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Juvenile Dermatomyositis

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3. EVERYDAY LIFE

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

Attention should be paid to the psychological impact of the disease on children and their families. A chronic disease like JDM is a difficult challenge for the whole family and of course, the more serious the disease, the harder it is to cope with. It will be difficult for a child to cope properly with the disease if their parents are having problems coping. A positive attitude from parents to support and encourage a child to be independent as much as possible, despite the disease, is extremely valuable. It helps children to overcome the difficulties related to the disease, to cope successfully with peers and to become independent and balanced. When needed, psychosocial support should be offered by the paediatric rheumatology team.
Allowing the child to have a normal adult life is one of the main goals of therapy and it can be reached in the majority of cases. The treatment of JDM has improved dramatically in the last ten years and it is conceivable that several new drugs will be available in the near future. The combined use of pharmacological treatment and rehabilitation is now able to prevent or limit muscle damage in most patients.

3.2 Can exercise and physical therapy help my child?

The purpose of exercise and physical therapy is to help the child to participate as fully as possible in all the normal daily activities of life, and to fulfil their potential within society. Exercise and physical therapy can also be used to encourage active healthy living. To be able to

achieve these goals, healthy muscles are needed. Exercise and therapy can be used to achieve better muscle flexibility, muscle strength, coordination and endurance (stamina). These aspects of musculoskeletal health allow children to successfully and safely engage in school activities, as well as activities outside school such as leisure time activities and sports. Treatment and home exercise programs can be helpful to reach normal fitness level.

3.3 Can my child play sports?

Playing sports is an essential aspect of the everyday life of any child. One of the main aims of physical therapy is to allow children to lead a normal life and to consider themselves no different from their friends. The general advice is to let patients play the sports they want, but to instruct them to stop if muscle soreness is present. This will enable the child to start early in the treatment of their disease; partially restricted sports activities are better than being excluded from exercise and playing sports with friends because of disease. The general attitude should be to encourage the child to be independent within the limits imposed by the disease. Exercise should be undertaken after advice from a physical therapist (and sometimes requires the supervision of a physical therapist). The physical therapist will be able to advise which exercises or sports are safe, as this will depend on how weak the muscles are. The workload should gradually increase to strengthen the muscles and improve stamina.

3.4 Can my child attend school regularly?

School for children is similar to work for adults: it is a place where children learn how to be independent and self-reliant as an individual. Parents and teachers need to be flexible in order to allow children to participate in school activities in as normal a way as possible. This will help the child to be as successful as possible academically, as well as helping them to integrate and be accepted by both their peers and adults. It is extremely important that children attend school regularly. There are a few factors that may cause problems: difficulty in walking, fatigue, pain or stiffness. It is important to explain to the teachers what the child’s needs are: help because of difficulty in writing, proper tables to work on, being allowed to move regularly to avoid muscle stiffness,

and help in participating in some of the physical education activities. Patients should be encouraged to take part whenever possible in PE (physical education) lessons.

3.5 Can diet help my child?

There is no evidence that diet can influence the disease process, but a normal balanced diet is recommended. A healthy, well-balanced diet with protein, calcium and vitamins is recommended for all growing children. Overeating should be avoided in patients taking corticosteroids, as these cause increased appetite which can easily lead to excessive weight gain.

3.6 Can climate influence the course of my child’s disease?

Current research is looking at the relationship between UV-radiation and JDM.

3.7 Can my child be vaccinated or have immunisations?

Immunisations should be discussed with your doctor, who will decide which vaccines are safe and advisable for your child. Many vaccinations are recommended: tetanus, poliomyelitis by injection, diphtheria, pneumococcus and influenza by injection. These are non-live composite vaccines which are safe for patients on immunosuppressive drugs. However, live attenuated vaccines are generally avoided because of the hypothetical risk of inducing infection in patients receiving high dose immunosuppressive drugs or biologic agents (such as mumps, measles, rubella, BCG, yellow fever).

3.8 Are there problems associated with sex, pregnancy or birth control?

JDM has not been shown to affect sex or pregnancy. However, many of the medications used to control the disease can have adverse effects on a foetus. Sexually active patients are advised to use safe methods of birth control, and to discuss issues of contraception and pregnancy (especially before they try to conceive) with their doctor.