

Let's talk about psoriasis



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Introduction

Psoriasis can cause a lot of stress for the people who suffer from it and their family and friends. When you are diagnosed with psoriasis you may worry about how this will affect your life. The symptoms can sometimes cause other people to look away and distance themselves, and it can have a negative impact on your relationships. You may feel self-conscious and not want to take part in sport and social activities.

We have put together this short booklet with the help of people with psoriasis and their families. It will give parents, teachers, sports coaches and friends some ideas to help young patients deal with everyday situations. It also offers suggestions for older patients on how to improve their confidence and talk about their condition more openly. We hope it will help you deal with some of the misunderstandings about psoriasis.

1

Finding out you have psoriasis

“Where have these red patches come from?

Why aren't they going away?

Have I been infected by a virus?

Is it serious?”

It can be very worrying when psoriasis patches first appear. The patches are caused by the cells that make up the outer layer of the skin being renewed too quickly. Your skin thickens in some places, becoming red and covered in white patches. You may just have patches on certain areas such as your scalp, nails, knees or elbows, or it can affect your whole body.

What should I do?

Your GP or family doctor may be able to diagnose you or they may refer you to a dermatologist (skin specialist). Sometimes it may take a while to diagnose as psoriasis can be mistaken for eczema or an allergy. You may feel stressed and worried as you go through tests to find out.

Finally, you get the diagnosis:

“You have psoriasis. This is a benign (harmless) condition that is not contagious. Psoriasis outbreaks may recur from time to time but can be controlled with treatment.”

Don't panic

Psoriasis is a genetic disease. One third of people with psoriasis have someone in their family with the condition. It may develop in some people at a young age and in some people when they are adults. It can be triggered by a number of factors, such as stress, infectious illness and injury. There is nothing that can stop it happening – it is not linked to a lack of washing or being clean. You cannot spread it to other people.

You may find the diagnosis hard to deal with.

You may worry about other people's reactions, or an outbreak happening at an awkward time. It may affect how you feel about yourself and how you look. You may worry about things like dating and whether people will find you attractive.

There are treatments available. There are treatment options available today that can allow you to lead a normal life. See page 22 for more information on these.

2

Other people's reactions

We hope this booklet will help to reduce some of your worries. We will give you, your family, classmates, team mates and friends some tips to help you feel more comfortable in your skin. Other people's attitudes can make a big difference.





Everyone's looking at me

"What do the people around me think? They may not say anything, but their looks speak volumes..."

Other people's attitudes can be hard to deal with and even hurtful. These can take different forms – whispering and lowered voices, staring or funny looks, looking away or lowering their eyes...

"Keep away from him, it might be contagious"

"Let's pretend we haven't seen her..."

Sometimes people can say mean things about your symptoms... **"It must be because she doesn't wash..."**

Other people may try to give you advice, and recommend things that are not suitable for psoriasis or may even make it worse. **"You should try Auntie Mary's powder or Uncle Sean's cream..."**

"The heating is kept too high at school. That's what causes your skin problems."

This can be very hard on the parents of children with psoriasis. Other people's opinions can be as irritating as the psoriasis patches – there is nothing more frustrating than having to explain the illness over and over again.

Take the initiative

Your family and friends may react the way they do because they don't really understand what psoriasis is. The best way to stop negativity can be to pre-empt questions and to encourage them.

If you are a parent ...

