Coping with Ichthyosis at Pre-School and Primary School

A GUIDE FOR:
Pre-school staff, primary school teachers, teaching assistants, and school nurses

Produced by
Ichthyosis Support Group
People who care about ichthyosis
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Ichthyosis Support Group
People who care about ichthyosis
Welcome to the Ichthyosis Support Group Schools Pack: Coping with Ichthyosis at pre-school and primary school. This pack has been funded by the Ichthyosis Support Group, as a resource to help the child at pre or primary school.

This guide is for pre-schools and primary schools and all the staff who work there. It provides information for pre-school staff, primary school teachers, teaching assistants and school nurses, with the purpose of helping to support the child, parent/carer and their families.

The aims of this guide are focused around the child, so pre-schools and primary schools can provide the support required for a child with ichthyosis. Please note there are many types of ichthyosis, some rarer and more severe types may require specialist care that is not covered in detail in this guide.

**OUR AIMS**

**Enable the child with ichthyosis to feel totally included and involved with every aspect of school life.**

**Information provision and advice on how to support a child with ichthyosis to have a fulfilling school life.**

**Helping other children (and adults in pre-/school setting) understand about ichthyosis and what it means to the child and those close to them.**

**Support parents in ensuring the needs of their child are met at pre-school, school or playgroup.**
What is the skin condition ichthyosis?
Ichthyosis (pronounced Ick-thee-o-sis and from the Greek word meaning ‘fish’) describes a collection of conditions, which run in families and are present for life. Ichthyosis may appear at birth, in the first few months or in early childhood. It causes extremely dry and scaly skin, which can become sore and cracked. There are several types of ichthyosis. The most common type is Ichthyosis vulgaris other forms of the condition, can be much rarer for example X-linked (recessive) ichthyosis (or XLRI); and some extremely rare forms, Bullous ichthyosis, Non-bullous ichthyosis, Lamellar ichthyosis, Harlequin ichthyosis and Netherton syndrome.

How many children does it affect?
Ichthyosis can affect as many as 1 in 250 children (Ichthyosis vulgaris) to only a few children a year developing extremely rare forms. For example 1 in 3,000 (boys only) have X-linked (recessive) ichthyosis; 1 in 100,000 have Bullous ichthyosis (dominant) and 1 in 300,000 will have the rarer types such as Non-bullous ichthyosis, Lamellar ichthyosis, Netherton syndrome and Harlequin ichthyosis which is often considered the most severe type.

What causes ichthyosis?
Ichthyosis is a genetic disorder and different types of ichthyosis are caused by mutations in different genes. So ichthyosis tends to run in families, and all affected individuals within a family will have the same type. Some types are passed from parent to child while others may skip one or more generations. Most types affect girls and boys equally except for X-linked recessive ichthyosis which affects only males, but can be carried and transmitted by females.

How does ichthyosis affect the skin?
In ichthyosis, the outermost layer of the skin (epidermis) is faulty, and appears dry, scaly and sometimes red and cracked. The skin is seen to be dry and flaky, and sometimes red, with the build-up of scales, which can vary from fine pale scales to thick dark scales.

The severity and extent of ichthyosis vary widely from mild dryness to extensive areas of thickened skin and scaling over the body, arms, legs and face. Palms and soles may be particularly thickened and cracked, and the scalp may shed scales like heavy dandruff.
Does ichthyosis affect the child in other ways apart from the skin?
Children with ichthyosis are usually otherwise healthy and develop normally unless they have one of the very rare syndromes. However, the ichthyosis itself affects the child in many ways:

- The hair may be thin and sparse
- The nails may be thickened
- Tight skin on the face may prevent the eyelids from closing properly so the eyes become dry, sore and sometimes scratched
- A build-up of scales in the ears can impair hearing
- Tight skin on the fingers can affect manual dexterity and sensation
- Children with ichthyosis tend to have low vitamin D levels and need to take regular supplements
- The child will experience discomfort, itching and pain
- The child will be aware of looking different, with likely psychological consequences
- Sometimes ichthyotic skin can produce odour which is embarrassing for the child
- Some types of ichthyosis are prone to recurrent skin infection and generally poor health

Is ichthyosis catching?
Absolutely not, ichthyosis is not infectious at all. However, children with ichthyosis may be more susceptible to catching skin infections from others, for example, impetigo.

