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Scleroderma

Version of 2016

3. EVERYDAY LIFE

3.1 How long will the disease last?

The progression of localised scleroderma is usually limited to a few years. The skin hardening often stops after a few years from the start of the disease. Sometimes it can take up to 5 – 6 years and some patches may even become more visible after the inflammatory process is over due to colour changes, or the disease may appear worse due to unequal growth between affected and unaffected parts of the body. Systemic sclerosis is a long-term disease that can last for many years. However, early and appropriate treatment can lessen the impact of the disease.

3.2 Is it possible to recover completely?

Children with localised scleroderma may recover completely. After some point even the hard skin may soften and only hyperpigmented areas may persist. Recovery from systemic sclerosis is much less probable, but significant improvements and stabilisation of disease may be achieved, allowing a good quality of life.

3.3 What about unconventional/complementary therapies?

There are many complementary and alternative therapies available and this can be confusing for patients and their families. Think carefully about the risks and benefits of trying these therapies as there is little proven benefit and they can be costly both in terms of time, burden to the child and money. If you want to explore complementary and alternative therapies, please discuss these options with your paediatric

rheumatologist. Some therapies can interact with conventional medications. Most doctors will not be opposed, provided you follow medical advice. It is very important not to stop taking your prescribed medications. When medications are needed to keep the disease under control, it can be very dangerous to stop taking them if the disease is still active. Please discuss medication concerns with your child's doctor.

3.4 How could the disease affect the child and the family's daily life, and what kind of periodic check-ups are necessary?

Like any chronic disease, scleroderma does affect the child and the family's daily life. If the disease is mild, without major organ involvement, the child and family generally lead a normal life. However, it is important to remember that children with scleroderma may frequently feel tired or be less resistant to fatigue, and they may need to change position frequently because of poor circulation. Periodic check-ups are needed to assess how the disease is affecting your child and whether treatments need to be changed. Because important internal organs (lungs, gut, kidneys, heart) may be involved at different time points during the course of systemic sclerosis, regular assessment of organ function is necessary for early detection of possible impairment.
Certain drugs need side-effects monitoring which may include regular blood tests.

3.5 What about school?

It is essential to continue education in children with chronic diseases. There are a few factors that may cause problems for school attendance and it is therefore important to explain the child's possible needs to teachers. Whenever possible, patients should take part in gym lessons; in this case, the same considerations discussed below with respect to sports should be taken into account. Once the disease is well-controlled, as is generally the case using the currently available medications, the child should have no problems whatsoever in participating in all the same activities as their healthy peers. School for children is what work is for adults: a place where they learn how to become independent and productive individuals. Parents and teachers should do whatever they can to allow the child 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.

3.6 What about sports?

Playing sports is an essential aspect of the everyday life for any child. One of the aims of therapy is to allow children to conduct a normal life as much as possible and to consider themselves no different from their friends. Therefore, the general recommendation is to allow patients to participate in the sports they choose and to trust that they will stop if there are limitations due to pain or discomfort. This choice is part of a more general attitude that tends to psychologically encourage the child to be autonomous and able to cope by himself with the limits imposed by the disease.

3.7 What about diet?

There is no evidence that diet can influence the disease course but a normal balanced diet is recommended. A healthy, well-balanced diet with sufficient protein, calcium and vitamins is recommended for all growing children. Overeating should be avoided in patients taking corticosteroids because these drugs may increase appetite and lead to excessive weight gain.

3.8 Can climate influence the course of the disease?

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

3.9 Can the child be vaccinated?

Scleroderma patients should always consult their physician before receiving a vaccination of any kind. The physician will decide which vaccines the child can receive, considering case by case. Overall, vaccinations do not appear to increase the disease activity and do not cause severe adverse events in scleroderma patients.

3.10 What about sexual life, pregnancy, birth control?

There are no restrictions on sexual activity or pregnancy due to the

disease. Nevertheless, many medications used to treat scleroderma may have adverse effects on a foetus. Sexually active patients are advised to use contraception and and to discuss issues of contraception and pregnancy with their doctor.