

A Guide for Carers and Teachers

What is ichthyosis?

The name ichthyosis covers a family of related disorders whose primary symptoms include dry, thickened and scaly skin. In some forms, the skin blisters and peels. The skin may become darkened rough and appear as scales separated by deep cracks. It is an inherited, genetic disease which may be present at birth, or appear later in life. It is **not** contagious. The body's ability to produce the outermost layer of the skin is disrupted. The outer layer is either manufactured too rapidly, or fails to shed normally from the skin surface.

Symptoms of ichthyosis

Symptoms vary significantly from child to child. Mild forms, such as *ichthyosis vulgaris* may appear only as dry skin affecting such areas such as the hands and feet, whilst others exhibit total body involvement. The skin may be reddish, extremely flaky, or the body may be covered in plate-like scales. Hair growth may be retarded if the scalp is affected.

Problems

The following problems may be encountered:-

- 1) Susceptibility to infection due to cracks or breaks in the skin's barrier. This may be more prevalent in cold weather.
- 2) Difficulty with achievement of gross or fine motor skills due to tautness of the skin on the hands, and cracking of the skin on the soles of the feet. (Some children have problems wearing shoes).
- 3) Sensitivity to bright sunshine and/or increased susceptibility to eye irritation resulting from the pulling away of the margins of the eyelids due to the tautness of facial skin.
- 4) Overheating resulting from active play and/or too warm an environment. This is due to the body's inability to sweat through pores that are blocked by thickened skin.
- 5) Excessive water loss through the skin, leading to dehydration in extreme situations. The skin's barrier function becomes disrupted.
- 6) Body odour resulting from normal accumulation of bacteria between and beneath scales.
- 7) Possible hair loss, receding hairline, and/or excessive dandruff.
- 8) Hearing impairment due to exfoliated skin binding with natural waxes blocking the ear canal.
- 9) Itching as a result of dryness of the skin.
- 10) Side effects from medication.

Carer's Involvement

Toddlers & Pre-schoolers

- 1) Let the child explore his environment, do not over-protect. Allow child to overcome separation anxiety to which he/she may be vulnerable, through literature and open-ended dramatic play. The child then has opportunities to explore his/her feelings about separation.
- 2) Encourage the child to tell other children that he/she has ichthyosis, a genetic disorder. It is essential that children be allowed to articulate their own grasp of the situation.
- 3) Explain to the child's peers the reasons for visible differences. Open and positive responses to other children's questions will set the tone for how children deal with more general differences.

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School Age Children

- 1) Be aware of signs of overheating. Reddening of the skin, particularly the face (usually the first sign, though not necessarily an indicator of serious overheating). In hot weather, or in a very warm environment, the child must have easy access to drinking water. The child should perceive that teachers/carers are supporters in this respect, rather than obstacles to comfort and health. Interrupting the game or activity that causes the overheating should be allowed so that the child can rest and apply damp cloths to reduce the temperature. Irritability, listlessness, lethargy and weakness may be the outcome of overheating, so that the child is labelled slow, lazy or a poor athletic performer by uninformed teachers. The child is then at risk of developing poor self-esteem.
- 2) Teachers and N.T.A.'s must have the same academic expectations for children with ichthyosis that they have for 'normal' children.
- 3) Social isolation, teasing, ridicule and bullying should be handled carefully. A true balancing act is needed, on the one hand being supportive, whilst at the same time not singling the child out for special attention, which could cause further ostracism and ridicule. General class discussions about prejudice, differences and the reasons for them, and friendships may address these important issues without focusing on a child with ichthyosis.
- 4) At the beginning of a school year, it is important that all teachers/carers are aware of any problems so as to ascertain the child's base level of comfort and physical mobility. It is difficult for a child to concentrate on learning if the skin is taut, cracked, sore or itching. The child's parents are the best source for this information as well as day-to-day requirements. These may include the need to apply topical creams and lotions to moisturise the skin during the school day. Provision should be made to allow the time and privacy for this. This should be carried out to fit around the normal school day so it does not affect the child thus possibly making them feel isolated. Children with *Epidermolytic Hyperkeratosis* (or more simply, *EHK*), which is also known as *Bullous Congenital Ichthyosiform Erythroderma (BCIE)* should have access to a topical antibiotic to be applied to incidental cuts and scratches.
- 5) Children of all ages should be encouraged to be active participants in their own treatment in order to create a responsibility for self care.

Teenagers

By this time, teenagers have probably mastered the physical management of ichthyosis. The need for social acceptance becomes paramount. At this stage, the teacher in charge of pastoral care can be supportive in the role of listener and mentor as well as help the teenager to coping mechanisms and a personal style that works best for them.

Keys points to remember: -

- 1) Start with the positive, focusing on the things in which the student excels.
- 2) Respect the child's/teenager's physical limitations, and endeavour to find meaningful and productive alternatives when outdoor activities are limited.
- 3) Communicate to fellow pupils that difference is not bad. Answer questions about all physical differences with openness and frankness. Bullying and depression are only heightened by the ignorance that grows out of evading the issue altogether.

This leaflet is a general source of information, teachers and carers should seek more specific guidance from the individual's parents as ichthyosis conditions vary immensely.

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People who care about ichthyosis

Further help

There are a number of online forums about Ichthyosis where individuals can share their experiences and detail their own treatment recommendations. Not everything will work for everyone but these forums are a good place both to receive and offer support.

Contact the Ichthyosis Support Group for information, advice, details on useful products, and to be connected with other people to share experiences and helpful advice.

To find out more about the ISG or become a member please get in touch in one of the following ways:

By Phone or Fax:

Tel: **0845 602 9202** Fax: **0560 343 8046** (on request)

By Email:

isg@ichthyosis.org.uk

By Post:

Ichthyosis Support Group

PO Box 1242, Yateley GU47 7FL

Facebook:

facebook.com/ichthyosissupportgroup

Twitter:

twitter.com/ISG_Charity