



Managing the impact of JIA on your family

>>> Information for parents of children newly diagnosed with JIA

Juvenile Idiopathic Arthritis (JIA) can affect not just your child but also the whole family. How it affects a family can depend on several things, including the type and severity of arthritis symptoms, the treatments required, and whether or not your child is in a flare-up. The ways that your child and family learn to cope with the demands of JIA are also important.

Most children and families manage the ongoing challenges of JIA very well. This sheet describes strategies to help your family deal with the impact of a child's JIA.

Time for everyone

Parents, and sometimes older children, often need to spend large amounts of time helping a child with JIA, especially during flare-ups when they need practical assistance and support. These extra demands are likely to shorten the amount of time that other family members would otherwise have for themselves, or other children. This can create frustration and resentment in the family. For example, a child may not understand why her parents are spending so much time with one of her siblings. To her, it may appear as if her parents are playing favourites. For very young children this problem may be made worse because they don't really understand that their sibling is unwell or in pain. Helping siblings understand about JIA symptoms and treatment is important to help prevent these problems. It is also important for parents to make sure they spend time with other children, and that they allow time for themselves as a couple, and as individuals. If parents' own needs for support and 'time out' are met, they are more likely to be able to provide ongoing support and care for their child with JIA in the long run.

The 'special' child

Parents are often tempted to treat their child with JIA as 'special'. This is understandable, as parents want to 'treat' their child to 'make up for' being unwell. Some parents also use treats as a way of showing love and support. Parents may also want to make sure that their child does not 'overdo it', and may expect them to do fewer chores, or attend school less than their siblings.

Although all children benefit from being 'treated' and feeling special every now and again, it is important both for your child with JIA, and their siblings, that the rules and expectations for each are roughly the same. This will avoid jealousy on behalf of siblings. It is also important for your child with JIA to understand that they can live a normal life, despite their condition.

Communication

The overall goal of managing JIA is for your child and family to lead as normal a life as possible. A return to normal does not mean that life will be the same as before, however. Managing JIA is likely to mean changes in the routines and organisation of your family. It may also mean that problems and feelings arise from time to time that need to be dealt with. To achieve this, families need to be able to communicate well with each other. Although it may be difficult, all members of the family need to be able to talk about how they feel and what they would like to happen. Some families find that having a weekly 'family meeting' helps make sure that everyone's feelings are heard. Others find that it is more helpful to spend one-on-one time with family members to discuss feelings and problems. Whatever works for your family is fine. The important thing is to be aware that every family member will be affected by JIA, and every family member will have feelings or problems they need to talk about from time to time.

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