



People who care about ichthyosis

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TO WHOM IT MAY CONCERN

This individual unfortunately suffers from **ichthyosis**, a serious and incurable disorder of the skin. In people with ichthyosis the skin does not exfoliate in the normal way, and so a thick outer layer builds up, usually affecting most if not all of the body surface. The condition is caused by faulty genes and is congenital and life-long. The skin has an appearance that has been likened to fish scales, hence the name “ichthyosis” from the Greek word for fish.

People with ichthyosis suffer from extreme and constant discomfort. The skin feels dry, tight and itchy. There is constant shedding of scales, and sometimes painful cracks and even blisters occur. In hot weather the itching is much worse, while cold causes cracking. The hair may be constantly caked with thick scale. In some patients the facial skin is so tight that the eyes cannot shut completely, leading to visual impairment from exposure and drying of the cornea. The ears become blocked with dead skin and require regular evacuation. Tightness of skin around the joints can cause disabling contractures. Some types of ichthyosis are occasionally associated with problems in other organs such as impaired immunity, spasticity and learning problems.

Patients with ichthyosis suffer psychologically from the disfigurement caused by this condition. Throughout their lives they are stared at and sometimes bullied or discriminated against because of their unusual appearance. The necessity for grease on the skin, and time-out for skin care causes problems at school, seriously limits employment and leisure options, and impairs social relationships.

The treatment of ichthyosis is laborious and often unrewarding. Patients must apply emollient creams and ointments repeatedly throughout the day to try and stop the skin from drying out. Additional treatments include eye ointments, antiseptics and dressings. Some patients have to be treated with potentially toxic drugs requiring regular hospital visits and blood tests. Contractures require physiotherapy and splints. An additional burden is the cost of extra clothing and laundry because ointments applied to the skin inevitably rub off onto clothes, bedding and upholstery.

Because ichthyosis is very rare, many people including some doctors know nothing about it. Further information on all aspects of ichthyosis is available from the Ichthyosis Support Group.

Yours faithfully,

Dr Celia Moss
Consultant Dermatologist
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ISG Medical Advisory Board

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