What is this booklet about and who is it for?

The Psoriasis & Psoriatic Arthritis Care Partners booklet is part of a series of educational materials on psoriasis and psoriatic arthritis (together called psoriatic disease). This booklet is for the caregivers, family and friends of people with psoriatic disease.

This booklet gives an overview of psoriasis and psoriatic arthritis and answers questions about how to support someone you care about with psoriatic disease, such as:

- What can someone living with psoriatic disease expect?
- What are key questions to ask when someone with psoriatic disease is making treatment decisions?
- What are some strategies and tips for speaking with your loved one about psoriatic disease?
- How do I care for my own health?

This booklet has been reviewed for accuracy by health care providers who have experience treating psoriatic disease.

If you have questions about psoriasis or psoriatic arthritis, contact an NPF Patient Navigator.

Our navigators understand psoriatic disease and the issues that affect those living with it. Whether your loved one was diagnosed yesterday or 20 years ago, Patient Navigators find solutions to help both you and them overcome any barriers that are challenging your loved one in managing their disease.

- 800-723-9166
- education@psoriasis.org
- psoriasis.org/navigationcenter

What is a care partner?

As a care partner you may be a spouse, partner, child, parent, other relative, friend or neighbor. No matter what your relationship is to the person you are helping to care for, your role is to support them as they manage day-to-day life with a chronic (lifelong) disease.

People living with a chronic disease like psoriasis or psoriatic arthritis often need support from loved ones. Having a trusted partner in their corner is an invaluable resource as they face the ups and downs of managing their disease.

Some care partners are fully immersed in caring for someone with a high level of needs, while others are there to offer an occasional helping hand. The level of support people need can vary greatly, but may include things like:

- Arranging medical appointments
- Offering emotional support
- Researching disease and treatment information
- Assisting with medications (for example, giving injections, getting prescriptions filled, applying topicals)
- Attending medical appointments, taking notes and helping with treatment decisions
- Assisting with activities of daily living (physical therapy, mobility, dressing, bathing)
- Buying groceries, cooking, cleaning/laundry
- Providing transportation

While everyone’s journey in being a care partner is unique, there are many common experiences. Learning more about how psoriasis and psoriatic arthritis can impact people’s lives and bodies is an important step in supporting your loved one.
Psoriasis

What is psoriasis (sore-EYE-ah-sis)?
Psoriasis is a chronic (lifelong) disease. It is related to the immune system. When you have psoriasis, your immune system becomes overactive. The overactive immune system causes inflammation (swelling and redness) of the skin and speeds up skin cell growth. This results in itchy or painful, scaly, inflamed patches on the skin.

Psoriasis affects over 8 million people in the United States. Symptoms often start between ages 15 and 25 but they can start at any age. Anyone can be affected by psoriasis.

Psoriasis varies from person to person. It can be mild, moderate or severe, and easy or hard to treat. It can affect quality of life, limit activities, cause constant pain and itch, lead to depression and anxiety, and raise the risk for diabetes and heart disease.

While there’s currently no cure for psoriasis, there are many ways to manage symptoms. Over the last 15 years, new treatments have been approved for psoriasis and psoriatic arthritis. Today, there are more effective ways to manage psoriatic disease than ever before – and the results can be life-changing. Treatment is the best way to improve quality of life and lower the risk of related diseases.

It is important to find a health care provider who specializes in psoriasis, called a dermatologist (skin doctor).

Odds that a child will develop psoriasis

- One parent has psoriasis
- Both parents have psoriasis

What causes psoriasis?
No one is sure what causes psoriasis. Normally, the immune system fights illnesses and infections. When someone has psoriasis, their immune system overreacts, or flares, when they experience a trigger (discussed on page 7). This causes inflammation of the skin and speeds up skin cell growth. Typically, skin cells completely grow and shed (fall off) in a month. Psoriatic skin cells do this in only 3 or 4 days, but instead of shedding, these cells pile up at the surface. This forms psoriasis lesions (abnormal changes to the skin in the form of plaques, pustules or areas of scaling, redness and swelling).

Genes also play a role. Even though psoriasis runs in families, people with no family history can develop it and people with a family history may never get the disease.
Is psoriasis the same for everyone?
Psoriasis differs from person to person. Psoriasis severity can be measured by how much of a person’s skin it affects. As a rule of thumb, the entire hand (the palm, fingers and thumb) is equal to about 1% of the body surface area.

Other factors to consider when measuring severity include the areas affected and how much it impacts quality of life. Psoriasis can be severe even if it’s only on a small area of skin, like the hands, feet, scalp, face or genital area.