Can ichthyosis ever go away or be cured?
There is no cure for ichthyosis. This is a lifelong condition that may improve with age. Environmental factors may influence the condition, for some types warmer summer months improve the skin yet for others it exacerbates the condition, for example inability to sweat can cause the body to overheat.

Similarly the winter months may affect the condition causing the skin to worsen with the cold or central heating may cause the skin to dry further.

How is ichthyosis treated?
Treating ichthyosis can be hard work for the child and carers, and every effort must be made to adjust the treatment so that it becomes an acceptable routine rather than a burden. The key elements of treatment are:

- Frequent applications of moisturisers. Greasy ointments work best but can be messy. Creams are an acceptable alternative during the school day
- Use of soap substitutes to avoid further drying out of the skin
Bandages or body suits are sometimes used to keep a layer of grease close on the skin rather than on clothing and furniture.

Regular vitamin D supplements

Sometimes a retinoid drug is used which requires regular monitoring blood tests.

Lubricant eye drops are needed if the eyelids are too tight to close properly.

Regular eardrops may be needed if occlusion of the ear canals is a problem.

What is the difference between eczema and ichthyosis?

Eczema is an intensely itchy form of skin inflammation, which can come and go, and children may grow out of it. It is sometimes associated with asthma and hay fever. Ichthyosis, by contrast, is due to a fault in the structure of the skin; it is constant and children do not grow out of it. The commonest type of ichthyosis, Ichthyosis vulgaris, may coexist with eczema.
What problems may be encountered at pre-school, playgroup and school?

Physical effects

- The child’s skin may be itchy and sore

- **Cracks** in the skin can make the child susceptible to **infection**

- **Tight skin** may impair fine and gross motor function. On the hands this may affect writing and drawing and on the soles can cause problems with mobility.

- The **eyes** may be sore because the lids do not close properly. Discomfort is exacerbated by sensitivity to sunlight

- Certain materials may **irritate** the skin, such as sand, clay, and paint. Clothing with rough seams and labels may also irritate

- **Overheating** – due to the body’s inability to sweat through pores blocked by thickened skin

- **Dehydration** – due to excessive water loss through skin because of a disrupted skin barrier function. More common if overheated, due to weather or hot classrooms

- **Body odour** – due to normal accumulation of bacteria beneath skin scales

- **Hearing loss** (temporary) – due to skin scales binding with ear wax and blocking the ear canal

- **Side effects** from medication – for example very dry lips and eyes

As well as the physical effects, the child with ichthyosis faces emotional challenges.

There may be times at school when a child with ichthyosis feels different, self-conscious or anxious about fitting in at school. For example, taking part in classroom activities that may affect their ichthyosis.
Emotional challenges

- **Self-conscious** – because of visible dry skin, flaking and getting overheated

- **Different** – because they look different to their peers

- **Irritable** – they may be short tempered or tired due to discomfort from symptoms or itch, which can affect concentration in class

- **Frustrated** – due to having to adapt to coping with ichthyosis and triggers at school

- **Overwhelmed** – in coping with ichthyosis generally, including managing emollients at school

- **Upset** – may become more easily upset, when coping with ichthyosis symptoms and looking different

- **Angry** – perceived injustice of having ichthyosis when others don’t

- **Left out** – when they can’t take part in social activities with friends, for example sleepovers. This should never happen at school but may inadvertently happen if emollients are administered at play or break time

- **Ostracised** – other children may leave them out, for example not wanting to hold the hand of a child with ichthyosis

- **Teased or bullied** – especially if a child is reluctant or refuses to go to school; or is extremely upset in school – this may be a sign that they are being singled out because of their ichthyosis and are perhaps being teased or bullied

A useful resource to help school-aged children answer questions about ichthyosis is on page 18 of this guide and is also available to download at www.ichthyosis.org.uk

Equally remember that some children actually cope well with ichthyosis, adapt well to coping at school. All children need support to help them to have a normal and enjoyable experience at school.

Meanwhile parents and other family members/carers might feel...

