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Juvenile Spondyloarthritis / Enthesitis Related Arthritis (SpA-ERA)

Version of 2016

3. EVERYDAY LIFE

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

During the periods of active arthritis, almost every child will experience limitations in his/her daily life. Since lower limbs are often affected, walking and sports are the activities most frequently affected by the disease. A positive attitude from parents who support and encourage the child to be independent and physically active is extremely valuable in overcoming the difficulties related to the disease, successfully coping with peers and developing an independent, well-balanced personality. If the family cannot cope with the burden of the disease, psychological support is needed. Parents must support their child in physical therapy exercises and encourage them to take their prescribed medications.

3.2 What about school?

There are a few factors that may cause problems for school attendance: difficulty walking, minor resistance to fatigue, pain or stiffness. It is therefore important to explain the child's possible needs to teachers: proper desks and regular movements during school hours to avoid articular stiffness. Whenever possible, patients should take part in gym lessons; in this case, the same considerations discussed below, in terms of sports, should be taken into account. Once the disease is well-controlled, the child should have no problem participating in all the same activities as their healthy peers.

School for a child is what work is for an adult: a place where he/she learns how to become an independent and productive person. 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.

3.3 What about sports?

Playing sports is an essential aspect of the everyday life of any normal child. Sports in which mechanical stress to the joints is absent or minimal, such as swimming or riding a bike, are recommended.

3.4 What about diet?

There is no evidence that diet can influence the disease. In general the child should observe a balanced, normal diet for his/her age. Overeating should be avoided in patients taking corticosteroids because these drugs may increase appetite.

3.5 Can climate influence the course of the disease?

There is no evidence that climate can affect the disease manifestations.

3.6 Can the child be vaccinated?

Since most of patients are treated with either NSAIDs or sulfasalazine, a normal vaccination scheme can be followed. A patient being treated with high-dose corticosteroids or biologic agents should avoid vaccination with live attenuated viruses (such as anti-rubella, anti-measles, anti-parotitis, anti-polio Sabin). Otherwise, they should be postponed due to the potential risk of infections spreading as a consequence of reduced immune defences. Vaccines that do not contain living viruses but only infectious proteins (anti-tetanus, anti-diphtheria, anti-polio Salk, anti-hepatitis B, anti-pertussis, pneumococcus, haemophilus, meningococcus) can be administered. Theoretically, immunosuppression may reduce or cancel the effect of a vaccination.

3.7 What about sexual life, pregnancy, birth control?

There are no restrictions on sexual activity or pregnancy due to the disease. Nevertheless, patients taking medications should always be very careful about the possible toxic effects of these drugs on a foetus. There is no reason to avoid having children, despite the genetic aspects of the disease. The disease is not lethal and even if the predisposing genetic factor could be inherited, there is a good chance that siblings will not develop any form of juvenile SpA-ERA.

3.8 Will the child have a normal adult life?

This is one of the main goals of therapy and it can be achieved in the majority of cases. Therapy for these kinds of diseases in childhood has improved dramatically over recent years. The combined use of pharmacological treatment and rehabilitation is now able to prevent joint damage in the vast majority of patients.