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Majeed Syndrome

Version of 2016

3. EVERYDAY LIFE

3.1 How might the disease affect the child and the family's daily life?

The child and the family face major problems before the disease is diagnosed.
Some children must deal with bone deformities, which may seriously interfere with normal activities. Another problem may be the psychological burden of life-long treatment. Patient and parent education programmes can address this issue.

3.2 What about school?

It is essential to continue education in children with chronic diseases. There are a few factors that may cause problems for school attendance and it is therefore important to explain the child's possible needs to teachers. Parents and teachers should do whatever they can to allow the child participate in school activities in a normal way, in order not only for the child to be successful academically but also to be accepted and appreciated by both peers and adults. Future integration in the professional world is essential for a young patient and is one of the aims of the global care of chronically ill patients.

3.3 What about sports?

Playing sports is an essential aspect of the everyday life of any child. One of the aims of therapy is to allow children to conduct a normal life as much as possible and to consider themselves not different from their

peers. All activities can therefore be performed as tolerated. However, restricted physical activity or rest may be necessary during the acute phase.

3.4 What about diet?

There is no specific diet.

3.5 Can climate influence the course of the disease?

No, it cannot.

3.6 Can the child be vaccinated?

Yes, the child can be vaccinated. However, parents need to contact the treating physician for live attenuated vaccines.

3.7 What about sexual life, pregnancy, birth control?

So far, no information on this aspect in adult patients is available in the literature. As a general rule, like for other autoinflammatory diseases, it is better to plan a pregnancy in order to adapt treatment in advance due to the possible side effect of biologic agents on a foetus.