

THE IMPACT OF CLIMATE TREATMENT ON QUALITY OF LIFE FOR PSORIASIS PATIENTS

– How can we secure equal access now and in the future?



NORDIC WHITE PAPER
ON CLIMATE TREATMENT

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INTRODUCTION BY NORDPSO

Today, almost 10 percent of people in the Nordic countries are living with psoriasis diesses and are dealing with the life impacting symptoms this entails (Tveit et al. 2019). Climate treatment is an important regimen among multiple treatment options for people living with psoriatic diseases. This treatment can be life-altering for the patients and help relieve and prevent painful and life restraining symptoms. However, it is often not given the same status and clinical focus as, for instance, pharmaceutical treatments, which may be the reason why health authorities are reluctant to include it in the subsidized treatments for psoriatic disease. Thus, ultimately reducing the number of patients who could benefit from a treatment improving both their health and overall well-being.

The Nordic Psoriasis Association NORDPSO, represents people living with psoriasis in Denmark, Faroe Islands, Finland, Norway, Sweden, and Iceland.

With this Nordic White Paper, we are taking the first important step towards a joint effort to create awareness of this particular unmet need psoriasis patients in the Nordic countries face

and create a foundation for acceptance of the value of climate treatment for their quality of life.

We know the patients firsthand and understand what it is like to deal with misconceptions and stigma every day. Unfortunately, this stigma also applies to the perception of climate treatment. Here there is a lack of recognition of the need for treating and preventing restraining symptoms that affect the quality of life.

The existing undervaluation of the effect and importance of climate treatment causes an unequal and declining access to climate treatment, which for some patients might very well be the best option to significantly improve their health and quality of life.

In cooperation with leading clinicians, our mission is to establish a common understanding across the Nordic countries of the need for climate treatment for psoriasis patients. Where quality of life is accepted as a key factor, and where stigma and misconceptions that psoriasis patients face daily are challenged. As such equal access to climate treatment can become the reality for people suffering from psoriasis.

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THE PURPOSE OF THIS WHITE PAPER

The purpose of the White Paper is to provide a comprehensive overview of the current status for the use of, and access to climate treatment in the six Nordic countries and create a foundation for a common understanding of the challenges we are facing when it comes to securing access to climate treatment now, and in the future.

To establish this common understanding, the six associations in NORDPSO have collected and structured the existing official recommendations and guidelines on how these are implemented across the countries.

This White Paper thus constitutes an overview of the status quo in the six Nordic countries, and based on the mapped situation today this White Paper appoints two main improvement areas.

With the White Paper the associations in NORDPSO strive to create acceptance of the need for

climate treatment of psoriasis patients now and in the future, and engage decision makers, political and clinical stakeholders in finding solutions that can secure and strengthen the access to climate treatment in the future.

Partners

This White Paper has been created on basis of clinical inputs provided by Jørgen Serup, professor, dr.med, who has contributed to the description of climate treatment, and on how state of the art climate treatment can relieve the burden of disease for psoriasis patients.

The White Paper has been created with the support of the Nordic Welfare Center, who has financially contributed to the project of developing this White Paper.

HOW DOES CLIMATE TREATMENT HELP PEOPLE LIVING WITH PSORIASIS?

What is climate treatment?

Climate treatment is offered to patients with moderate to severe psoriasis and is used as one among other treatment options for moderate to severe psoriasis. The patients are sent to countries with favorable climate conditions offering natural sun and the access to salty ocean water. In other words, conditions very different from the rather cold and dark Nordic climate. The Mediterranean region, and in particular Israel with access to the Dead Sea, are often preferred destinations. Other destinations are also used such as the Canary Islands. However, some locations within the Nordic countries, such as The Blue Lagoon in Iceland and Læsø in Denmark, are also suitable for climate treatment.

The specific course of the treatment varies from country to country; however, the main components of climate treatment generally consist of exposure to natural sunlight, bathing in mineral-rich water (concentration of salt 30%) supplemented with lubrication, ointments, and in some cases bathing in pool water rich in Sulphur.

