



Managing the impact of JIA on your child's life

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

Juvenile Idiopathic Arthritis (JIA) can affect all aspects of a child's life, however the impact it can have on a schooling, socialising and mood can be potentially the most significant. This information sheet is about strategies you can use to help children live as normal a life as possible, despite having JIA.

School

School is the focus not only for education but also for children's social and sporting activities. During a long absence from school a child can fall behind in their studies, lose their place on teams, and sometimes lose their place in friendship groups. The longer it takes to return to school, the more difficult it may be for your child to settle back in.

Most children with JIA miss school at times, but may miss a lot of school when they are diagnosed or during a flare-up. Some children are pleased to be 'getting out of' school and may resist attempts to get them back into class. Other children can't wait to get back to school. The aim should be for children to return to school as soon as possible to help them maintain a 'normal' life and minimise difficulties settling back in.

Planning to return to school

It is helpful to make a 'return to school' plan with the help of your child's treatment team. These plans work best if they focus on specific goals that are important to your child. For example, your child's goal might be "I want to attend school." To help your child achieve this, it might be best to start slowly and attend a few half days per week before gradually building up to full-time. If your child has goals about not missing particular classes or extra-curricular activities, make a plan that involves them attending at these times. You can arrange for schoolwork to be sent home if your child is not attending regularly.

The 'return to school' plan should include how your child will cope with symptoms at school. It is helpful to plan this together with your child's teachers. Children should know where they can go if they need to rest, what to do if they are not feeling well, and who to speak to if they need special consideration with a task or activity. Staff will need to know about any medications your child takes at school, and plans made for where it will be kept. Information sheets about JIA for teachers and P.E. teachers should be given to the school, and a nurse can talk to the school if necessary. It may also be helpful for your child's classmates to learn about JIA, to explain your child's absence from school, and any differences in their behaviour when they return. Your child should be involved in deciding how much information to disclose, and to whom.

How to help your child cope with school

It is important to help your child have realistic expectations about their schooling. Stress from trying to achieve high grades or catch up on missed work may make pain worse, or increase the risk of depression. Intense pain and some medications can affect a child's ability to concentrate on schoolwork. Alternatively, your child may need to be encouraged to work hard at school, to remind them that JIA does not have to limit their achievements. Helping your child to be realistic and to pace themselves with schoolwork is important.

Pacing is also important with activities at school. Children often want to 'keep up' with their friends, and need to be reminded and encouraged to alternate between active and quiet activities throughout the day to minimise pain and stiffness. Your child can use strategies to manage pain at school such as pacing, changing activities and breathing and relaxation exercises. Help children learn to problem-solve and become confident in managing JIA by discussing difficulties they have had during the day, and suggesting strategies they could use to help.

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Socialising

Difficulties with friendships are common for children with JIA. They can have trouble keeping up with their friends due to physical limitations and absences from school, and are acutely aware of feeling 'different'. From primary school age, children desperately want to be the same as everyone else, and children can feel picked on when others ask questions about arthritis, although they may simply be curious about their condition. However, some children can be cruel, especially in primary school, and it is important to listen to your child's concerns to make sure they are not being bullied. For some children, 'being different' is the hardest part of having JIA.

Hobbies

Like school, hobbies such as sports, music and other activities should be continued to give your child as normal a routine as possible. Depending on the severity and nature of the arthritis symptoms, your child may not be able to return to their previous hobbies. For example, if your child used to build model planes but has arthritis in their fingers, this may no longer be realistic. It might be necessary for your child to develop new hobbies that can be enjoyed within the limits of their abilities.

Mood

Children with JIA may experience feelings of sadness and anxiety, low self-esteem and poor self-image. Many things contribute to these feelings, such as feeling different from others and unable to keep up with their friends, and worry about what will happen to them in the future. These worries generally get stronger during adolescence. Physical limitations and pain also contribute to feelings of depression. However this can be a vicious cycle, as feeling depressed reduces the motivation to be active, which can make pain and stiffness worse. Children with JIA are most at risk of depression if they feel defined by having JIA, rather than feeling like a whole person with lots of different strengths and qualities.

Ideas to improve your child's emotional health

Parents have an important role in helping children adjust well to JIA. Here are some ideas to help your child live as normal a life as possible, despite JIA.

- Help your child understand and manage their condition, and live a full and enjoyable life despite it.
- Help them learn to manage pain and physical limitations. See the information sheets on managing pain and relaxation, and ask your nurse about pain management strategies.
- Talk about thoughts and feelings.
- Make sure you have time to spend together to relax and have fun.
- Tell them that you love them, are on their side and will tackle problems together.
- Help your child develop confidence by encouraging their efforts and demonstrating how to solve problems.
- Say how proud you are of them.
- Involve them in activities they enjoy and can do to build their self-esteem.
- Talk about how to build friendships and deal with social difficulties.
- Talk about the situation with the whole family and face the problem together.

Sometimes parents underestimate how much their child is struggling with feelings of anxiety or depression. This is easy to do if your child is naturally quiet, or if they express their distress through anger and 'bad behaviour'. Sometimes parents think that their child's feelings are 'normal' adolescent moodiness. If children are often upset, worried or angry or are having big problems at school or home, it may help to be referred to a psychologist to learn skills and strategies to cope with feelings, pain, or relationships.

Sleep

Children with JIA often sleep badly. Pain and worries can both interfere with sleep. This is a vicious circle as lack of sleep can increase pain and emotional problems and make it hard for your child to concentrate. Healthy sleeping patterns are an important part of the overall goal of achieving a life that is as normal as possible.

There are several strategies that can be used to help your child sleep well:

- Take pain-relief medication early, as intense pain is harder to control.
- If possible, take pain medication just before bedtime to help your child have a pain-free and uninterrupted sleep.
- Establish a nightly bedtime routine that helps your child relax and wind down.

