

Information Leaflet for Patients

# SUCCESSFULLY TREATING PSORIASIS

### The aim of this leaflet

This leaflet is designed to help you understand more about how to successfully treat psoriasis. It includes information about setting realistic expectations, how to stop and start treatments and being adherent when taking them, dealing with side effects, how to choose a good clinician, and the power of positive thinking.

#### How can you set realistic expectations?

Depending on the mode of action of your treatment, you may need to adjust your expectations. Some medications will work faster than others. And depending on which lesion you're treating, your patience may be put to the test. For instance, nails only grow 0.1 mm per day, so it may take a few weeks before you see any improvement with the naked eye. That's why it's important to ask your clinician what to expect and to fully understand his/her instructions. Moreover, besides some patience, it is important to schedule a follow-up appointment to evaluate the treatment's efficacy and progress together with your clinician. Reconsider together whether another treatment is needed. Of course, leave sufficient time for the treatment to show results.

If you start a new treatment, but you're not sure how to use it or you encounter a practical issue (like clumsy application or sickness), consult your clinician or pharmacist before giving up! It's better to give it a try and ask for advice, rather than giving up and getting nowhere.

#### What are tips for using topical treatments?

Spreading the treatment may require a lot of time and organization in comparison to a pill, but it remains absolutely necessary!

A few of the following tips may facilitate spreading:

- Incorporate spreading into your daily routines and make it a habit
- Spreading is treating, but also avoid becoming worse by hydrating your skin
- If you find yourself having trouble combining both hydration and treatment, try to first apply the hydrating cream, let it dry for a bit, and then apply the medical treatment on the lesions. Consequently, only the lesions will be treated with the medication.

#### What are tips for using conventional systemic treatments?

*Cyclosporin:* Swallow the capsules whole with a glass of water. Other drinks are allowed, except for grapefruit juice, which affects the absorption of cyclosporin. Leave the capsules in the blister pack until it is time to take the medicine. The capsules have a characteristic odour, which is completely normal.

**Methotrexate** (MTX): Take the tablets with a meal. Avoid dairy products as they reduce your body's ability to absorb MTX. It is best to avoid dairy products within 2 hours before and after taking MTX. If MTX is injected, you don't need to take these rules into account.

**Apremilast:** You may experience diarrhoea the first four weeks, so you need to stay well-hydrated by drinking sufficiently. It is best to take apremilast with a meal and to eat small portions regularly. Try to avoid caffeine, dairy products, and sweeteners as much as possible.

## Why should you not stop a treatment on your own?

If you find a treatment that works for you, that's great! But being "psoriasisfree" needs maintenance. Never stop a treatment by yourself without consulting your dermatologist first, and if you want to reduce the dose, revise the treatment regimen together with them when your psoriasis is stable or clear. Never experiment alone: psoriasis cannot be cured with the current treatments, which means that the symptoms will come back once you stop your treatment. This is even more important when you use biologicals, as disrupting the treatment without medical supervision may lead to a significant flare and even resistance to the biological! Again, always consult your clinician when you want to lower or stop a treatment. Don't forget that during maintenance treatment, your skin will still require appropriate skin care!

#### What about side effects?

You may experience side effects, but it is very difficult to predict which side effect you'll experience. However, it is understandable that possible side effects may worry you and convince you you're better off without the medication.

But this is not true for many of the following reasons:

- First of all, pharmaceutical companies are obligated to mention all possible side effects, even the ones with extremely low risks. In other words, the printed information leaflet including the drug labelling is a legal reflection for your own safety.
- Second, it is extremely unlikely that you'll develop all the side effects mentioned on the leaflet.
- Thirdly, if your clinician prescribes a treatment, they will already have considered the potential side effects and potential beneficial effects, and decided that you're better off with the drug.
- Lastly, untreated psoriasis is guaranteed to give you problems later on since it represents chronic, low inflammation in your body, making you more susceptible to develop comorbidities and reduce your life expectancy if severe and left untreated.

