

Parent Guide

For Primary Caregivers
of Young People Who
Have Psoriasis



The National Psoriasis Foundation wrote this booklet for people who care for children with psoriasis.



This guide provides essential information to help parents or caregivers understand and cope with their child's disease. It is to be used as a reference. It is not intended to replace the advice of physicians or other health care professionals.

The Psoriasis Foundation is committed to improving the lives of people who have psoriasis and to supporting research to find a cure for the millions of people who live with this chronic skin disease.

Psoriasis is a genetic skin disease associated with the immune system. The immune system causes 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 can be mild, moderate or severe. Three to 10 percent of the body affected by psoriasis is considered a moderate 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.



It is not contagious. People do not “catch” psoriasis from other people, nor can they transmit the disease to others. Psoriasis does not spread on an individual's skin because of self-contagion.

Who's affected?

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.

Every year, roughly 20,000 children under 10 years of age are diagnosed with psoriasis. Sometimes it is misdiagnosed because it is confused with other skin diseases. Symptoms include pitting and discoloration of the nails, severe scalp scaling, diaper dermatitis or plaques similar to that of adult psoriasis on the trunk and extremities. Psoriasis in infants is uncommon, but it does occur. Only close observation can determine if an infant has the disease.

Cause

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.

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.

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.

TREATMENTS

Currently, there is no cure for psoriasis. However, researchers around the world are seeking better treatments with fewer side effects and control that is more lasting. Until then, many people with psoriasis can manage the symptoms of their disease with one or a combination of many medically recognized treatments and countless home remedies.

Although psoriasis in children is similar to that in adults, there are some real differences, especially regarding treatments. Many treatments used for adults may not be appropriate for children due to possible long-term or delayed side effects. Physicians decide which treatments to use according to the type and severity of the psoriasis, the areas of the skin affected and the patient's age and past medical history.

Infants: Treatment is very conservative. Moisturizers can be a good first step. Oatmeal baths and anti-itch creams can help relieve the itching. Consult a physician before starting any treatment with an infant.

Children: For mild psoriasis, sunlight may be helpful. For moderate cases, broad-band or narrow-band ultraviolet light B (UVB) therapy can help clear the lesions. Strep infection can trigger an outbreak, so antibiotics may help clear the bacteria that could have triggered the psoriasis.

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Teens: Ultraviolet light B (UVB) therapy can help clear the psoriasis. Oral medications may have different side effects for teens, and apply potent topical steroids with caution because they can be absorbed too quickly.

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. Once an effective treatment is found, there is a chance it may not remain effective for that person. It may require experimentation to see which treatments work for an individual.

There are three basic categories of psoriasis treatments:

1. Topical treatments like creams and ointments are used on the psoriasis plaques.
2. Light therapies (Ultraviolet light A or UVA and ultraviolet light B or UVB) work by exposing the skin to light waves.
3. Systemic medications are taken by mouth or injected into the muscle.

Topical medications

Most people with psoriasis begin treatment with topical medications because they pose the least risk of long-term side effects. Some treatments

are available by prescription and some can be purchased over-the-counter. Moisturizers, including bath oils and products like mineral oil and petroleum jelly, provide hydration to the skin.

Steroids

Doctors commonly prescribe topical steroids for teenagers. They may prescribe very weak steroids for younger children. These come in a variety of forms, such as creams, ointments and foams. They vary in strength from very mild to super potent medications. Because side effects can occur from using topical steroids over a long period, or from misusing them, it is especially important to follow directions carefully.

Injection of steroid medication into limited psoriasis lesions is also a treatment. It can be painful but does not commonly cause serious side effects. However, it can cause unwanted thinning of the skin and inflammation in the joint when injected over joints (for example, at the elbow).

Calcipotriene

Calcipotriene is a derivative of vitamin D₃ sold under the brand name Dovone x. This prescription medicine has few side effects when used as directed. It is not approved for children under 12 years of age, but a physician may prescribe it. The prescription medication for psoriasis is not the same thing as vitamin D sold as a dietary supplement. Vitamin D supplements are not effective in treating psoriasis and taking them in large doses can have serious consequences.

Tazarotene

Tazarotene is a topical retinoid that is a derivative of vitamin A prescribed for mild to moderate psoriasis. The brand name is Tazorac. Although it has not been studied for use with young people, a doctor may prescribe it for a limited time. Do not take over-the-counter vitamin A supplements for the treatment of psoriasis.