...that it is hard to ‘let go’ of a child with ichthyosis, especially as they will have cared for their child’s skin from babyhood onwards. Parents themselves may be anxious or worried; and also feel overwhelmed with helping their child prepare for coping with ichthyosis at school.
4 How can pre-school and school staff help the child with ichthyosis?

The Department of Education (2015) statutory guidelines on ‘Supporting pupils with medical conditions in schools’ clearly state that:

- Pupils at school with medical conditions should be properly supported so that they have full access to education, including school trips and physical education
- Governing bodies must ensure that arrangements are in place in schools to support pupils at school with medical conditions
- Governing bodies should ensure that school leaders consult health and social care professionals, pupils and parents to ensure that the needs of children with medical conditions are properly understood and effectively supported

For more information on Department of Education legislations, guidance and resources please see the appendix.

Pre-school staff

Need to know about ichthyosis and the importance of providing skin care for the baby or small child at pre-school. This will involve applying emollients at every nappy change and being aware of other symptoms, which may affect the baby/child, depending on type and severity of ichthyosis. It is also important to be aware of how ichthyosis may affect the child during the pre-school session and how ichthyosis may be affected by play activities and the environment. Pre-school staff should also be prepared to answer questions other children have about ichthyosis with open and positive responses.

School teachers

Need to know about ichthyosis and be aware how ichthyosis may affect the child during the school day and what the impact of ichthyosis may have on school lessons, activities and the classroom environment. This information should be recorded and discussed with an action plan in the child’s individual health plan for school (the school nurse may also be involved). Teachers should respect any physical limitations but also encourage the child to join in everything at school and have a fulfilling school life. Teachers need to understand from the parents and child, any treatment required in the school day – this will generally be emollients. Teachers should be aware that the child with ichthyosis may experience social isolation, teasing ridicule (and possibly bullying). A true balancing act is needed by the teacher and school staff, on one hand being supportive, whilst at the same time not singling the child out, which could cause further ostracism.

Teaching assistants

Need to know everything above expected of teachers. In addition, teaching assistants may be responsible for helping the child to put on their emollient
at school, ensuring a private area is used and supporting the child with their treatment needs in the school day.

School nurses
Need to know about ichthyosis and be aware how ichthyosis may affect the child during the school day. School nurses are responsible for notifying the school when a child has been identified as having a medical condition, which will require support in school (this should be done with the parents/carers and school before a child starts school). In addition, school nurses should provide on-going support to the school staff on implementing a child’s individual health plan.

Managing ichthyosis at pre-school and school
Pre-school children will need to be helped with every aspect of their skin care. Even very young children will become quickly aware of their own needs as they adapt to coping with ichthyosis. School-aged children will often be best placed to provide information to school staff on their skin care in school. Children should be fully involved in discussions about the support they need at school and contribute to the development of their individual health care for their treatment needs at school.

It is important that children do not miss out on the same activity every time they have to apply emoilllients/treatments – whether that is a lesson or a break time – social development is very important especially in early education, as it helps form connections between the child and their peers. Early connections and friendships are carried with the child throughout their school life. Feelings of isolation or exclusion are more likely without these.
Dry skin care – emollients
Emollients are medical moisturisers, which will be prescribed for the child by their GP. Emollients come in cream, ointment and gel forms, and the one the child uses at pre-school or school will be the emollient that suits the child and helps manage dry skin symptoms. Emollients come in a pump, tubs or sometimes a tube. In general a pump dispenser is preferred to prevent hands being dipped in and out potentially introducing bacteria into the container. If the child has an emollient in a tub, a disposable spatula or spoon and a dish should be provided for decanting.

It is very important that the skin is kept moisturised at all times and that emollients are applied frequently, which may be several times a day. Remember emollients need to be applied liberally, as a guide on average a 500g pump should last a week, so make sure stocks are replenished – it is a good idea to have two pumps at pre-school/school.

Emollients are applied all over the body in long smooth downward sweeping strokes, in the direction of the hair, leaving a thin film on the body to gradually soak in. Do not rub in, as this prevents the emollient forming a protective barrier, therefore increasing itching.

Pre-school/playgroup
A child at pre-school/playgroup should be helped with applying emollients at every nappy change/toilet break, to ensure skin is moisturised several times a day. Pre-school and playgroup staff, in conjunction with the child’s parents/carers can also help prepare a child for school by encouraging them to learn to apply their own emollient with supervision. This is very helpful in preparation for school due to the ‘no touch’ policy in most schools.