If you wish, you or your child can talk to friends about the condition. You may not be able to stop the curious looks that the symptoms create, but you can at least clear the air. Try to speak in a calm, simple and clear tone. **"I can see you are curious about the patches on my child, so let me explain what they are."**

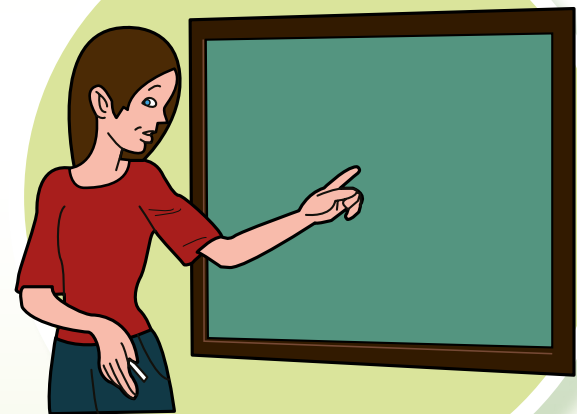
Remember that the aim is to start a conversation and inform them about the condition. This will help avoid misunderstandings. It's not about keeping a low profile or defending yourself – you don't have anything to be ashamed of!

Let children speak too. Always be there to listen to them, and go along with what they want. Don't stop them wearing a short skirt or t-shirt if they want to. Try not to make your child self-conscious with an overly protective attitude, for example by saying **"Don't wear short skirts, as people can see your patches."**

Bear in mind that people don't always see what you think they do. If you're a teenager or young adult with psoriasis, you might be surprised to find out that many of your close friends have not even noticed your new patch, while you can see little else.

3 At school

"The kids at school will make fun of him... He'll be miserable."



If you are a parent ...

The school environment can often be the cause of anxiety for young people with psoriasis and their parents. Will their classmates be more concerned with your son's or daughter's patches than with their maths or spelling?

Lots of parents ask themselves how they can protect their children from hurtful remarks. You want to help them feel comfortable and thrive as any other child.

Where's the problem?

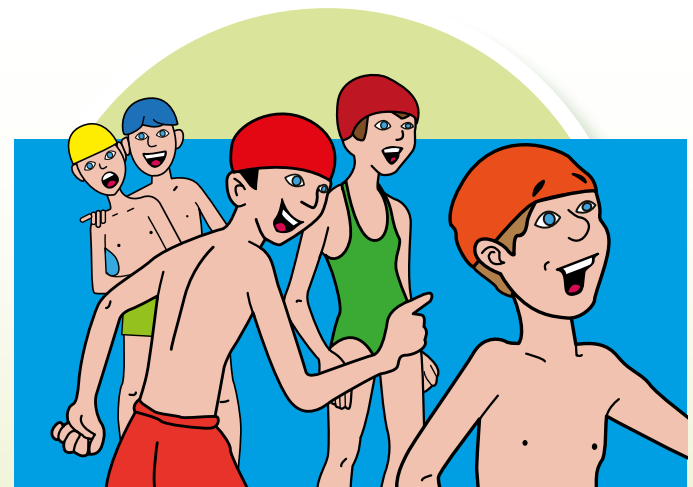
Your fears may not be justified. While you are apprehensive about what your child may have to deal with during the long school day, it may surprise you to learn that the psoriasis patches don't bother their classmates. **"Everyone knows that Patrick's patches are not contagious and sometimes he has to put cream on them."**

Give information to classmates as early as possible. Explain what psoriasis is to classmates, using simple terms, and answer questions before they crop up. This can often have a liberating effect, for children, their parents and teachers.

At the next parent teacher meeting, why not propose a presentation or a class discussion about psoriasis?

4 Sports

"I've got swimming class tomorrow. Everyone will see my patches."



Sports activities usually involve uncovering the patches that you spend so much time trying to hide. You may fear swimming class or gymnastics so much that you ask the doctor to excuse you from them. You may feel that lying is the only way out: **“I can’t go with you to the pool, as I don’t know how to swim.”**

You may really want to take part in sport, but feel you can't. You may often find yourself stuck in the changing room or sick room, treating your skin.

