

# ***Małgorzata Kułakowska***

*"No Disguise"*

*"If someone is ill-mannered and doesn't know how to behave, I don't want them among my friends. Let's be open to people who are open-minded. We should live our life to the best of our abilities".*

***How long have you had psoriasis?***

*I have a very long history of psoriasis. It started when I was just 10 years old, but I was diagnosed 9 years later. Today I am 47 years old and I know much more about psoriasis than ever before.*

***What came to mind when you learned you had psoriasis?***

*On the day I heard the diagnosis, I went back to my office and told my colleagues. One of them said psoriasis was a serious condition, but I had no idea about it. I thought my colleagues were talking nonsense. I had skin manifestations on my arms and legs but I thought that I'd be fine as long as I used the emollient I got from my doctor. However, since then it has never been fine... I was completely unaware of the seriousness of this condition. If I had been, I would have gone to a library to learn more. I didn't realise the scale of my problem. I was fully ignorant until I heard some news about psoriasis on the media. Today, in the Internet age, you have access to all sorts of information online.*

*Newly diagnosed patients are very privileged to have access to knowledge about psoriasis. If you don't learn how to mentally cope and live with psoriasis, you can be in trouble. When you get used to it, you should learn what is harmful and what is beneficial for your psoriasis, what causes flare-ups or spread of the disease.*

***Do you think psoriasis is a disease of the body and the soul?***

*In many cases, psoriasis is more about the soul than the body. Even if you have very few spots on the skin, but you are mentally weak, you won't be able to live normally. I often watch my friends who have just one itching spot. I tell them: "If you had psoriasis, you would scratch your skin off." Even a few spots on the skin can make you very miserable.*

***What did your family and friends know about your disease?***

*They didn't know much about psoriasis. They were convinced I'd be fine if only I applied the prescribed medicine to the spots on my skin. We didn't speak much about it in my family. There was one simple rule: I had to apply the ointment, then it would all be OK. I started to conceal my psoriasis by wearing long-sleeved blouses and long skirts. Many people believed I had some kind of an allergy and I didn't want to set them straight because I was afraid to speak the word "psoriasis" loud and clear. I think many people have problems with that. People with psoriasis feel worse and feel limited in so many different ways. My psoriasis has definitely made me the way I am today. There are families in which parents hide this condition from their children. I've never hidden psoriasis from my child, which is why my child is now so tolerant.*

However, I used to conceal my condition from my friends and colleagues for so long that I became a master of concealment. About 10 years ago, I experienced a breakthrough and I decided to speak about psoriasis openly. Unfortunately, there is still widespread social intolerance. I was so afraid of rejection that I withdrew into myself and didn't go anywhere until I started seeing other people who also had psoriasis. This was a turning point. I realised that I was not alone, I found out some people were in a much worse situation. I was no longer so embarrassed about my condition, I frequently used the word "psoriasis". To my astonishment, I was surrounded by people who had similar problems. When I once spoke openly about my psoriasis, I was approached by a woman who asked me about my doctor because she didn't know where to find help. Now I'm not afraid to go to work with exposed arms when it's hot, but a few years ago I always wore sleeves to the elbow.

**Did you have to change the type of clothes you wear because of psoriasis?**

Even if you are mentally strong, you might still feel weak because your skin in psoriasis looks really terrible. You try to hide it under clothes so that other people don't feel uncomfortable, so that you don't feel uncomfortable. The sad reality is that the scales on the skin fall off and you keep applying emollients over and over again. The pyjamas and bed sheets are always oily and they have to be easy to wash. A person with psoriasis who knows how to manage this condition can wear short sleeves, shorts or miniskirts. But that's all. You can't accept psoriasis, you simply learn how to live with it and to accept the fact you'll never look the way you want to.

For example, I used to travel with my own pillow case because I was ashamed to leave oily stains on hotel bedsheets. You can still leave oily stains on your pillow if you apply emollients an hour or two before going to bed. I thought: "What will they think of me when they clean my hotel room?"

**Is your psoriasis expensive to manage?**

Yes, it can cost quite a lot. I have to buy emollients – creams and body lotions. I have to be careful about the soaps, shower gels, cosmetics, hygiene products I buy. They can be much more expensive because of the ingredients they contain. I use a lot of emollients so I wash my things very often, which is also expensive.

**How would you evaluate the social awareness about psoriasis? What is the social approach to people with psoriasis?**

People can be very rude. I used to be afraid people might frown on me or point fingers at me. That they would think my skin was dirty. That's very sad. That's what people with psoriasis are afraid of. Nobody wants to hear people

saying: "Don't get any closer, I can catch it too." Or when people back off a little when they see my skin. Because of reactions like this, people with psoriasis prefer to hide, to make themselves inconspicuous. Nobody stares, makes a face, or says anything unpleasant. Psoriasis is a taboo. There is much to be done to educate people that psoriasis is not contagious. People should learn what psoriasis looks like. I think they would change their mentality; they should be familiar with it.

I also think newly diagnosed patients should have someone to talk to. The wide access to knowledge may also become a disadvantage. Patients learn too much about psoriasis and they may feel scared. Patients diagnosed with an incurable, chronic disease, especially psoriasis, should be immediately referred to a mandatory consultation with a psychologist. They should have an appointment with a psychologist in two, three days instead of a week or a month. The optimum solution would be to have a psychologist waiting for you in an office next door. Perhaps a psychologist cannot offer an immediate solution, but talking to patients is very important so that they do not feel alone. The best psychologist would be a psychologist with psoriasis.

**What is your advice to people with psoriasis?**

I'd like to say to all of you: remember, you are not alone. Look for other people with psoriasis and open yourself to them. I know you can't be friends with everyone, but try to get in touch with other people suffering from psoriasis and your life will become much easier. If someone doesn't like my skin, doesn't want to stand next to me, talk to me, then this person is not worth my time.

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