These physical elements of the treatment are combined with more educational parts and thus takes on a holistic approach. This includes an intensive focus on maintaining a healthy diet, regular physical exercise, and tools for stress relief such as yoga and meditation.

Another focal point in the treatment is the peer-to-peer support, making it possible for patients to meet people facing the same daily obstacles as them. Furthermore, they get the opportunity to exchange experiences outside the medical context and support each other in coping with psoriasis.

Further, disease-education at group and individual level is provided by specialized registered nurses and dermatologists monitoring the treatment. For each patient, an individual treatment plan is outlined based on an individual assessment of the severity of disease and symptoms, taking the patient's skin type and light sensitivity into account. The length of a treatment course differs from country to country however, the duration usually lies at 2-4 weeks with treatment up to 6 or 7 days per week.

Most patients express a significant relief of both their physical and mental burden, and generally the patients experience a clinically important improvement in their quality of life following the climate treatment (Mørk C and Wahl A. 2002).

How does climate treatment help psoriasis patients?

People living with psoriasis are dependent on treatment that can prevent and treat the severe visible symptoms and manifestations, that are often a mandatory part of suffering from the disease. Symptoms typically include scaling of the skin (92% of patients), itching (72% of patients), erythema (69% of patients); 20-30% experience fatigue and swelling, burning, or even bleeding from the affected skin. These symptoms often have a highly disabling impact on the everyday life and quality of life of the individual patient (World Health Organization 2016).

There is a long line of medical publications documenting the clinical efficacy of climate treatment having an effect comparable to those of the new biological treatments.

Climate treatment should not be seen as a permanent cure, however the duration of effect often lasts 6-10 months, with slow reoccurrence, and in some cases with no reoccurrence at all. At the same time, climate treatment is a less invasive form of treatment with fewer side effects (if any) compared to the new systemic and biologic treatment options, which can have severe side effects not acceptable to the patients. For some patients who have used other medical/biologic treatments with extensive side effects, climate treatment can be the final relieving treatment option without side effects. For some cancer patients, climate treatment is a crucial option, as they are not able to use biological treatment the following five years due to the preceding cancer treatment procedure. Young women are also often advised to be careful with biological treatment, if they are planning on getting pregnant.

Research from a recent Danish follow-up study on the relapse rate published in 2020 (Emmanuel et al., 2020) showed, as many other similar studies, an 88% reduction of the area of the skin affected with psoriasis, and even a complete clearance with 55.6% of patients examined at follow-up visits 3-6 months after the return to their daily lives in Denmark. On average, more than three months passed without visible skin symptoms reappearing, and at the same time their quality of life improved significantly. Previous research has also shown significant long-term effects of climate treatment, some even with relapse time measured in years (Snellman et al., 1993).

Especially the patients' quality of life is often an overlooked treatment outcome when comparing climate treatment to other treatment methods. The referred Danish study on relapse rate after climate treatment, as well as other recent studies, concludes that climate treatment has a well-documented effect on the quality of life (Trøstrup et al, 2020).

The study exemplifies that the effect on the patient's own perception of life quality is an eminent factor, often outweighing the observed physical effects:

"The results five months after climate treatment shows that while the objective physical effect on the skin remains significant, more patient rate the effect on their quality of life as being more significant. Thus, there is a significant difference between the observed and the perceived effect" says Professor, Chief Physician at Department of Dermatology, University of Zealand Hospital Roskilde, Gregor Jemec (The Danish Psoriasis Association, 2020).

This is further backed by an extensive review of the world literature on climate treatment published by the Department of Dermatology, Bispebjerg University Hospital, Copenhagen. This review concludes that climate treatment has a high efficiency and a notably favorable risk profile.

Generally, climate treatment is evidence-based and the effect on the burden of disease and the improvement of quality of life for psoriasis patients is thoroughly documented (Mansouri and Serup, 2019).



