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Systemic Lupus Erythematosus

Version of 2016

3. EVERYDAY LIFE

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

Once children with SLE are treated, they can lead a quite normal lifestyle. One exception is exposure to excessive sunlight/UV-light in discos, which may trigger or make SLE worse. A child with SLE should not go to the beach all day or sit out in the sun by the pool. Regular sunscreen with SPF 40 or higher is mandatory. It is important that children by the age of 10 start assuming a progressively greater role in taking their medication and making choices about personal care. Children and their parents should be aware of the symptoms of SLE in order to identify a possible flare. Certain symptoms such as chronic fatigue and the lack of drive may persist for several months after a flare is over. Regular exercise is important to maintain a healthy weight, maintain good bone health and stay conditioned.

3.2 What about school?

Children with SLE can and should attend school except during periods of severe active disease. If there is no central nervous system involvement, SLE in general does not affect the ability of the child to learn and think. With central nervous system involvement, problems such as difficulty concentrating and remembering, headaches and moods changes may occur. In these cases, education plans need to be discussed. Overall, the child should be encouraged to participate in compatible extracurricular activities as much as the disease permits. However, teachers should be made aware of the child's diagnosis with

SLE so that changes can be made during times when there are SLE-related problems, including joint and other body pains that may affect learning.

3.3 What about sports?

Restrictions on general activity are usually unnecessary and undesirable. Regular exercise is to be encouraged in children during disease remission. Walking, swimming, cycling and other aerobic or outdoor activities are recommended. Appropriate sun protection clothing, sunscreens with high spectrum protection and avoiding sun exposure during peak hours is advised for outdoor activities. Avoid exercising to the point of exhaustion. During a disease flare, exercise should be restrained.

3.4 What about diet?

There is no special diet that can cure SLE. Children with SLE should observe a healthy, balanced diet. If they take corticosteroids, they should be eating foods low in salt to help prevent high blood pressure and low in sugar to help prevent diabetes and weight gain. Additionally, they should have calcium and vitamin D supplements to help prevent osteoporosis. No other vitamin supplement is scientifically proven to be helpful in SLE.

3.5 Can climate influence the course of the disease?

It is well known that exposure to sunlight may cause the development of new skin lesions and lead to flares of disease activity in SLE. To prevent this problem, use of highly protective topical sunscreens is recommended for all the exposed parts of the body whenever the child is outside. Remember to apply the sunscreen at least 30 minutes before going out to allow it to penetrate the skin and dry. During a sunny day, sunscreen must be applied every 3 hours. Some sunscreens are water resistant, but reapplication after bathing or swimming is advisable. It is also important to wear sun protective clothing such as wide-brimmed hats and long sleeves when out in the sun, even on cloudy days, as UV rays can penetrate clouds easily. Some children experience problems after they have been exposed to UV light from fluorescent lights,

halogen lights or computer monitors. UV filter screens are useful for children who have problems when using a monitor.

3.6 Can the child be vaccinated?

The risk of infection is increased in a child with SLE; therefore prevention of infection by immunization is particularly important. If possible, the child should keep the regular schedule of immunizations. However, there are a few exceptions: children with severe, active disease should not receive any immunization and children on immunosuppressive therapy, high-dose corticosteroids and biologic agents should in general not receive any live virus vaccine (e.g. measles, mumps and rubella vaccine, oral poliovirus vaccine and varicella vaccine). Oral polio vaccine is also contraindicated in family members living in homes with a child on immunosuppressive therapy. Pneumococcal, meningococcal and annual influenza vaccines are recommended in children with SLE receiving high dose corticosteroids and/or immunosuppressive drugs. Vaccination with HPV of adolescent girls and boys with SLE is recommended.

Note that children with SLE may need vaccinations more often than their peers because the protection provided by the vaccinations seems last shorter with SLE.

3.7 What about sexual life, pregnancy and birth control?

Adolescents may enjoy a healthy sex life. However, sexually active adolescents treated with certain DMARDs or with active disease must use safe pregnancy prevention methods. Ideally, pregnancies should always be planned. Notably, some blood pressure medicines and DMARDs can harm the development of the foetus. Most women with SLE can have a safe pregnancy and a healthy baby. The ideal time for pregnancy would be when the disease, especially kidney involvement, has been well controlled for a prolonged time. Women with SLE may have trouble staying pregnant either because of the disease activity or the medication. SLE is also associated with a higher risk of miscarriage, premature delivery and a congenital abnormality in the baby known as neonatal lupus (appendix 2). Women with elevated antiphospholipid antibodies (appendix 1) are considered at high risk of problematic pregnancy.

Pregnancy itself can worsen symptoms or trigger a flare of SLE. Therefore, an obstetrician who is familiar with high-risk pregnancies and who works closely with the rheumatologist must monitor all pregnant women with SLE.

The safest forms of contraception in SLE patients are barrier methods (condoms or diaphragms) and spermicidal agents. Progesterone-only systemic contraceptives are also acceptable, as are some types of intrauterine devices (IUDs). Birth control pills containing oestrogen may increase the risk of flares in women with SLE, although there are new options that minimize this risk.