



NATIONAL
PSORIASIS
FOUNDATION®

a handbook for

Teens with psoriasis



In this guide

- Facts about psoriasis
- Psoriasis treatments
- Living with psoriasis
- Lifestyle and social life

IF YOU ARE A TEENAGER LIVING WITH PSORIASIS, WE CREATED THIS BOOKLET ESPECIALLY FOR YOU.

It will answer many of your questions and help you gain insight into the disease. But psoriasis has many variables, and you may have questions based on your individual condition. Don't hesitate to contact the National Psoriasis Foundation for ongoing support or for answers to your questions. Or talk to your parents, a counselor, your doctor or other health care professionals when you need help. This handbook will serve as a reference, but it should not replace the advice of your physician.

A DIAGNOSIS OF PSORIASIS

When you develop psoriasis, it can affect more than your physical being. Very likely, it affects your emotional well-being as well. That's why it is important to learn as much as possible about psoriasis. Knowledge takes away the anxiety associated with psoriasis and puts you in charge.

FACTS ABOUT PSORIASIS

What is psoriasis?

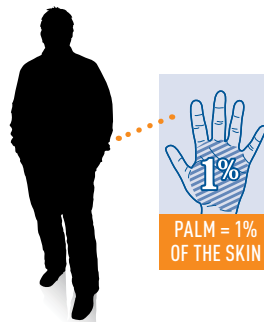
Psoriasis is a genetic skin disease associated with the immune system. Your immune system causes your skin cells to reproduce too quickly. A normal skin cell matures and falls off the body's surface in 28

to 30 days. However, skin affected by psoriasis takes only three to four days to mature and move to the surface. Instead of falling off (shedding), the cells pile up and form the lesions. The skin also becomes very red due to increased blood flow.

Psoriasis is not contagious. It is not something you can "catch" or "pass on." The lesions may not look good, but they are not infections or open wounds. People with psoriasis pose no threat to the health or safety of others.

Psoriasis can be mild, moderate or severe. Three to 10 percent of the body affected by psoriasis is considered a moderate

MODERATE CASE:
3-10% of body is affected



case. More than 10 percent is considered severe. The palm of the hand equals 1 percent of the skin. However, the severity of psoriasis is also measured by how it affects a person's quality of life. Psoriasis can have a serious impact even if it

involves a small area, such as the palms of the hands or soles of the feet and face.

Who gets psoriasis?

The disease affects as many as 7.5 million people in the U.S., about 2.6 percent of the population. Psoriasis affects an estimated 2 to 3 percent of the world's population, and about

125 million people have it worldwide. Psoriasis occurs nearly equally in men and women across all socioeconomic groups. It occurs in all races, though Caucasians are slightly more affected. Ordinarily, people have their first outbreak between the ages of 15 and 35, but it can appear at any age. Approximately one third of those who get psoriasis are under 20 years old when the disease first surfaces.

What causes psoriasis?

No one knows exactly what causes psoriasis, but it has a genetic component. Most researchers agree that the immune system is somehow mistakenly triggered, which speeds up the growth cycle of skin cells.

GENETICS?

Researchers believe that for a person to develop psoriasis, certain steps must happen. The individual must receive a combination of different genes (a combination that is likely to be different for different people) that can work together to cause psoriasis.

The individual must then be exposed to specific factors that can trigger those genes to cause disease. Scientists don't fully understand these triggers yet. However, stress and certain types of infection are potential triggers.

If one parent has the disease, there is about a 25 percent chance of a child contracting it. If both parents have psoriasis, the chance

increases to 65 percent. No one can predict who will get psoriasis. Scientists now believe that at least 10 percent of the general population inherits one or more of the genes that create a predisposition to psoriasis. However, only 2 to 3 percent of the population develops the disease.

A person can have the genes for psoriasis without having the disease on their skin. Genes may be passed through several generations of a family before someone encounters the "right" mix of genes and environmental factors that lead to the development of psoriasis.

INFECTION?

TRAUMA?

Some young people report the onset of psoriasis following an infection, particularly strep throat. One-third to one-half of all young people with psoriasis may experience a flare-up two to six weeks after an earache, strep throat, bronchitis, tonsillitis or a respiratory infection.

Areas of the skin that have been injured or traumatized are occasionally the sites of psoriasis, known as the "Koebner [keb-ner] phenomenon." However, not everyone who has psoriasis develops it at the site of an injury.

Is there a cure?

Currently, there is no cure for psoriasis. However, there is hope for a cure.