If you still have any doubts after reading this leaflet, talk to your clinician and/or local pharmacist.

# What makes a "good" clinician good?

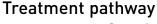
The quest for a good clinician is as important as the quest for a good treatment. In some countries, you are allowed to freely choose your clinician. But the downside is that many people will go "doctor-shopping," which can result in frustration. As explained earlier, treatments require adapted expectations and patience; this is not any different for choosing your clinician. Know that they are often bound by rules (for example, for medication reimbursement) and should follow a treatment pathway (see the figure below), and that it takes time to evaluate if the treatment was a success. If you're not satisfied with a treatment, let your clinician know. A good doctor is somebody who

makes you feel comfortable, who you can share your worries with, and who is willing to take you on a quest for a long-term solution.

Lastly, a good consultation is a prepared, time-efficient consultation: write down your worries, your expectations, your experiences, and other questions you may want to ask your clinician. Use the figure below as a guidance to prepare your visit.

# Why is positive thinking important in treating psoriasis?

Whether you're using medical or non-medical treatments, the power of your psyche and positive attitude shouldn't be underestimated either. This effect is also known as the placebo-effect, and is used in scientific research as a control to adequately measure the effect of a medical intervention. Hence, it is possible to distinguish between the actual effect of your mind and the effect of a (medical or non-medical) treatment. Importantly, it can contribute to the success of your treatment.





#### **Topical**

Corticosteroids
Vitamin D-derivates
Combination
Supportive treatment with
salicylic acid (scales)

Strength of treatment depends on the location (elbows, face, groin) and will be considered by your doctor

### Light therapy

UV-B PUVA Blue light

Sunlight has a positive effect as well, but cannot be controlled and is therefore more dangerous to develop skin cancer

### Systemic treatments

#### Conventional

Methotrexate Acitretin (retinoid acids) Cyclosporin Apremilast

Pills are convenient, but require monitoring by your doctor

#### **Biologicals**

Adalimumab Etanercept Infliximab Ustekinumab Secukinumab Ixekizumab Brodalumab

Biologicals are administered through injections. Never stop treatment without medical supervision!

Healthy lifestyle Non-medical treatments

Supportive

#### The ideal visit to the doctor

History	Goal	Questions	Future
Does it run in your family?	What bothers you most?	Express any concerns you might have	Make a new appointment
What did you already try?	What do you want to achieve?	Check if you understand everything	Discuss realistic expectations
Why weren't you happy with prervious treatments?	When would you like to achieve this?	Ask for the (dis)advantages of your treatment options	Integrate your treatment into your daily routine



You can also relate to the effects of the psyche when doing physical and mental exercises such as yoga, pilates, and mindfulness. In fact, these exercises are excellent for those who prefer calmer sports and rather focus on agility, breathing, and awareness. They will also help to control stress, a well-known trigger for flares. Moreover, some people manage itch through physical and mental exercises! The best part is that you don't need to be an expert or be fit: just some loose clothing and a yoga mat will help get you started.

In conclusion, you can certainly view non-medical treatments as a supportive means that you should apply with caution. Make sure to discuss this with your clinician, so you can both evaluate which effects are from which treatments.

#### To avoid itch, what should you avoid?

- dry skin (to treat this, moisturize every so often, especially after a bath/shower)
- irritating fabrics such as wool
- waterproof clothing such as nylon
- · tight clothes
- perfumed fabric softeners
- regular soap (replace with a mild unperfumed bath/shower oil with a neutral pH)
- · daily baths/showers
- baths/showers that are too hot (max. 30-32°C)
- rubbing your skin dry after bathing/cleaning (gently pat dry)
- setting the hairdryer too high (don't dry your hair for too long or too hot)
- long fingernails (keep them smooth and short)
- excessive use of alcohol

#### Itch: what to do?

If you're itchy, you can:

- apply a moisturizing or medical cream/ointment
- throb the itchy lesion
- seek distraction (e.g. walk around the neighbourhood, solve a puzzle/Sudoku, perform a household task, etc.)