Psoriasis can change over time. Some people rarely have symptoms while others have symptoms all the time. Symptoms can get better or worse, last a short or long time, and appear on different parts of the body at different times.

Psoriatic arthritis

What is psoriatic arthritis?
Psoriatic arthritis is a chronic, inflammatory disease of the joints and the places where tendons and ligaments connect to bone. The immune system creates inflammation that can lead to swelling, pain, fatigue and stiffness in the joints.

About 1 in 3 people with psoriasis develop psoriatic arthritis. It can start at any age, but often appears between ages 30 and 50. For most people, it starts about 10 years after psoriasis begins. While it is less common, people can develop psoriatic arthritis without having psoriasis.

Though there is no cure, there are a growing range of treatments available to help stop the disease progression, lessen pain, protect joints and preserve range of motion. Left untreated, psoriatic arthritis can cause permanent joint damage. For people who have or suspect they may have psoriatic arthritis, it is extremely important to work with a rheumatologist (arthritis doctor) to find the right treatment plan.

How is psoriatic arthritis diagnosed?
There is no single test that can diagnose psoriatic arthritis – though the National Psoriasis Foundation is funding research to develop one. A health care provider (usually a rheumatologist) will evaluate their symptoms and may order X-rays, an MRI, an ultrasound and/or blood tests to check for psoriatic arthritis and/or rule out other joint diseases.

Symptoms may include:
- Stiffness, pain, swelling and tenderness in joints or tendons
- Fatigue (extreme tiredness or exhaustion)
- Swollen fingers and toes
- Nail changes
What triggers a flare?

Psoriasis and psoriatic arthritis are diseases of the immune system. When something triggers an immune response in the body it can lead to inflammation that can cause skin and/or joint symptoms to flare.

For psoriasis a flare may include new psoriasis lesions, itch, irritation or burning. With psoriatic arthritis, a flare may include new or increased pain, tenderness, swelling, or stiffness in joints. Flares may last for various amounts of time and may vary in level of severity.

Triggers vary from person to person. What can be a trigger for one person may not affect another. Common psoriatic triggers include:

- Stress
- Tobacco, alcohol or other substance use
- Injuries or trauma to the skin and/or joints
- Illness, such as infections
- Certain medicines, such as anti-malarials, tumor necrosis factor (TNF) inhibitors, beta blockers, interferons, lithium, nonsteroidal anti-inflammatory drugs (NSAIDs), prednisone and other steroids

Allergies, diet and changes in the weather may also cause flares for some, but this is not scientifically proven. Sometimes it can be very clear what might be triggering a flare and other times it is not easy to identify.
What are the treatment options?

There are safe and effective treatment options for psoriatic disease. Treatments for psoriasis can reduce symptoms like inflammation and help achieve clearance or remission. For psoriatic arthritis, treatments can reduce joint pain, keep joints working well and prevent future joint damage.

Topical treatments (also called topicals) are medicines that are applied directly onto the skin to treat psoriasis. They can work to moisturize the skin, relieve pain and itch, reduce inflammation or slow down the high rate of cell growth. Topicals are available in over-the-counter (OTC) or prescription strength.

Phototherapy (also called light therapy) uses ultraviolet (UV) light to treat psoriasis under the supervision of a health care provider. Treatment can be given in a health care provider’s office, psoriasis clinic or at home with a prescription and instructions from a health care provider. Phototherapy can be used on small areas of the body with targeted treatments or large areas of the body with whole body treatments.

Biologics and biosimilars are medicines made from living cells that are given as an injection or intravenous (IV) infusion. Biosimilars are medicines that are modeled after a biologic that has already been approved by the Food & Drug Administration. Biologics and biosimilars target specific proteins in the immune system that play a role in psoriatic disease. There are currently 5 types of biologics that treat psoriatic disease.

Biologics are categorized according to how they work, and the specific proteins that they target (block or lessen) in the body:

<table>
<thead>
<tr>
<th>Immune System Target</th>
<th>Name of Biologics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tumor necrosis factor-alpha (TNF-alpha)</td>
<td>Cimzia, Enbrel, Humira, Remicade, Simponi and Simponi Aria</td>
</tr>
<tr>
<td>Interleukin 12 and 23 (IL-12/23)</td>
<td>Stelara</td>
</tr>
<tr>
<td>Interleukin 17 (IL-17)</td>
<td>Cosentyx, Siliq and Taltz</td>
</tr>
<tr>
<td>Interleukin 23 (IL-23)</td>
<td>Ilumya and Tremfya</td>
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<td>T cells</td>
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Oral treatments are medicines taken by mouth, most often in the form of a pill. This is a wide category of treatments. Some act throughout the body. Others target specific cells. Oral treatments for psoriasis include: cyclosporine, methotrexate, Otezla (apremilast) and acitretin (Soriatane).

