

# 4 Ichthyosis

### *How can I support a student with ichthyosis?*

- ✓ Ask the student and their family directly how you can help. Take this opportunity to listen to their individual needs.
- ✓ Provide the opportunity for them to discuss their condition with the class if they wish to do so. They may prefer for the teacher to provide information to their class. This can allow their peers to ask questions in a productive setting.
- ✓ Immediately address any teasing and bullying. Provide education to any students saying harmful things and offer effective support for the affected student.
- ✓ Recognize their interests and acknowledge their successes in the classroom and in social settings.
- ✓ Students may need psychological support if suffering emotional distress due to their condition. Discuss this with their parents and refer to counseling as appropriate.

### OVERVIEW

Ichthyosis is the name of a group of skin disorders characterized by thick, dry, and scaly skin. It is a genetic condition which is inherited at birth and does not currently have a cure. The disorder is caused by a change in the body's ability to produce new skin, which causes problems with the outermost skin layer.

There are at least 20 types of ichthyosis that can range from mild skin dryness to severe full-body involvement and scales. Most people with ichthyosis have a normal lifespan.

There is no cure for ichthyosis and it requires lifelong treatment with moisturizing creams and non-soap cleansers. In severe disease, oral medications may be used.



## What symptoms does someone with ichthyosis experience?

### The affected areas of skin may be itchy or uncomfortable.

Affected children are at higher risk for infection due to cracks in the skin and decreased protection from the skin barrier.

Affected children may experience hair loss or significant dandruff. Due to trapping of bacteria in the skin, there can be associated body odor. Hearing impairment can

occur due to blockages in the ear canal from skin and wax buildup. Tight skin around the eyes can cause sensitivity to bright light and tight skin on the fingers and hands may limit motor skills and dexterity.

Importantly, due to decreased ability to sweat, students with ichthyosis may overheat in hot environments or during play.

Students may feel self-conscious or anxious about their visible skin condition, particularly if they experience teasing and bullying from classmates. Ichthyosis has been associated with isolation, low self-esteem and depression.

## What special measures might students with ichthyosis need?

The child may need application of creams and moisturizers throughout the day and should be given time to go to the bathroom for this when needed. It may also be helpful for the child to have a small container at their desk to apply at any time. Students also need sunscreen whenever outside, to be applied around 30 minutes after moisturizer.

Look for signs of overheating in hot weather – these include reddening of the skin, crankiness, slowness, which can then lead to passing out or convulsions if not addressed.

Students need frequent and easy access to drinking water to prevent dehydration. As a result of frequent drinking, child may also need frequent toilet breaks which should be allowed.

Certain materials may irritate the skin of the hands (sand, clay, paint), so it is important to adjust an activity if the child is unable to use a certain material. Students may also have discomfort with their feet that may make walking and running difficult.

It is important to not overprotect students and allow them to participate in all possible activities, while respecting any physical limitations expressed by the student or parents. Students do not have any developmental delay and should have the same academic expectations as their classmates.

## Is it contagious?

**No, ichthyosis is not contagious.** Other students will not get ichthyosis with physical contact or play.

### > Guide for Carers and Teachers

Ichthyosis Support Group

<https://www.ichthyosis.org.uk/Handlers/Download.ashx?IDMF=87bcb315-3c22-4bfa-81af-462b268c8aaa>

### > Coping With Ichthyosis at Pre-School and Primary School

Ichthyosis Support Group

<http://www.pcids.org.uk/ee/images/uploads/general/ISG-School-Pack.pdf>

### > Ichthyosis: A Guide for Teachers & School Personnel

Foundation for Ichthyosis & Related Skin Types

[http://www.firstskinfoundation.org/content.cfm/category\\_id/0/page\\_id/833](http://www.firstskinfoundation.org/content.cfm/category_id/0/page_id/833)

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