School
A school-aged child should be supported with dry skin care and applying emollients throughout the school day. Schools need to be aware that a medical emollient, although an essential treatment is bland and will not cause harm to other children.
This is a big difference to medication, which will need to be locked in a cupboard at school. Emollients should be accessible and available to the child at all times in school – however do keep emollient pumps or tubs stored in a cool dry place, away from heat or light; and where they cannot be opened or tampered with:

- A small pot kept in the desk for moisturising wherever skin is dry and uncomfortable
- An emollient wash container or small pot in the toilets for hand washing
- A 500g pump kept for more extensive moisturising in a private, hygenic location, which should be provided for the child at appropriate times – i.e. when the child needs to moisturise

The child should be in a daily routine of applying emollients, so will be able to tell the school staff when they need to apply emollients. However some younger children may forget, so the best times should be documented on the individual health plan.

Other skin symptoms, such as cracks, breaks and skin infections tend to come and go but continual care with moisturisers is essential to keep the skin as healthy as possible.

Remember that dry skin is usually itchy skin, so if a child starts to scratch or pick their skin, encourage them to apply emollient to relive the itch.
Sunscreen and emollients
In the summer months, it is important to leave a gap between applying emollients and putting on a sunscreen – ideally 20 minutes. This is important in making sure the emollient is properly absorbed, and does not dilute the sunscreen. Remember that the application of emollient in the summer months without appropriate sun protection will result in a “frying effect” as it is oil based. This can lead to sunburn that needs to be prevented at all times. Sunscreens should be a SPF 25 or above and have a 4-5 star UVA rating. It is a good idea for a child to have sun protective clothing, including a Legionnaires hat.

Preventing overheating and dehydration
Be aware of the signs of overheating, as children with ichthyosis tend to overheat as they have limited ability to sweat. Reddening of the skin, particularly the face (usually the first sign, although not necessarily an indicator of serious overheating). Be aware that irritability, listlessness, lethargy and weakness may be additional signs of overheating.

The child must always have easy access to drinking water; and if overheating occurs should be encouraged to drink and be helped to cool down. If a child becomes very hot, they will need iced water and damp towels to help reduce body temperature. A cooling fan may also need to be used in the classroom, especially on hot summer days. As the child is drinking lots of water, they will need extra toilet breaks – which may need to occur in class time. The child should never be afraid to ask to use the toilet.

Overheating is more likely in a warm centrally heated room and in the summer months. Try and prevent the child from becoming overheated, in the classroom make sure they do not sit in direct sunlight or next to a radiator, make sure their desk is in the coolest area of the classroom. If overheating occurs, the child should be encouraged to drink and be helped to cool down, sucking on ice cubes can help.
During physical activities, be aware of overheating and dehydration. Allow the child to rest for periods, if necessary.

**Environmental effects**
It may also be necessary to avoid environmental conditions that can worsen ichthyosis. Some examples include excessive hand washing or water based activities, dry, cold and windy weather.

The parent/carer and child will be aware of any environmental factors that may cause skin soreness, irritation or dryness; so the school environment should be adapted to try and reduce these triggers for the child.

**Being aware of individual physical needs**
The child may have other individual physical effects due to ichthyosis. For example some children have weepy and sore eyes. They may require eye drops, a constant supply of tissues and extra emollient for their face, which may become sore.

Some children with ichthyosis may develop skin infections, they may have time off school but may also attend school and require oral antibiotics administered during the school day.

As children with more severe ichthyosis are susceptible to infection, access to a topical antibiotic should be provided, if incidental scratches and cuts occur at school.
Helping with psychological and emotional aspects

The child
Make sure the child knows you understand about their ichthyosis and are always there to talk to. Children will be very aware of their skin care needs and what their own triggers are. Always be aware that the child with ichthyosis needs support with both physical and psychosocial aspects of their skin condition.

Social isolation, teasing, ridicule and bullying should be handled very carefully. A true balancing act is needed, on the one hand being supportive but on the other hand not singling the child out for special attention, which could cause ostracism.