You and your loved one can work with a health care provider to set goals for managing their psoriatic disease. Setting treatment goals can be helpful in understanding whether a treatment is working well. If a treatment is not meeting the treatment goals, keep working with their health care provider and explore other treatment options. This might mean increasing the treatment dosage, adding another treatment or switching treatments. Your support may be critical in helping your loved one persist through any challenges in finding the most appropriate treatment for them.

Finding the treatment that gives the most relief from symptoms may take time. No one treatment works for everyone. Some treatments work for a while and then stop. Some treatments work better combined. Health care providers can talk with you about potential benefits, side effects or risks if you have concerns.

<table>
<thead>
<tr>
<th>Disease Type</th>
<th>General Treatment Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild-to-moderate psoriasis</td>
<td>Topicals and/or phototherapy</td>
</tr>
<tr>
<td>Moderate-to-severe psoriasis</td>
<td>Phototherapy, biologics and/or oral treatments. May also include topicals.</td>
</tr>
<tr>
<td>Psoriatic arthritis</td>
<td>Biologics and/or oral treatments. May also include physical therapy.</td>
</tr>
</tbody>
</table>
Communicating with your loved one

With all of the challenges that can come with having psoriatic disease, it’s crucial to have people to talk with and trust. People diagnosed with chronic conditions like psoriasis or psoriatic arthritis can go through periods of sadness, fear and even grief. These episodes can occur long after diagnosis, and sometimes happen during times of change or transition.

Managing a chronic disease is hard. Your loved one may at times feel isolated. Feeling accepted and supported by loved ones like you can be incredibly uplifting. They may also benefit from talking with someone else with psoriatic disease. Encourage them to learn more about their disease(s) and get additional support from others.

Keys to good communication include patience, humor and listening as much as you speak. Your relationship with the person you are caring for is unique and together you will find your own path to communicating effectively.

Your loved one may need different amounts of support at different times. Check in with them occasionally to see if they feel they are getting the support they need. People living with psoriatic disease – like any condition – aren’t looking for pity, but a little acknowledgement and a kind word can go a long way.

It’s important to be a strong advocate while making sure to protect your loved one’s privacy and ability to make their own decisions. You are a partner in their care. Look for moments to step up for them, and other moments to step back and let them take the lead.

How do I help with treatment decisions and medical information?

With multiple effective treatment options for psoriatic disease, it can be overwhelming to make treatment decisions. Prepare for medical appointments by writing a list of questions and researching treatments ahead of time.

Ultimately, the goal is to help your loved one have a two-sided conversation with their health care provider so they can decide on a treatment plan that’s a good fit. You can support your loved one in bringing up any of the following during the appointment:

- Benefits of the various treatment options
- Questions about side effects
- How different treatments would fit into your loved one’s lifestyle
- How various treatments may impact family-planning decisions
- How long it takes to see results

You are a critical member of your loved one’s care team. When joining them for medical appointments, ask questions, take notes on what is said in the appointment and be sure to let the health care provider know if you and your loved one don’t understand something or need more information.

If you have questions or concerns between appointments, call and ask to speak with a medical assistant or nurse or see if they have a system to email with patients. Your loved one may need to complete a form to give you permission to have health care discussions on their behalf.

Consider creating a binder with appointment notes, a medication list, important lab results or medical documents and lists of questions for upcoming appointments. There are also several free electronic medical record apps designed to help you keep track of these things.
Emotional health of care partners

The stress of caring for someone can take a toll on your physical and emotional health. You may become overwhelmed with all the responsibilities or experience burnout (physical or emotional exhaustion from long periods of stress).

Balancing other responsibilities, such as work, in addition to caring for the person in your life who has psoriatic disease, can be overwhelming. Most care partners have periods when they experience emotions like stress, guilt, anger, anxiety, resentment and sadness.

Life as a care partner is often just as challenging as it is rewarding, and an impact on emotional health is common. Studies show that anywhere between 40-70% of family caregivers experience depression. It is important to get treatment from a mental health professional if you feel depressed. A mental health professional may be a counselor, social worker, therapist, psychologist or psychiatrist.

Opportunities for self-care

If you’re like the majority of care partners, you may have a hard time dedicating time or resources to yourself. People who take care of a loved one are less likely to take care of their own health. Remember that you are a better care partner when you are feeling good. You deserve to be healthy, too.

