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Rare Juvenile Primary Systemic Vasculitis

Version of 2016

3. EVERYDAY LIFE

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

The initial period, when the child is unwell and the diagnosis is yet to be made, is usually very stressful for the whole family.
Understanding the disease and its therapy helps the parents and the child to cope with often unpleasant diagnostic and therapeutic procedures and frequent hospital visits. Once the disease is under control, home and school life can usually return to normal.

3.2 What about school?

Once the disease is reasonably controlled, patients are encouraged to go back to school as soon as they can. It is important to inform the school about the child´s condition so that it can be taken into account.

3.3 What about sports?

Children are encouraged to take part in their favourite sport activities once disease remission is achieved.
Recommendations might vary according to the possible presence of organ functional impairment, including muscles, joints and bone status, which may be influenced by previous corticosteroid use.

3.4 What about diet?

There is no evidence that a special diet can influence the disease

course and outcome. A healthy, well-balanced diet with sufficient protein, calcium and vitamins is recommended for a growing child. While a patient is receiving corticosteroid treatment, sweet, fat or salty food intake should be limited in order to minimise the side effects of corticosteroids.

3.5 Can climate influence the course of the disease?

Climate is not known to influence the course of the disease. In the event of impaired circulation, mainly in cases of vasculitis of the fingers and toes, exposure to cold can make the symptoms worse.

3.6 What about infections and vaccinations?

Some infections may have a more serious outcome in individuals treated with immunosuppressive drugs. In case of contact with chickenpox or shingles, you should contact your physician immediately in order to receive an anti-virus drug and/or specific anti-virus immunoglobulin. The risk of ordinary infections may be slightly higher in treated children. They may also develop unusual infections with agents that do not affect individuals with fully functional immune system. Antibiotics (co-trimoxazol) are sometimes administered long-term to prevent lung infection with a bacteria called Pneumocystis, which can be a life-threatening complication in immunosuppressed patients. Live vaccines (e.g. mumps, measles, rubella, polios, tuberculosis) should be postponed in patients receiving immunosuppressive treatments.

3.7 What about sexual life, pregnancy, birth control?

In sexually active adolescents, birth control is important as the majority of drugs used may damage the developing foetus. There are concerns that some cytotoxic drugs (mainly cyclophosphamide) might affect a patient’s ability to have a child (fertility). This depends mainly on the total (cumulative) dose of the drug received over the period of treatment and is less relevant when the drug is administered in children or pre-pubertal adolescents.