Researchers are studying psoriasis more than ever before. They understand much more about its genetic causes and

how it involves the immune system. The National Psoriasis Foundation and the federal government are promoting and funding research to find the cause and cure for psoriasis. In the meantime, **YOU CAN manage the symptoms of your disease with one or a combination of many treatments.**

TYPES OF PSORIASIS

There are five forms of psoriasis. The most common is **plaque**, characterized by inflamed skin lesions topped with white scales.

Other forms are:



Guttate psoriasis on chest

★ **Guttate [GUH-tate]**

characterized by small dot-like lesions



Pustular psoriasis on palm of hand

★ **Pustular [PUHS-choo-ler]**

characterized by pussy, blister-like lesions and intense scaling



Inverse psoriasis in armpit

★ **Inverse**

characterized by intense inflammation in the folds of skin



Erythrodermic psoriasis on knees

★ **Erythrodermic**

[eh-REETH-ro-der-mik]

characterized by intense shedding and redness of the skin. If this rare form develops, see a doctor immediately

Approximately 10 percent to 30 percent of people with psoriasis will develop psoriatic

arthritis. This form of arthritis is similar to rheumatoid arthritis. It can develop at any time, but for most people it appears between the ages of 30 and 50. In psoriatic arthritis, the joints and the soft tissue around them become inflamed and stiff. Psoriatic arthritis can affect the fingers and toes and may involve the neck, lower back, knees and ankles. In severe cases, psoriatic arthritis can be disabling and cause irreversible damage to joints. **Having psoriasis does not guarantee that you will eventually develop psoriatic arthritis.**

Psoriasis Treatments

Psoriasis treatments work by slowing skin cell reproduction.

Some help remove scale. Others help soothe itchy or uncomfortable skin. All psoriasis medications are effective in clearing lesions, but not all people with psoriasis react the same way to medications. It may require experimentation to see which treatments work for you.

What are the different types of treatments?

There are three basic categories of psoriasis treatments:

1. **Topical treatments** like creams and ointments are used on the areas of skin that have psoriasis plaques
2. **Light therapy (ultraviolet light B or UVB and UVA)** works by exposing the skin to light waves, sometimes over the whole body and

sometimes only on affected areas, like hands or feet.

- 3. Systemic medications** are medications taken by mouth or injected into the muscle.

How do doctors decide which treatment to use?

Doctors select treatments according to the **type and severity** of the psoriasis, the **areas** of the skin affected, your **age** and **past medical history**. Some of the treatments available for adults are used less often for teenagers because of the possibility of long-term or delayed side effects. Long-term effects on childbearing potential are important considerations for teenage girls.

What is my role in treatments and treatment decisions?

Your overall goal is to **gain control of your psoriasis and manage it**.

You'll need to work closely with your parents and doctor to understand your treatment options and to be sure you understand exactly how to follow the treatment directions. Half of all patients with a treatment prescribed by a doctor do not follow through as directed and, therefore, don't give the medication a fair chance to work.

Psoriasis patients report that the more they know about a treatment and take part in managing their treatment, the better prepared they are to develop reasonable expectations about treatment. They know what to expect

and are more likely to use their medications correctly.

What kinds of things should I know when discussing treatment options with my doctor? Here are some questions you can ask your doctor:

- > How long has this treatment been used for psoriasis?
- > What are the potential benefits of the treatment?
- > What percent of people improve on this therapy?
- > How quickly will it work?
- > How long will it work?
- > What are the common side effects of the therapy?
- > Will tests be required to monitor the side effects? If so, what kinds of tests and how often will I need them?
- > Will the side effects go away if I stop the medicine?
- > Can I stop this treatment suddenly or do I need to quit gradually?
- > What are the other options?
- > What if a treatment fails?

Most treatments will produce some improvement, but not necessarily 100 percent clearing. However, when a treatment fails, there is nothing to say or do to ease the disappointment. To keep this in perspective and

to keep psoriasis from controlling YOU, try to remember all the things you know about the disease as you process your feelings.

- * Millions of others have psoriasis and share your exact feelings.
- * It is not contagious.
- * There are often periods of clearing that aren't due to a treatment.
- * Try many treatments if needed. Finding the one that works best is a matter of trial and error for each person.
- * Researchers are working hard to develop better treatments and a cure.
- * Psoriasis is part of your life, but it is not your whole being.

LIVING WITH PSORIASIS

Psoriasis creates a mixed bag of emotional reactions. Some people show little emotion over having psoriasis, while others react intensely. You may think this is because of the extent of someone's psoriasis, but in reality that doesn't seem to be the case. Whether someone has a few lesions or many, the emotional response is not always the same. What's important is to know you may experience definite feelings about having psoriasis. Once you understand the extent of your emotions, you can deal with them constructively. Here are some common questions teens ask about coping with psoriasis.