Coal tar

Coal tar for psoriasis treatment comes both over the counter and by prescription. Apply tar to the skin, mix it with bath water or apply to the scalp in a tar shampoo. It works best for people with psoriasis lesions limited to areas such as the knees, elbows, scalp and shins. Few side effects are associated with coal tar, and it is often combined with ultraviolet light therapy. Tar has an odor and can stain clothing and bedding.

Anthralin

Anthralin is a synthetic derivative of an ingredient found in Goa powder from the bark of the araroba tree of South America. This substance has been used to treat psoriasis for more than 100 years. Anthralin has no known long-term side effects, but can be messy to use and can stain hair or unaffected skin.

Salicylic acid

Salicylic acid removes built-up scale so medications can penetrate the lesions and slow the excessive skin cell production. It is available over the counter in many products and is often used with tars and steroid medications to increase their effectiveness.

Moisturizers

Apply moisturizers on a daily basis to keep the skin lubricated. Skin experts say the greasiest products (creams and ointments) work the best for locking water into the skin. Cooking oils and even shortening can be effective and economical substitutes for commercial moisturizers.

Light Therapies

Light therapy involves exposing the skin to wavelengths of ultraviolet light. This is done in a doctor's office, a light therapy clinic or by sitting in natural sunlight.

Sunlight

Ultraviolet light (UV) occurs in natural sunlight. Frequent sunbathing can control some cases of psoriasis. The problem with using sunlight is it isn't available year-round in most areas. Another thing to consider is the amount of ultraviolet light B (UVB) in sunlight. This is the wavelength most effective for psoriasis and it varies with the time of day, the seasons of the year and the amount of clouds in the sky. It is essential to use sunscreen on unaffected skin, avoid sunburn and have skin checked frequently for cancer if sunbathing is used as a therapy for psoriasis.

UVB

UVB treatments are administered in a physician's office, clinic or at home with a home phototherapy device. There are two types of UVB treatments: broad band and narrow band. The major difference between broad-band and narrow-band UVB is that narrow-band UVB

units emit a more specific range of UV wavelengths.

Once the skin clears, the treatments can be stopped. If lesions reappear, resume treatment. Sometimes people continue UVB on a maintenance basis. The main potential side effect of UVB is a burn resembling sunburn.

PUVA

PUVA combines a psoralen drug with exposure to ultraviolet light A (UVA). Psoralen makes the body very sensitive to UVA rays and comes in oral or topical form. It may be used on a short-term basis to bring a severe or disabling case of psoriasis under control. The main long-term side effect of PUVA is the increased risk of skin cancer, which your doctor can monitor. Never use psoralen drugs with sunbathing or tanning salons because of the risk of severe, even life-threatening, burns.

Lasers

There are two kinds of lasers approved to treat psoriasis: excimer lasers and pulsed dye lasers. Both lasers treat chronic, localized plaque lesions. The excimer laser emits a very small, high-intensity beam of UV light. It is very similar to the light delivered by narrow-band UVB units. Pulsed dye lasers destroy the tiny blood vessels that contribute to and support the formation of psoriasis lesions.

Systemic medications

Doctors do not usually prescribe systemic medications for children and teenagers. However,

they might if a young person has a severe case of psoriasis. Methotrexate, acitretin, cyclosporine and some biologics are drugs that may be prescribed. Sometimes topical medications are used with these potent drugs to help speed clearing and make the person more comfortable.

Etanercept (brand name Enbrel) is a biologic medication that has been studied in children as young as 4 years of age with psoriasis. It was submitted to the FDA for approval in 2008 to treat children and adolescents. Some of the other biologics may be prescribed off-label for children.

Complementary medicine

Complementary and alternative medicine (CAM) treatments are popular with many people.

However, it is difficult to assess their effectiveness because they have not been studied adequately. Also, treatments can be administered differently from practitioner to practitioner.

Acupuncture, balneotherapy and climatotherapy (natural water and sun exposure), chiropractic adjustments, diets and dietary supplements have all been reported to help treat the symptoms of psoriasis in some individuals. Like conventional approaches, not all CAM approaches work for everyone. Results may vary from person to person. It's important to talk to your child's primary care provider before starting any CAM treatment.

If you are interested in trying a CAM treatment with your child, be sure to look for a licensed CAM provider. Your child's primary care provider may be able to give you a referral or recommendation.

Treatment Compliance

Once you, your child and a physician settle on a treatment plan, follow through with it. Half of all patients do not adhere to the treatment plan prescribed by their doctors. This makes it seem like the treatment isn't working, when the reality is that the individual didn't use it in the correct way or give it enough time to be effective.