General class discussions about prejudice, differences and the reasons for them – and friendships may address these important issues without focusing on the child with ichthyosis. Please see appendix for books and resources for addressing this.

The parents/carers
Keep talking and communicating any concerns. Encourage a good two-way communication with parents or carers. It is important school staff know how the child is doing at home and are aware of any relevant issues concerning their skin care. In turn, it is also important the parents/carers know how the child is coping at school with their ichthyosis.

Parent – pre-school/school carer checklists and the individual healthcare plan (IHCP) for school
Individual health care plans (IHCPs) can help schools effectively support pupils with medical conditions. They provide clarity about what needs to be done and by whom. IHCPs will often be essential for children with ichthyosis, as it is a long-term medical condition, which requires daily skin care. However if a child has mild ichthyosis they will not necessarily require an IHCP.

The school, healthcare professional and parent should agree based on the evidence when an IHCP would be appropriate or inappropriate. If consensus cannot be reached the head teacher is responsible to take final view.

This is advice and legislation provided by the Department of Education. In the appendix, there is a process model and templates of an IHCP are provided.
The Ichthyosis Support Group
The Ichthyosis Support Group (ISG) was formed in 1997 by a group of individuals affected by ichthyosis to create a network of parents, sufferers and medics, and became a UK registered charity in 2001 (Charity Number 1142457).

Our Vision
The ISG is committed to the ongoing provision of an information network and support structure for sufferers and families affected by ichthyosis. Associated with that we need to create a greater awareness and understanding within the medical profession, and lobby for greater research into this distressing condition.

Our Aims
- To preserve and protect the health of and to relieve persons affected by ichthyosis and any associated condition
- To advance the education of the medical profession and the general public on the subject of ichthyosis and its implications for the family
- To promote research into the management of ichthyosis and to publish the useful results thereof, and to support organisations promoting research into ichthyosis

The ISG provides:
- Information and advice about living with ichthyosis
- Regular contact to keep you up to date
- Advice from our Medical Advisory Board
- Links to a Support Team
- Access to our annual event – bringing families together
- To share experiences and to learn about living with ichthyosis
- Summer camps for children

What ISG does:
- Lobby for greater research into ichthyosis
- Raise awareness of ichthyosis and promote greater understanding within the medical profession
- Fund research
- Share information within the European Network for Ichthyosis

Contact the ISG:
Support Line: 0845 602 9202
Address: Ichthyosis Support Group, PO Box 1242, Yateley GU47 7FL
Email: isg@ichthyosis.org.uk

ichthyosis.org.uk

People who care about ichthyosis
Resources provided by the ISG

Example of an ISG resource:
How to help school-aged children answer questions about ichthyosis

What happened to you?
I was born with different skin

What is wrong with your skin?
It's a skin condition called ichthyosis and you say it Ick-thee-o-sis

Why does it look like that?
I have dry skin, just like you have brown eyes and I have blue eyes

What does it feel like?
My skin is very dry, sometimes it itches and sometimes it hurts a lot

Why do you have weepy eyes?
They get sore because my eyelids don’t work very well. It is part of my ichthyosis

Why do you get red and hot?
My ichthyosis means my body gets too hot sometimes and can’t cool down very well

Why can’t you hear very well?
It’s because I get dry skin all over my body, even in my ears, which sometimes makes me a bit deaf

How do you get rid of it?
I was born with it and it won’t go away

Can I catch it?
No, it is not catching, I was born with it

Will it get better?
No but I can make it feel much better by putting on my creams lots of time a day, to stop my skin being dry and sore

Are you really ill?
No, I try to do the same things as you but sometimes it is hard because my skin is stiff and sore
Department for Education: Policies and Template

Statutory Frame for early years (under 5 years) foundation stage (July, 2014)

www.gov.uk/government/publications/early-years-foundation-stage-framework--2
Guidance on standards schools and childcare providers must meet for the learning development and care of children under 5. Includes setting out specific requirements on early years settings in managing medicines for children under 5 years of age.

Supporting pupils at school with medical conditions (updated December 2015)

Statutory guidance about support pupils with medical conditions should receive at school. Includes downloadable templates and web links to other useful resources.