I feel depressed and fear my psoriasis is affecting my self-esteem. Is this normal?

It's common to experience a sense of shock, confusion and anger about what's happening to your skin. These feelings may give way to profound sadness or depression. Accepting your skin's condition is possible, but it takes time to achieve. Therapy, support groups or an online community may be of benefit, or discuss these issues with your doctor or an adult.



What can I do to help myself deal with my emotions?

Talking about psoriasis can help. Find someone, whether they have psoriasis or not, who is willing to listen and recognize the strong feelings that accompany psoriasis. Your feelings are real. Don't dismiss them or trivialize them.

Find a dermatologist you can talk to about your feelings. He or she may have suggestions on dealing with the emotional aspects of psoriasis.

Find healthy ways to release strong emotions such as anger or sadness. Exercise, art and journaling are just a few ways to express your emotions in a healthy way.

Once I come to terms with my psoriasis, what's next?

One of the hardest things about living with psoriasis is that you can go through repeated cycles of strong emotions, usually when the psoriasis goes into remission or reappears. The disease is unpredictable, and the emotions it triggers may occur repeatedly. Apprehension about psoriasis returning or getting worse is common.

Will I have to deal with others' reactions to my skin all the time?

Not necessarily. Psoriasis is a reality that you live with, but you don't have to let it take control. There are ways to avoid dealing directly with others about your psoriasis if you choose, and you can use these techniques whenever you want. Wearing long sleeves, for example, can make coping in public a lot easier on days when you don't have the emotional energy to accept the stares and questions. Another way of dealing with other's reactions is to educate them and spread public awareness of the disease.

What about my future?

Your intelligence, character, and relationships will be the determining factors in life's important decisions, such as your choice of work, whether to attend college, responsibility for being on your own and the kind of person you want to be. Your skin does not define who you are or what you will become. People who have

psoriasis lead positive and productive lives. Often, they find themselves better adapted to deal with stress and change because of the skills developed when living with psoriasis.

What guiding principles are there to help me live with psoriasis?

The more people know about and understand psoriasis, the better and easier it will be for you. Be willing to discuss your psoriasis with others and educate them.

- * Real friends will want to know about you and will want to help. The psoriasis won't put them off.
- * There is nothing to be ashamed of or embarrassed about. You didn't do anything wrong. Skin disease has no meaning other than what it is, even if other people attribute other things to it.
- * It is natural to feel anxious, angry and depressed. Friends can help.
- * You can help friends support you by letting them know that psoriasis is not contagious and that it's the result of skin cells rapidly reproducing.
- * Ask for support, or no one will know that you need it.
- * Find what works for you.

LIFESTYLE AND SOCIAL LIFE

In your teens, you're ready to make decisions about the person you want to be and the way you want to live your life. Psoriasis may complicate things, but don't let it hold you back.

If this booklet doesn't answer your questions, call your doctor, a counselor or the National Psoriasis Foundation. Never give up. The role of accurate information and good emotional support is important when you consider psoriasis in your life decisions.

Teens often wonder how psoriasis fits into some of their choices, and ask these kinds of questions:

What effect does stress have on psoriasis?

Stress is a proven trigger in some people. It can cause psoriasis to flare for the first time or aggravate existing psoriasis. Relaxation and stress reduction may help people with psoriasis. For example, not only does relaxation help lower stress levels, but also it gives people a feeling of control. These techniques, however, seem to work best with traditional medical treatments, instead of using the techniques alone.

Does the chlorine in swimming pools affect psoriasis?

Chlorine causes skin drying and irritation. Before swimming, it might help to protect your skin by applying a thin layer of either petroleum jelly or mineral oil to the areas with

psoriasis. Immediately after swimming, rinse with plain water and apply moisturizer while the skin is still damp. Using these safeguards, you should be able to swim whenever you wish, unless your doctor has advised otherwise because of your particular circumstances.

Is it okay to spend time outside playing or sunbathing?

Yes. Most people get better when they expose their psoriasis lesions to the sun. However, avoid getting sunburn! It might make your psoriasis worse. Regular, consistent exposure times that do not cause sunburn are best. Make sure to use sunscreen on the areas of your skin that do not have psoriasis lesions, especially your face, ears, neck, etc.

Would body or ear piercing or tattoos affect psoriasis?

Psoriasis sometimes develops in areas of skin injury, particularly when the disease is flaring, so it may develop in areas with piercings or tattoos. However, this psoriasis will often respond to the use of topical therapy, as long as the area heals without infection. Always get these procedures from a professional under sterile conditions.