## Why is treatment compliance/ adherence so important?

One of the biggest challenges of combatting chronic diseases is treatment compliance (also known as treatment adherence). Treatment compliance means following the prescription instructions carefully. Although some therapies are more challenging to adhere to, it is important to be adherent every day. Why is this? Since psoriasis is associated with a low yet constant presence of inflammation, it is crucial to keep this inflammation as low as possible. In addition to a healthy lifestyle, adherence to your treatment is the best way to achieve this.

Treatment adherence is challenging since it is interwoven with your expectations: if you don't see results soon enough, you'll feel like the treatment isn't working and be more likely to give up. That's why it's so important to reschedule an appointment with your clinician at a realistic time point to evaluate whether the treatment is a success or a failure. In addition, some treatments may be more comfortable or better-tolerated than others, which can add to the challenge of treatment adherence. Nonetheless, it's only possible to tell whether a treatment helps you if you have been adherent. If you are not adherent to the treatment, be honest with your clinician and explain why it's such a challenge to follow their instructions. Perhaps you can work out a solution together and otherwise, you can reconsider another treatment that will not pose the same difficulty. Either way, never disregard the importance of adherence in the treatment of a chronic disease...

# How can you improve adherence by having certain habits?

Perhaps you find it difficult to integrate treatment in your daily life? Find a way to integrate the treatment in your daily routine. Below, we will give you some examples on how to turn treatments into habits. But it's up to you to make treatment a habit. Surely, you already have some daily or weekly routines, so you only have to couple your treatment to one of your routines. Adhering correctly to your clinician's instructions all the time will definitely pay off both in the short and long term in comparison to adhering "just once in a while," when your psoriasis is really bad. Remember that your psoriasis is a form of chronic, low inflammation, which you need to tackle each day and not just at its worst. Still having trouble? Ask your partner, family, or friends for advice, as they may see certain habits more clearly than you.

How can you improve adherence to topical treatments, light therapy, and oral treatment (tablets/capsules)?

#### **Topical**

Not only your lesions require care, but your healthy skin does, too. We can't emphasize the importance of moisturizing your skin enough. Combine the moments you apply the topical medical treatment together with the moment you moisturize your skin along with another daily habit. For instance, do this just before you brush your teeth: begin with the moisturizing cream, brush your teeth (whilst you let the cream soak in), and then apply the medical cream/ointment. If you've just showered/bathed, don't put clothes on just yet: gently pat dry your skin, moisturize it, and apply the medical treatment. While you let it soak in, you can brush your teeth, do some breathing exercises, or prepare your next meal. If you're not a morning person, shift your skin care to the evening. Choose a moment that repeats daily, for instance when you read the newspaper, remove your lenses, or brush your teeth. Make sure to have an outfit for these moments, like a dressing gown, that you don't mind getting a bit of cream/ointment on. Keep an extra tube or sample in your purse, car, or at the office in case you forgot to apply or in cases of itch.

#### Light therapy

Most people fail phototherapies because it doesn't fit in their schedule. However, phototherapy is very effective for psoriasis and thus certainly worth it. The best way to make it fit your schedule is when you combine it with a fun or relaxing activity. For example, this can be seeing a friend or relative who happens to live in the neighbourhood or on the way to the phototherapy, or going to the gym or a favourite restaurant. That way, you'll gladly make time to go to the light therapy, because it will be associated with something fun.

#### Tablets/Capsules

This class of drugs is easily forgotten if you don't associate them with a daily habit. So choose a very specific place and moment where you'll be sure to take the tablets/capsules. For instance, the nightstand where you keep your glasses, in the bathroom next to your toothbrush or in a cute box at the breakfast table. Should you already have other medications, ask your clinician if it's okay to take them simultaneously. In case you're forgetful, keep an emergency blister pack/strip in your car, at your office, or in your purse.



While every effort has been made to ensure that the information given in this leaflet is accurate, not every treatment will be suitable or effective for every person. Your own clinician will be able to advise in greater detail.

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