Health and Safety Executive

School trips – tackling health and safety myths

www.hse.gov.uk/services/education/school-trips.htm
To tackle some of the myths about red tape and prosecution, HSE has published a policy statement to encourage all schools (in both maintained and independent sectors) and local authorities to remove wasteful bureaucracy imposed on those involved in organising school visits and outdoor learning activities.

Health Conditions in Schools Alliance

www.medicalconditionsatschool.org.uk
The Health Conditions in School Alliance is made of over 30 organisations, including charities, healthcare professionals and trade unions that work collaboratively to make sure children with health conditions get the care they need in school. The website site offers guidance and tools to schools looking after children with health conditions. You can download a template medical conditions policy a sample individual healthcare plan and advice on what it should contain, guidance on the legal situation across the UK and a process for making sure children who require education in different settings get the support they need to.
Resources for parents and children

**Books**

Ichthyosis Support Group’s *My Story*
Booklet available at
[www.ichthyosis.org.uk](http://www.ichthyosis.org.uk)

*Blue hand book*
[www.truebluehand.com](http://www.truebluehand.com)

**Other organisations**

Changing Faces
[www.changingfaces.org.uk](http://www.changingfaces.org.uk)

Contact a Family
[www.cafamily.org.uk](http://www.cafamily.org.uk)

Skin Support
[www.skinssupport.org.uk](http://www.skinssupport.org.uk)

YP Face It
[www.ypfaceit.co.uk](http://www.ypfaceit.co.uk)
Model Process for developing individual healthcare plans – IHCP
(Department for Education, 2015)

Parent or healthcare professional (Health visitor or school nurse) informs school that child has a medical condition – adapted for children with ichthyosis

Head teacher or senior member of school staff to whom this has been delegated co-ordinates meeting to discuss child’s medical support needs and identifies member of school staff to provide support to pupil

Meeting to discuss and agree on the need for an IHCP to include key school staff, child, parent, relevant healthcare professional’s as appropriate (or to consider written evidence provided by them)

Develop IHCP in partnership – agree who leads on writing it. Input form healthcare professional must be provided

School staff training needs identified

Healthcare professional commissions/delivers training and staff signed off as competent

IHCP is circulated to all relevant staff

IHCP is reviewed annually. Parents to initiate
## Template A: Individual healthcare plan
(Department for Education, 2015)

<table>
<thead>
<tr>
<th><strong>Name of school/setting</strong></th>
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<tbody>
<tr>
<td><strong>Child’s name</strong></td>
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<td><strong>Group/class/form</strong></td>
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<tr>
<td><strong>Date of birth</strong></td>
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<td><strong>Child’s address</strong></td>
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<td><strong>Medical diagnosis or condition</strong></td>
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<td><strong>Date</strong></td>
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<td><strong>Review date</strong></td>
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### Family Contact Information

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<th><strong>Name</strong></th>
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<td><strong>Phone no. (work)</strong></td>
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<td><strong>(home)</strong></td>
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### Clinic/Hospital Contact

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**G.P.**

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<td><strong>Phone no.</strong></td>
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**Who is responsible for providing support in school**
Describe medical needs and give details of child’s symptoms, triggers, signs, treatments, facilities, equipment or devices, environmental issues etc

<table>
<thead>
<tr>
<th>Name of medication, dose, method of administration, when to be taken, side effects, contra-indications, administered by/self-administered with/without supervision</th>
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Daily care requirements

<table>
<thead>
<tr>
<th>Specific support for the pupil’s educational, social and emotional needs</th>
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</table>

Arrangements for school visits/trips etc

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<tr>
<th>Other information</th>
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Describe what constitutes an emergency, and the action to take if this occurs

<table>
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<tr>
<th>Who is responsible in an emergency <em>(state if different for off-site activities)</em></th>
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Plan developed with

<table>
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<th>Staff training needed/undertaken – who, what, when</th>
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Form copied to
**Template B: Parental agreement for setting to administer medicine**  
*(Department for Education, 2015)*

The school/setting will not give your child medicine unless you complete and sign this form, and the school or setting has a policy that the staff can administer medicine.