CLIMATE TREATMENT IN THE NORDIC COUNTRIES TODAY

The case of climate treatment in Denmark and Faroe Islands

In Denmark and the Faroe Islands, climate treatment has since the beginning of 1971 been a treatment option for psoriasis patients. However, this is only approved if the psoriasis is assessed to have an extensive negative effect on their daily lives, and when other treatments prove to be insufficient. Generally, the Faroe Islands follows the Danish recommendations and practices and are in cooperation with Zealand University Hospital providing climate treatment for 10-20 patients each year.

Even though Denmark has a long-standing tradition for making use of climate treatment, the access to getting the treatment is not equal across the country, as the frequency and assessment of the treatment vary from region to region.

The reason for the variation between the regions is partly due to the difference in who oversees the assessment and approval of the treatment. In some regions this is located in the primary sector where the private practicing dermatologist is responsible for making the assessment. In other regions, the assessment takes place in the secondary sector at hospital level in the dermatological unit.

The data further shows that the number of patients who are granted the treatment vary from up to 35-40 patients a year in the Zealand Region, down to only 1-2 patients a year in the Region of Southern Denmark.

The Region of Southern Denmark observed the tendency, that some of the dermatologists in

the region were more likely to prescribe climate treatment than others. Instead of securing equal access to the treatment in the region, the attempt to standardize the assessment process within the region, resulted in precluding the opportunity for the patients in the entire region.

Consequently, a larger number of patients in the Region of Southern Denmark will have to settle with other forms of treatment even if these are not adequate to fulfil their needs. This ultimately puts the patients in the region in a worse position compared to the patients in other regions. These patients are left with the feeling that their lives do not have the same value as patients in other parts of Denmark (The Zealand Region 2020).

Beside the lack of national standardization and variation between the regions, the Danish patients also face misconceptions and neglections of the necessity of climate treatment. The testimonials from the Danish patients underline how misconceptions occur even from the clinicians in the Danish healthcare system:

“

When I asked my doctor when it would be possible to resume my climate treatment, the doctor responded that they were not a travel agency, and therefore if I wanted to travel, it would be something I had to find out myself”.

/ Danish psoriasis patient



This case highlights the often-occurring stigmatizing framing of climate treatment, where it is merely reduced to a holiday and not recognized as an important treatment equal to other treatment options for psoriasis. Further, the effect of climate treatment on the patient's quality of life and the holistic approach is not accepted as an important treatment factor.

The case of climate treatment in Sweden

In Sweden the national prioritization guidelines from The National Board of Health and Welfare, recognize the need for climate treatment for psoriasis patients with a high to very high degree of severity, as they proclaim that:

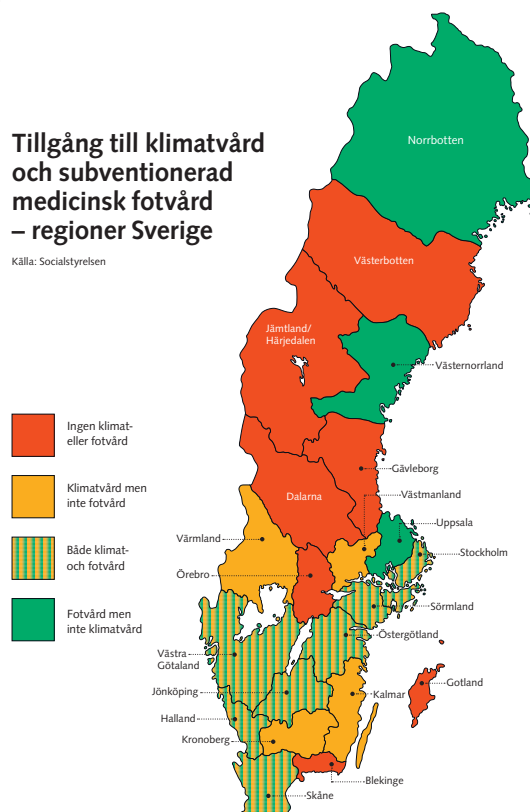
“The climate treatment should be offered to (...) people with severe psoriasis who do not experience a sufficient effect of other treatment options and special needs for education, lifestyle changes and physical activity” (Socialstyrelsen 2020).

