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Chronic Atypical Neutrophilic Dermatosis with Lipodystrophy and Elevated Temperature (CANDLE)

Version of 2016

3. EVERYDAY LIFE

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

The child and family face major problems before the disease is diagnosed.
Some children have to deal with bone deformities, which may seriously interfere with normal activities. The daily injections may be a burden, not just because of the discomfort, but also because the storage requirements of anakinra may interfere with travel.
Another problem may be the psychological burden of life-long treatment. Patient and parent education programs 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 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 into normal adult life is essential for the young patient and is one of the general aims of the 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 phases.

3.4 What about diet?

There is no specific diet.

3.5 Can climate influence the course of the disease?

As far as we know, climate cannot influence the course of the disease.

3.6 Can the child be vaccinated?

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

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 with other autoinflammatory diseases, it is better to plan a pregnancy in order to discuss the effects of disease and treatments on the developing baby.