PSORIASIS AND EMOTIONS

When young people develop psoriasis, it affects them not only physically but emotionally as well. It may influence how they view and interact with the world, the activities they take part in, the people they seek out as friends and the interests they develop.

Some children may show little emotional reaction; others may be embarrassed, angry or sad. Children may be apprehensive about their psoriasis getting worse or recurring over time. Anxiety over rejection by peers is very common and is hard to keep in check, especially as the child moves toward the teenage years.

Psoriasis can bring on a range of emotional responses. Coming to terms with having the disease may take some time. No one can predict how a child with the disease will act or feel. Because psoriasis tends to ebb and flow, the child's feelings may shift and change as well. The swing in feelings alone can cause confusion. Helping your child to communicate effectively about the disease and his or her feelings is as important as developing ways to help your child manage the physical symptoms of psoriasis.

It is common for children who have psoriasis to experience strong feelings about their skin. Older children and teenagers should find someone they feel safe talking to about these feelings. It could be a family member, friend, physician or counselor. What's important is that they find someone who is willing to recognize the feelings that accompany psoriasis. These feelings are real. Do not dismiss them as trivial or self-indulgent.

SUPPORTING YOUR CHILD

A child with psoriasis needs support from family and friends. Support can take many forms, from being able to listen to the child's feelings to simple, common acts of friendship. You may need to remind your child periodically to ask for support or others won't know that it's needed.

Education

Explain to your child that the more people know about psoriasis, the better. Allow the child to practice telling you about his or her disease as if you were a teacher, a new friend or a stranger. Help your child find ways to communicate that psoriasis is not contagious, self-inflicted or mystical. Remind them that it is a medical condition in which the skin cells grow too rapidly and build up on the surface of the skin.

Connecting to others

Connecting to other children with psoriasis will help your child realize he or she is not alone. It can be helpful to share stories and treatment tips with someone who knows what it's like to live with psoriasis. Encourage your child to create

a support system. This could include teachers, coaches, friends, youth group leaders and other people who care about your child.

Selecting a doctor

Finding the right physician and other health care providers and developing a good relationship with them is critical. Managing your child's psoriasis is a long-term team effort. Educated treatment decisions will grow increasingly important as your child gets older. Involving your child in those decisions is essential in carrying out an effective treatment plan.

Treatment plans

Actively involving children in their treatments gives them a certain amount of control over their disease. However, treatment can create frustration and stress. It requires a commitment of time by the young person and causes varying degrees of discomfort. Repeated treatments that produce minimal results can cause anger and a feeling that there is too much focus on the disease at the expense of other things. Over time, treatment can become a difficult, resented task, particularly if a treatment becomes ineffective and the disease reasserts itself.

To make treatment easier, experts advise setting up a "treatment center" in the home where all medicines and creams are kept. Generally, children over 6 or 7 years old may be able to apply moisturizing lotions and topical creams on their own. Children under 6 may not want creams applied. Play games with a young child's treatments. Try applying creams as "dots" and

then connecting the dots, or drawing pictures with the ointments and then “erasing” them with your hands. As children age, make treatment a timed event and try to break the last record for “least time needed” to apply a treatment.

Handling emotions

While emotional reactions to psoriasis are to be expected, some common techniques can help young people cope with these emotions. Listen for statements that suggest depression, apathy or anger about the disease. Always acknowledge the feelings and avoid downplaying the effects of psoriasis. If a child’s feelings are out of control, or if you cannot cope with the feelings your child expresses, do not hesitate to seek the guidance of a mental health professional.

Here are some ways to handle common emotional reactions in children and teens with psoriasis:

Distortion

“I must have done something to bring this on.”

Technique

Ask the child to base his or her feelings on the facts. While emotional states can worsen psoriasis, it does not cause the disease.

Disappointment

“I’ve done everything the doctor said, applied the treatments faithfully, and it’s back, worse than ever.”

Technique

Remind your child that it is normal for psoriasis to come and go. However, it is equally important

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to simply listen and accept your child’s disappointment and frustration. Just as they have to accept the realities of the disease, you have to accept that you can’t always make them feel better.

Hopelessness

“There is no point in continuing treatments. I still have the disease.”

Technique

Restate that psoriasis is treatable and that there are many treatment options. Although one type of treatment may not work, another might. Remember, sometimes all you can do is listen. With teenagers, you can delve further when you hear negative thoughts.