The Swedish health authorities also recognize that climate treatment improves symptoms relief and reduces the risk of future health related problems.

Furthermore, the Swedish Medical Products Agency mention Climate treatment in their guidelines as a supplement for patients with moderate to severe and / or treatment-resistant psoriasis.

Tillgång till klimatvård och subventionerad medicinsk fotvård – regioner Sverige

Källa: Socialstyrelsen



However, even though the Swedish national guidelines recommend climate treatment and the patients testimonials and evidence suggest how important the climate treatment is for the individual patient's quality of life, the number of Swedish patients in the regions who are granted climate treatment indicates, that these recommendations are implemented very differently across the country.

Thus, the reality for the Swedish patients is that the access and chances of getting climate treatment is not equal across the country.

Only 11 out of 21 County Councils in Sweden offer climate treatment to people with psoriasis.

It is also noticeable that none of the northern regions offer climate treatment, as shown in figure 1. This difference between the Swedish regions means that a big geographic part of people living with psoriasis in Sweden is cut off from getting climate treatment, and as such have to settle with other treatment options, which might not meet their needs sufficiently.

The case of climate treatment in Norway

In 1976, the first Norwegian patients with psoriasis were offered a publicly funded climate treatment trip abroad. Today, the scheme for climate treatment travel is made permanent and includes the possibility for all patients with psoriasis to apply (Sosial og Helsedepartementet 2000). However, the treatment is still not accepted as equal to other treatment forms, only considered a supplement to other treatments, and thus not viewed as a 'right' the patients have.

Every year approx. 424 patients are treated with climate treatment. The treatment's travel section receives approx. 639 applications annually. This illustrates that approx. than 33% of the Norwegian patients with psoriasis who have applied for the treatment due to an unmet need, will have to settle for other options, which for some patients, does not have the sufficient effect.

For some patients, just one course of climate treatment can be enough to keep the psoriasis in check for the rest of the year. This means that they can live a normal life while taking care of

their jobs without fearing for the consequences of their illness. This is true for the Norwegian psoriasis patient Anette:

“

I have been on a trip between March and April. And when I have been abroad on a climate treatment trip for three weeks, it has helped me to almost keep the disease fully in check.”

/Norwegian psoriasis patient

Climate treatment offers much more than just treatment of the skin condition, it is also a possibility to get peer-to-peer support and obtain the tools to prevent and manage any symptoms. At the climate treatment trips, the patients get to meet people with the same challenges as themselves, learn the newest information regarding their treatment and get specialized support from staff on how to handle their own skin type under the current UV index.

Furthermore, the climate treatment is combining the right exercise, stress handling, and diet to achieve the best possible treatment for the psoriasis patient. Thus, a big part of the patients that apply for the climate treatment is denied, they are not only cut off from the somatic part of the treatment that can ease the physical discomfort. They are also denied the important educational and peer-to-peer aspects, which are important factors in assisting the patients in managing their disease.

The case of climate treatment in Iceland

Since 2014 no Icelandic psoriasis patient has received climate treatment since this is no longer offered or reimbursed as a part of the national health system.

Before this, Iceland used to cooperate with Oslo University Hospital for the climate treatments,

however this cooperation has now been terminated.

At the moment there is no national strategy or any recommendations in place for treating Icelandic psoriasis patients with climate treatment.

Climate treatment has previously been temporarily offered to some patients in the Blue Lagoon, in Iceland. However, this was never made permanent, and has now been ended, and no alternative has since been offered.

This consequently means that Iceland, as the only Nordic country with an adequate climate for providing climate treatment, and therefore do not rely on sending patients abroad, does not offer any of their psoriasis patients this type of treatment.

The non-existing access to climate treatment for Icelandic psoriasis patients means, that every single psoriasis patient living in Iceland must settle for the other forms of treatments, even if they do not meet their needs. Thus, they must live with the consequences of their diagnosis and the possible severe symptoms, which can be restraining and have consequences on the possibility to live a normal life.