Can I participate in sports?

More than likely, psoriasis will never hold you back from participating in sports. Many teens that have psoriasis take part in many sports, such as swimming, soccer, tennis, football, gymnastics and track. Whatever sport you

choose, the deciding factor is the circumstances of your particular case. You decide what is achievable.

What should I tell interested strangers about psoriasis?

What you say is up to you. In general, a short, straightforward medical explanation is fine. Most people want to know what it is, how you got it and if they can get it, and they may want to know what you do about it. **You can give as much information as you are comfortable sharing.**

How much should I tell new friends about my psoriasis?

What you say, when you say it and how much detail you give about your psoriasis is always a judgment call. Aside from the medical explanation that you can give strangers, new friends will want to know about your treatments and the effect psoriasis has on you. Making new friends—real friends—means taking risks and revealing yourself.

You might be surprised by how supportive people can be once they know about you and how the disease affects you. Most people will want to know how they can help. Be sure to tell them. **Even friends**



with the best intentions won't know you need support unless you ask for it.

I want to get a job. How will my psoriasis affect this?

Psoriasis shouldn't affect your ability to get a job. Like friend and family relationships, work relationships require a certain amount of communication and honesty. Your co-workers may have questions about visible lesions, so be prepared to educate them about psoriasis. They may become a part of your support system.

Schedule a meeting with your manager to talk about how psoriasis may affect your work. The point is not to generate sympathy, but to come up with solutions for any problems that may arise.

What about dating? How do I tell a date that I have psoriasis?

It depends on the situation. There may be no point in letting a date know about your psoriasis until you know whether you're interested in developing an ongoing relationship with that person.

When you tell someone you like about your disease, you get a chance to see if he or she is worthy of your attention. Not everyone can understand that psoriasis does not affect one's ability to participate in a relationship. You can tell the person on your first date by sliding into the topic. You can talk about liking the

beach or swimming and that the sun is very good for your psoriasis. You might mention a psoriasis-related appointment or event you attended recently. Whichever approach you choose, remember that everyone has something different about him or her—psoriasis just happens to be something that shows.

Is psoriasis a concern with regard to having an intimate relationship?

Intimacy is a very personal decision. For those who choose to be sexually active, psoriasis will be a concern if you have it in the genital area. It is mainly a worry because the psoriasis can become irritated, especially if it is flaring. Usually, you can control genital psoriasis more easily than psoriasis elsewhere. If it doesn't affect the genital area, it most likely will not have any physical consequence.

The other aspect of intimacy and psoriasis is the psychological component—how you feel about yourself and your confidence with regard to your skin. If you feel self-assured, there should be no problem. If you don't, you will most likely need to discuss your feelings with your partner. **Open, honest communication in any relationship is the best guiding principle.**

Remember, it is important to practice safe sex and use condoms. You won't pass your psoriasis on to your partner, but having psoriasis does not reduce your risk of HIV or other sexually transmitted diseases.

What can I do on my own to make my psoriasis less noticeable?

Using moisturizers regularly can help improve the redness and scaling associated with psoriasis lesions. There are two ways you can get rid of psoriasis scale on your own:

- ★ **Occlude, or wrap the scaly area**, by coating each plaque with a thick layer of heavy, over-the-counter emollient cream and covering it overnight with plastic wrap. In the morning, wash away the scales in the shower. **Note: Never occlude a prescription medication without first consulting your doctor.**
- ★ **Hydration** (soaking the skin in water) can also eliminate scales. After soaking for 10 to 15 minutes in warm water and bath oil, gently rub your skin with a towel to remove the scales.

IN CONCLUSION

Though living with psoriasis can be difficult, **it doesn't have to control you.**

Researchers are developing many new treatments, and the advances in discovering why people get psoriasis are significant. The National Psoriasis Foundation supports a worldwide effort to locate the genes that cause psoriasis. If the specific genes responsible for the onset of the disease are identified, it will potentially lead to unique new ways of treating psoriasis.

Meanwhile, learn all you can about psoriasis, meet someone else who has it and never forget that psoriasis is a part of your existence—but it is not the whole of who you are.

Source of Psoriasis-Related Information and Support

The Psoriasis Foundation welcomes the opportunity to assist you. We publish a magazine full of information about psoriasis and educational booklets that cover numerous topics. We also have an interactive Web site that includes a teen message board and a chat room. In addition, we have a health educator available to answer specific questions over the phone or through e-mail. We are here to support you whenever you need us. Don't hesitate to ask.

For further information or support resources, contact:

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