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Cryopyrin Associated Periodic Syndromes (CAPS) (CINCA/Muckle Wells/FCAS)

Version of 2016

3. EVERYDAY LIFE

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

Quality of life can be affected by recurrent episodes of fever. There can often be considerable delay before the correct diagnosis is made, which may give rise to parental anxiety and sometimes to unnecessary medical procedures.

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 to 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 the 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 dietary advice. In general, the child should observe a balanced, normal diet for his/her age. A healthy, well-balanced diet with sufficient protein, calcium and vitamins is recommended for a growing child.

3.5 Can climate influence the course of the disease?

Cold temperatures may trigger symptoms.

3.6 Can the child be vaccinated?

Yes, the child can be and should be vaccinated; however, the treating physician should be informed before administering live attenuated vaccines so that proper advice can be provided on a case-by-case basis.

3.7 What about sexual life, pregnancy, birth control?

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