<table>
<thead>
<tr>
<th>Date for review to be initiated by</th>
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<tbody>
<tr>
<td>Name of school / setting</td>
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</tr>
<tr>
<td>Child’s name</td>
<td></td>
</tr>
<tr>
<td>Group/class/form</td>
<td></td>
</tr>
<tr>
<td>Date of birth</td>
<td>D D / M M / Y Y</td>
</tr>
<tr>
<td>Medical diagnosis or condition</td>
<td></td>
</tr>
</tbody>
</table>

**Medicine**

<table>
<thead>
<tr>
<th>Name / type of medicine (As described on the container)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Expiry date</td>
<td>D D / M M / Y Y</td>
</tr>
<tr>
<td>Dosage and method</td>
<td></td>
</tr>
<tr>
<td>Timing</td>
<td></td>
</tr>
<tr>
<td>Special precautions / other instructions</td>
<td></td>
</tr>
<tr>
<td>Are there any side effects that the school / setting needs to know about?</td>
<td></td>
</tr>
<tr>
<td>Self-administration – Y / N</td>
<td></td>
</tr>
<tr>
<td>Procedures to take in an emergency</td>
<td></td>
</tr>
</tbody>
</table>

N.B Medicines must be in the original container as dispensed by the pharmacy

**Contact Details**

<table>
<thead>
<tr>
<th>Name</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Daytime telephone no.</td>
<td></td>
</tr>
<tr>
<td>Relationship to child</td>
<td></td>
</tr>
<tr>
<td>Address</td>
<td></td>
</tr>
<tr>
<td>I understand that I must deliver the medicine personally to</td>
<td></td>
</tr>
</tbody>
</table>
Template C: Extended information for an individual health care plan relevant to a child with ichthyosis (adapted from Medical Conditions at Schools Alliance, 2016)

**Daily Care Requirements**

<table>
<thead>
<tr>
<th>Time</th>
<th>Care</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arrive at school</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Morning break</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lunch</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Afternoon break</td>
<td></td>
<td></td>
</tr>
<tr>
<td>School finishes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>After school activities</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please note the child may not necessarily have a ‘prescribed’ time for help with emollient application. The times should also be varied every day, depending on the child’s need for emollient and to ensure they do not miss out on lessons, activities or break-time on a regular basis.

**Impact on child’s learning**

<table>
<thead>
<tr>
<th>Effect on child</th>
<th>Care/coping strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>How may ichthyosis affect learning in the classroom? e.g. concentration affected by sore skin and itch, reduced hearing and weepy eyes</td>
<td></td>
</tr>
<tr>
<td>How may ichthyosis affect messy play and art activities?</td>
<td></td>
</tr>
<tr>
<td>How may ichthyosis affect physical education? e.g. are there any physical restrictions, actions before and after exercise</td>
<td></td>
</tr>
</tbody>
</table>
## Impact on child’s learning

<table>
<thead>
<tr>
<th>Can the school environment affect ichthyosis?</th>
<th>Effect on child</th>
<th>Changes by school to deal with these issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>How may the child with ichthyosis be affected?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Location of private area for child to moisturise at school – where is the emollient pump/tub kept?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## School trips

What needs to be put in place for the child to enjoy and participate in school trips? e.g. carriage of emollient and sun care.

## Educational, social and emotional needs

Pupils with medical conditions may have to attend clinic appointments to review their condition. These appointments may require a full day’s absence and should not count towards a child’s attendance record.

| Is the child likely to need time off because of their condition? | Effect on child |
| Is there a situation where the child will need to leave the classroom? | Changes by school to deal with these issues |
| Does the child require emotional support? |                   |
| Does this child have a ‘buddy’ e.g. help carrying bags to and from lessons? |                   |
Support Line:
0845 602 9202

Address:
Ichthyosis Support Group, PO Box 1242, Yateley GU47 7FL

For further copies of this guide, please contact the Ichthyosis Support Group

Acknowledgements:
We would like to thank the following for their commitment, help and advice in producing this School Pack:

Professor Celia Moss OBE, Consultant Paediatric Dermatologist
Julie van Onselen, Independent Dermatology Nurse
A number of ISG members who provided feedback based on their personal experiences

Visit our website ichthyosis.org.uk for more information about ichthyosis and how we can help you.

Coping with Ichthyosis at Pre-School and Primary School

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Designed by Alison Cummins Graphic Design
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