The case of climate treatment in Finland

The health authorities in Finland does not provide or reimburse climate treatment for people living with psoriasis.

Climate treatment as such is solely provided by the Finnish Psoriasis Association, who pro-

vides courses called “Sun-centered adaptation training” primarily held in the Canary Islands in a warm and adequate climate. These courses have been held since 2012 and approximately take in 168–200 persons/year. Some of these participants have attended these courses several times.

Even though the Finish healthcare system does not cover climate treatment, Finland has recognized the need for financial support from STEA (Funding Centre for Social Welfare and Health Organizations). Kela (The Social Insurance Institution of Finland) so far provides compensation for the loss of earnings during climate treatment and for the domestic travel costs. These expenses are however only supplemented, not fully reimbursed.

Climate treatment is mentioned in the national guidelines for psoriasis as effective as UVB treatment. This indicates that the Finnish authorities recognize the need for funding and compensation of courses in a warm and adequate climate. However, the treatment is still not fully subsidized by the authorities and therefore still perceived as a mere supplement to other treatments for psoriasis, not recognized as a necessity.

This perception limits the Finnish Psoriasis patients’ access and leaves them with an unmet need, as the effect of climate treatment is potential life changing, as one of the Finnish patients phrase it:

“

**It’s one of the turning points in my life.
From the viewpoint of self-acceptance and everything else.”**

/Finnish psoriasis patient

WHAT WE ARE FACING

Based on the overview of access to climate treatment in the six Nordic countries, the key challenges across the Nordic countries we need to overcome are:

Stigma and the lack of acknowledgement of quality of life as a key factor

The lack of factoring in and recognizing life quality as a key aspect – equal to other factors – ultimately leads to the misconception of climate treatment as a “nice to have” supplementary treatment – instead of recognizing it as a treatment equal to other treatment options.

Instead of acknowledging the empowering effect and improvement of quality of life that climate treatment gives the psoriasis patients, there is a tendency to devalue the treatment and merely perceive it as a holiday in the sun. This is due to a lack of awareness of the full concept of the treatment regimen and the possibility for patient empowerment and understanding of the elements of the psoriatic disease.

This prevalent perception across the Nordic countries is both condescending and at the same time stigmatizing, as the patients, who in some cases have no other treatment alternatives to meet their needs, are degraded to being perceived as opportunists looking for a paid vacation – not in serious need of treatment. None of the other treatment options would ever be framed in this way.

This lack of acknowledgement of the high value and life quality that climate treatment provide for psoriasis patients, ultimately prevents the patients from receiving the optimal treatment.

Furthermore, psoriasis severity is often measured with the focus on PASI and DLQI tools, but this has severe methodological limitations compared to a more qualitative approach that listens to the individual patient. This equally adds to the misconception that climate treatment is not as effective. Quite the opposite, climate treatment is highly effective as an induction treatment, in line with biological treatment (Mansouri 2019: 4).

Lack of acknowledgement of the need for a holistic approach

A key part of climate treatment is the holistic treatment course, where both physical (and observable) symptoms are treated and prevented, combined with education in self-management, how to identify triggering factors, counseling, and peer-to-peer support. However, this is often overlooked when evaluating the need for climate treatment even though this part is vital to help the patients to manage their disease, identify triggering factors, and generally create long-term effects on their quality of life.

In the Nordic countries today, the general approach is often to prioritize treatments with directly measurable effects, instead of using treatments that offer a more holistic approach and provides knowledge and empowerment for the patients.

In this way, comorbidities and other connected complications are neglected, which would have been countered in and treated with the holistic climate treatment approach. The holistic treatment course does not only help the patient with the management of their psoriasis, but also



counteract comorbidities as the patients are introduced to tools that can provide a lifestyle change and identify triggering factors.

The patient will learn about healthy diets, exercise, and how to implement these tools at home. This gives the patient the opportunity to manage their own disease, and in turn become more independent and empowered. It also provides the patients with tools they can use in the periods where it is not possible to receive the climate treatment.

