one of the most common as well as serious, persistent medical conditions of childhood. Depending on the type and severity of JIA, pain and discomfort experiences as well as the joints affected can change not only on a daily basis, but from one hour to the next. Puberty can be delayed by some medications and stiff joints and altered growth patterns can affect self image. With accurate early diagnosis and ongoing treatment, going to school, playing sport, partying with friends, learning a musical instrument, and holidaying with the family can be everyday activities for the young person with JIA.

Arthritis Australia

As the peak body for arthritis, Arthritis Australia is responsible for promoting awareness, early diagnosis and early intervention to improve and preserve sufferers' quality of life. In collaboration with its state and territory Affiliates it is providing a range of awareness, education and support services, as well as managing a national arthritis research program. Programs, including camps for children living with juvenile arthritis and support programs for parents are on limited offer. The gaps in service delivery have been identified and action is being sought to build capacity and reduce incidence and associated costs of arthritis. Priorities include:

- Increasing awareness and education activities
- Increasing consumer knowledge of treatments available and improving access to allied health services
- Ensuring quality use of medicines as well as access to appropriate medications to retard joint damage
- Maintaining quality services by evaluating consumer needs and service delivery

Media contact: Maggie Lanham on Ph 02 9975 7569 or 0412 281 277.