Self-care is not selfish, it enables you to take better care of your loved one.

Be gentle with yourself. Don’t ask yourself to always be perfect at taking care of yourself and others. Self-care is not meant to be another thing to add to your to-do list, but it is a chance to fill yourself back up when you are feeling drained.

On the next page you’ll find a list of opportunities to care for yourself. Take a moment to read these over. Is there an area that stands out to you that you would like to focus on building healthier habits around?

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Signs of caregiver burnout can include:

- Overwhelming anxiety about the future
- Sleeping too much or too little
- Loss of interest in activities
- Irritability
- Hopelessness
- Withdrawal from relationships
- Depression or mood swings
- Change in appetite and/or weight
- Neglecting own care and hygiene
- Lack of energy
Organization – Take time to prioritize your to-do list and break big things into small, manageable tasks. Think about how to organize things (medications, paperwork, etc.) as well as ideas.

Body – Check in with your body to see what it needs. Staying hydrated, daily physical activity, eating nourishing foods, and getting regular deep sleep can all be very beneficial.

Environment – Our surroundings can greatly affect our mood. Is there a place you step away to where you feel better? Is there something you can change or add to your home that would make it more comforting?

Recharging – Are there any hobbies or activities that bring you joy that you can do more often? Take at least a few minutes a day or a couple of hours a week to do the things that fill you back up.

Accepting help - No one can do it alone. Try keeping a list of things you can use help with. When someone offers a hand, let them choose something from the list (for example, bringing dinner, picking up prescriptions, grocery shopping).

Community – Are you feeling connected to others who understand you? There are both in-person and online communities and support groups for caregivers that can help you feel less alone in your journey. We also have a robust community here at NPF and can connect you with another care partner of someone with psoriatic disease.

Gratitude – Take time to celebrate the small wins! Getting through difficult times is much easier if you can remember what is going well and list things to be grateful for.

Professional care – All care partners feel overwhelmed at times. If you are feeling overwhelmed regularly or are experiencing signs of depression, you may want to consider talking with a mental health professional. It can help to have someone to talk with who is objective and supportive of you.

Self-care activity

Choosing an area of self-care to focus on
This month I am committed to caring for myself, even as I care for others, by spending time on _______________________________________.

Assessing and appreciating where you’re at now
What are things in this area that are already going well?

_________________________________________

_________________________________________

Are there aspects of caring for yourself in this area that aren’t going well or feel like barriers?

_________________________________________

_________________________________________

Making time for self-care
Building in habits that help caregiving feel sustainable doesn’t have to be time-consuming. Commit to a few small changes like calling a friend who is also a care partner once a week to share experiences or taking a 15-minute walk after dinner.

Name 3 small things that you can do in the next month to help improve your self-care practices.

1. _______________________________________

2. _______________________________________

3. _______________________________________
Next steps

Connect with other care partners

NPF’s One to One program allows you to connect with care partner volunteers who have experience caring for a loved one with psoriatic disease.

Share experiences, get tips and receive emotional support. Sign up and connect with someone today by phone or e-mail. Visit psoriasis.org/one-to-one to get started.

Contact our Patient Navigation Center

NPF’s Patient Navigation Center provides free and personalized assistance to anyone impacted by psoriatic disease, including families and caregivers.

It doesn’t matter if you have one question or need ongoing assistance – your Patient Navigator will help you find the information you need. We can help you:

- Understand your loved one’s disease
- Find a health care provider
- Learn about new treatments
- Deal with insurance issues
- Find financial help for treatments
- Connect with others who care for someone living with psoriatic disease

You can reach our navigators by phone, email, text and instant chat:

- Phone: 800-723-9166
- Text: 503-410-7766
- Email: education@psoriasis.org
- Learn more or chat: psoriasis.org/navigationcenter

Want more information?

Learn about the following topics in the other booklets in this series:

- Psoriatic arthritis, including how to manage flares and chronic pain
- Psoriatic disease in children and young adults
- Treatment options, including biologics and oral treatments, phototherapy and topicals
- Working with your health care providers, including how to find specialists and preparing for appointments

The National Psoriasis Foundation is a 501(c)(3) organization governed by a Board of Directors and advised on medical issues by a Medical Board.

NPF’s educational materials are reviewed by members of our Medical Board and are not intended to replace the counsel of a physician.

NPF does not endorse any medicines, products or treatments for psoriasis or psoriatic arthritis and advises you to consult a physician before initiating any treatment.