5 Team spirit

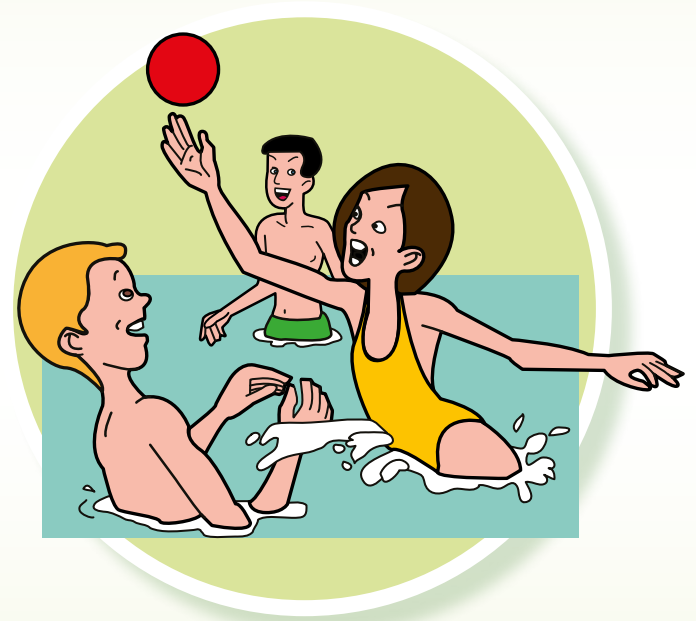
Like your school friends, your teammates may not have heard of psoriasis, so why not talk to them about it? Give them a simple explanation that reassures them it is not contagious or caused by not washing and answer any questions they have.



For your clothes, choose sleeves with detachable sections so you can go for long or short sleeves, depending on how your skin is. Wear a tracksuit top over a t-shirt so you can take it off if you feel like it.

At the swimming pool, teachers may think that you need to leave the pool before the others so you have enough time to put your cream on. Though they mean well, this may be embarrassing for you and make you feel self-conscious. If you are worried about this, ask your teacher to treat you the same as everyone else. If you need it, ask to have extra time after the session.

Even though psoriasis, when treated, needn't stop you taking part in sport, there are some precautions you should take. Your doctor may tell you not to expose your skin to the sun. It may be a shame to miss training sessions on sunny days, but it is better to be safe than sorry.



6

Parents' dilemma

"Scout or holiday camp is drawing near.
Does he have to go?
His psoriasis will make him
feel awkward.
Maybe it's better if he stays at home."



If you are a parent ...

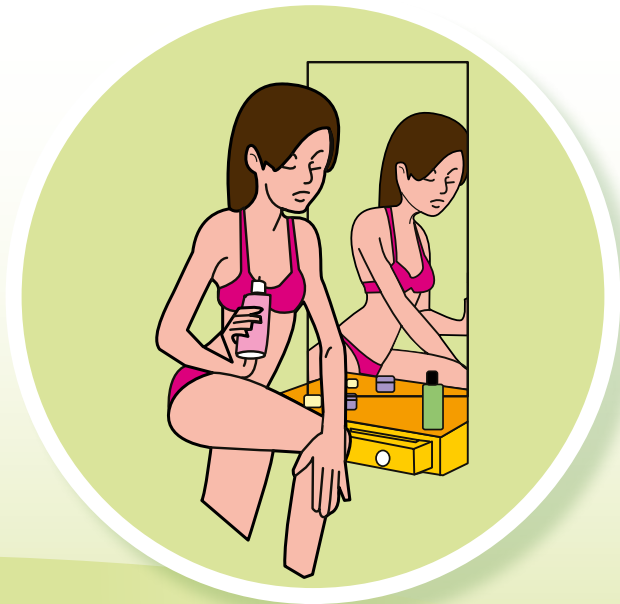
The fear of seeing your child or teenager being mocked by others may make you feel very protective. You may think of the outside world as cruel and dangerous. Why expose your child to this when you don't have to?

Though it is understandable to try and make sure your child avoids situations that make them uncomfortable, your attitude can make them nervous and anxious.

