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Deficiency of IL-1 Receptor Antagonist (DIRA)

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. After the diagnosis is made and treatment has been instituted, many children lead an almost normal life. Some children must deal with bone deformities that can 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 programmes can address this issue.

3.2 What about school?

When the disease has not led to permanent disability and is fully controlled by anakinra injections, there are no restrictions.

3.3 What about sports?

When the disease has not led to permanent disability and is fully controlled by anakinra injections, there are no restrictions. Skeletal damage incurred early in the disease may limit physical activities but there is no need for additional restrictions.

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 the live attenuated vaccine.

3.7 What about sexual life, pregnancy, birth control?
At present, it is not clear whether anakinra is safe for pregnant women.