Unequal access to treatment

Lack of national alignment creates geographically unequal access, primarily in Denmark and Sweden, which seems unfair in a universal healthcare system where the treatment should be the same regardless of your postal code. Since there are also psoriasis patients that do not tolerate pharmaceutical options, this makes climate treatment a crucial treatment option, regardless of which region you live in.

When e.g. patients from 1 out of 5 regions in Denmark do not have access to climate treatment, and only 11 out of 21 County Councils in Sweden offer climate treatment to people with psoriasis, they are denied an efficient treatment option, and risk being left without any adequate treatment for a potentially life-impairing disease.

There is also not equal access in Finland and Norway, since the treatment in Finland must be

funded out of one's own pocket and thus dependent on each patient's ability to pay for it, and in Norway the number of people who is provided the treatment (compared to the number of applications) is very limited.

In Iceland, the patients are equally denied access to climate treatment.

Lack of knowledge about the effect of climate treatment

The effect of climate treatment is well documented (Mansouri and Serup, 2019, Snellman et al., 1993, Trøstrup et al, 2020). However, awareness of the results and proven effects of climate treatment is limited – especially among politicians, clinicians, and even the patients themselves.

The lack of knowledge from especially the politicians in turn lead to a limited focus on fewer, conventional treatment options. This will naturally affect which treatments are offered to the patients and reduce their options of choosing the most adequate treatment for them. This consequently means that the patients are less empowered and in turn less compliant to follow other treatment regimes.

The lack of knowledge regarding the existing evidence can also be a reason for the supplementary status that climate treatment is often given today.

WHAT WE SHOULD STRIVE TO DO

The status of the use of climate treatment in the six Nordic countries has shown that the treatment is generally not given equal status to other treatments, partly due to a lack of recognition of the quality of life as an acknowledgeable factor.

Going forward we need to work together across the political, clinical, and patient field to overcome the challenges and secure equal access to life improving climate treatment for psoriasis patients now and in the future.

To do so, we should strive to:

Recognize quality of life as a key factor

In order to secure access to climate treatment in the future, it is necessary to create awareness on the unmet needs some psoriasis patients have when conventional medical treatments are not sufficient or adequate. To do so we should challenge the misconception many politicians, clinicians and patients have of climate treatment as merely supplementary and create a common acceptance of the crucial effect on the patient's quality of life, as well as the personal empowerment, climate treatment can have.

Provide data on the benefits of a holistic (preventive) approach

We know the patients are faced with misconceptions and stigma every day when it comes to the recognition of the need for climate treatment to treat and prevent restraining symptoms that affect their quality of life.

One step towards changing this is by secur-

ing more research on the total cost of climate treatment versus conventional medical treatment. All societal costs need to be factored in, as this can highlight the economic benefits of holistic treatment, where not only current and visible symptoms are treated, but future symptoms and comorbidity can be prevented and mitigated. And where the effect of life quality and self-management is factored in through the derived societal costs.

Secure equal access for all patients

Another important step going forward will also be to recognize the need for more general funding of climate treatment in order to secure equal access, not depending on the patient's own ability to pay. National strategies, including funding for climate treatment, would be a step toward securing access to adequate treatment for the patients suffering from psoriasis.

Every psoriasis patient across the Nordic countries should be able to receive the same treatment – and the treatment they need. A way to secure equal access and prevent regional inequality would be to implement more national alignment on climate treatment.

What we need

The Nordic countries are in many ways close, and yet so far from each other when it comes to climate treatment. As a Nordic community, we must pave the way for a better life for people living with psoriasis in the Nordic countries. If we want to solve the unequal access to treatment for Nordic psoriasis patients going forward, we need to:



- Learn from each other and establish a common acceptance of the need for climate treatment and recognize the quality of life as a key factor in treatment.
- Secure a stronger evidence-based foundation with a stronger focus on the societal economic benefits of climate treatment's holistic approach.
- Invest in equal access for all patients by increasing funding to climate treatment.
- Build national aligned guidelines that secure safety across country for all patients.

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