Challenge the negative thoughts by asking the teenager to:

- Identify the negative thought. Write it down. Test the thought. Are you jumping to conclusions? Are you making psoriasis the scapegoat?
- Dispute the thought. Offer arguments that illustrate psoriasis is not the cause of all negative events in a person’s life.
- Review options. Develop contingency plans. What will you do if . . . ?
- Carry out an action that indicates the negative thought can be overcome.

As the child’s primary caregiver, you will need to know as much as you can about the disease to help your child manage it throughout the course

of childhood. Decide what to tell your child about the disease and its management based on his or her age, maturity and emotional state. You will probably need to reinforce the basic messages you want to get across many times in different ways.

Be truthful about the course of psoriasis while fostering hope. As the child gets older, you can explain more about research and findings. Medical information about the disease is very important. However, it is crucial that your child learns to recognize his or her feelings about psoriasis and to express those feelings as part of managing them. Tell your child often that it is okay to feel angry, sad and frustrated, and it is okay to show that pain to others.

Communication

Psoriasis is a reality, but it need not take control of a young person's emotions. Honest, straightforward information delivered with compassion and sensitivity works best. Your openness and directness with your child will serve as a good example for handling social situations.

Here are some basic points to communicate to your child:

- When you have psoriasis, it means that your skin is producing skin cells faster than normal.
- Scientists haven't totally figured out what causes psoriasis, but things like a poor diet,

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bad hygiene or a certain personality type do not cause it. People do not bring psoriasis on themselves.

- It is not a contagious disease. You can't spread it to others or catch it from someone who has it.
- Psoriasis is something you were born with, just as you were born with your eye color.
- It is a chronic disease, which means that it is ongoing. It usually goes through cycles: Sometimes it seems better, sometimes it may get worse.
- Researchers are working to determine the exact cause of psoriasis and develop better methods to treat it. Researchers don't know yet why some people get the disease and others don't.
- Some people who see your skin won't know or understand what you have. They may make rude comments or tease you, or they may even avoid you altogether. The more you can explain about your skin condition to others, the less you'll have to worry about their reactions.
- Ask your doctor questions and tell him or her if there is anything you're worried about.

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- Write down your questions before you see the doctor so you don't forget them during your appointment.
- Ask your family members and friends for support when you need it. Other people want to help, but they don't always know how.
- Psoriasis may be part of you, but it is not all of who you are.

Of course, no single approach or technique will be appropriate for every situation or every child who has psoriasis.

These are some tips that may be beneficial:

- Once you, the physician and your child have settled on a treatment plan, be sure you follow through with it as directed. Changing the amount of medication, the frequency of treatments or any other part of the plan can make a significant difference in the results.
- Your attitude affects your child. Stay positive and hopeful.
- Acknowledge that having psoriasis is not easy, but it can be dealt with positively.

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- If a treatment fails, you probably won't be able to ease the disappointment. Let your child know that you, too, are disappointed. Encourage them to try something new.
- Listen for objections and problems and show that you are sympathetic, but do not let the child use psoriasis to manipulate others.
- Create games to play during treatment sessions.
- While it is important to recognize the impact psoriasis can have on the whole family, don't let the child's psoriasis run your life or your family's life. Your other children and significant relationships require your time too.
- Help your child find someone they can identify with, perhaps someone who has overcome a personal challenge.
- Be a good example when dealing with others' questions and reactions.
- If you use embarrassed or negative tones, your child will hear the message that the disease is something to be ashamed of. It isn't.

Bill of Rights

There is a “Bill of Rights” for people who have psoriasis, including children and teenagers. Keep these concepts in mind and help your child implement them.

Your child has the right to:

- A full explanation of psoriasis and the treatments or medications prescribed.
- The most potent treatment with the best result and the mildest side effects.
- Sympathetic, courteous management by physicians and other health care providers.
- The privilege of changing doctors or treatment centers.
- The freedom to experience emotional reactions from having psoriasis.
- The encouragement and support of family members and friends.
- Access to information about psoriasis, psoriatic arthritis and treatments.
- The public’s attention when describing psoriasis from a medical and scientific point of view.
- Deal with psoriasis in his or her own way and not as other people think they should cope.
- See himself or herself as a person of great worth who has a diagnosed medical condition called psoriasis.

The National Psoriasis Foundation welcomes your requests for more information and continued support. We provide an extensive selection of educational booklets, a magazine, individualized assistance and an interactive Web site. We have a message board on our Web site dedicated to parents and family members of people with psoriasis. You can connect with others who share your concerns on our Web site. Visit www.psoriasis.org to learn more.

We invite your comments about this booklet and our other services.

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