Try not to project your fears onto your child. Encourage them to take part in sports and youth clubs, but have a word with the staff in advance so they know how to deal with your child's condition.

7 Treatment

“Applying the cream in the morning and again in the evening, changing treatments, following recommendations... I feel so restricted. I want to give it all up.”



Psoriasis treatment can be frustrating and restricting. You must apply ointments, creams and lotions regularly without fail. Though it may be possible to take a break occasionally, you can never give up treatment completely.

Some treatments may cause a reaction, such as itching, and you may need to take precautions, such as staying out of the sun, after some therapies. Another annoying thing is that your treatments may be changed quite often.

These are all factors that make psoriasis treatment irritating, annoying and stressful. Children in particular do not always understand the point of all this effort.

Be inventive! Why not give treatment sessions a fun element? For example, a child could apply the cream for her patches while her mother moisturises her own face and her father puts on his aftershave lotion.

Talk to your doctor

Psoriasis treatment can be annoying and complicated. If you have questions, ask your dermatologist about anything that bothers you. Tell them if it is difficult to make their recommendations a part of your everyday life. It's important to have a good relationship with your doctor, as psoriasis is a long-term condition.

There is no such thing as a stupid question. If you find a course of treatment is difficult to follow as it is too restrictive or has unpleasant side effects (such as the smell makes you feel sick), there may be other options. Ask your doctor what they can offer instead.

Finding a doctor who listens to your worries and who you feel able to ask all types of questions is, without doubt, a key part of successful treatment.

8 Relationships

“Sooner or later, I’m going to have to tell him about my illness. How will he react?”



Psoriasis can make your love life difficult, and you may wonder whether or not you should tell your loved one in case it affects your relationship. Should you hide the symptoms, or is it better to talk about psoriasis immediately? Is it best to wait until the relationship is serious?

Psoriasis can sometimes cause tension between couples. You should talk about it from the start of the relationship rather than hide it. You may actually be surprised to find that your partner has barely noticed the symptoms that jump out at you from your mirror. On the other hand, if your psoriasis makes your partner uncomfortable, you need to consider the situation. Psoriasis is an illness for life, so your partner needs to come to terms with this.

It is important to share the same view of the condition. If there is a support group near you, you and your partner may wish to go along and meet other couples in the same situation.

9

Job interviews

“During the interview, I felt he was a little embarrassed. He was polite and pleasant, though at several points he glanced at the patches I had tried so hard to conceal.”



Some people's attitudes to psoriasis may be hard to read – they are not openly negative but not particularly friendly either. Though their conversation may be pleasant enough, they may act a little distant and stilted. You may be very aware of this difference between their verbal and non-verbal language. You may feel that you have been turned down for the job as a result of their reaction to your psoriasis, rather than the reason they give you.

Being open and honest

The mixed messages sent by your interviewer could be due to their lack of knowledge. If you're applying for a job in a restaurant, for example, they might think that your psoriasis is caused by poor hygiene.

Clear the air, start the discussion and anticipate questions before they come up. Why not talk calmly about psoriasis and the misunderstandings about it? The conversation will be more open and relaxed. Once you get your psoriasis out of the way, the job interview can really get going.

10

And finally...

A few things to remember

- You're not alone - psoriasis is more common than you might think! It affects nearly 3% of the world's population. Men and women of all ages and races have psoriasis.
- It is not contagious - you cannot catch it from other people and it cannot be transferred from one part of the body to another.
- Psoriasis cannot be cured but it can be controlled. There are many different treatments available that can clear it for periods of time. Remember, you may need to try out different treatments before you find one that works for you.
- Using a moisturiser regularly can help skin problems such as dryness, scaling, soreness and itching.

- Stress can make an existing condition worse.
To improve your psoriasis and the quality of your life you need to deal with stress and take some time out for yourself.
- Don't be afraid to talk about your condition.
This can help others understand its causes and treatments.
- If you would like more information or support please contact:

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Co. Dublin
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