

en



Living with Vitiligo

A guide for
people with vitiligo,
their relatives,
and friends



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Foreword

Dear reader,

You, someone in your family or one of your friends has been diagnosed with non-segmental vitiligo. This is a specific type of vitiligo. The disease is also known as leucoderma.

In this brochure, we want to help you better understand the disease by explaining the condition and all its associated facets. Even though vitiligo is not contagious or dangerous, many sufferers feel stigmatised and burdened by the visible skin changes.

The following pages give you an overview of what vitiligo is, the role played by the immune system, as well as the mental burden that patients suffer. We also outline the various treatment options, from current to newly developed therapies – thanks to recent advances in research. In addition, you will find out where and how you can get further help if necessary.

We want to accompany you, your family or friends, and all sufferers on your vitiligo journey and to support you with plenty of helpful information. You don't have to go it alone!

This brochure cannot and is not intended to replace medical advice. The information contained in this brochure is not to be used for self-diagnosis or treatment.

VITILIGO – what is it?

Vitiligo is the world's most common form of skin disease that leads to loss of pigmentation. In Germany alone, around 650,000 people suffer from vitiligo, with women and men being almost equally affected. The disease is also quite evenly distributed across ethnic groups. Vitiligo can occur at any age, but the first symptoms generally develop before the age of 30.



Good to know:

Vitiligo is neither contagious nor dangerous for sufferers or for those close to them. It is not possible to catch vitiligo from someone.

Vitiligo is a chronic autoimmune disease of the skin in which the immune system attacks the cells that produce pigment (melanocytes). This leads to a loss of the skin pigment melanin. Visible signs of vitiligo are depigmented white or pale pink patches on the skin. This is why vitiligo is also known as "leucoderma" (white skin).

Often, vitiligo is only regarded as a "cosmetic problem" or harmless skin condition – and not as a disease requiring treatment, which it actually is. The visible skin changes can be a massive burden for those affected, which can severely restrict the quality of life in many areas – everyday life, education and career, free time, partnerships, social life, and the enjoyment of life. No wonder that sufferers can experience immense mental stress, with the level of suffering being perceived differently by each individual. And that's not all: Sufferers can also experience other autoimmune diseases such as an underactive thyroid. As such, it is important to have thyroid levels checked regularly.

In an autoimmune disease, the immune system, which normally protects us against disease, attacks the body and destroys even healthy cells and tissue.



**"I raise people's awareness
of vitiligo – because I know
not everyone copes
well with the disease."**



CAUSES and DEVELOPMENT of vitiligo

The causes of vitiligo are not yet fully understood. Research suggests that multiple factors may play a role, such as genetics and various triggers like UV radiation, chemicals, and physical and psychological stress. Such a combination of factors causes the immune system to be activated. Normally there to protect our body, the immune system malfunctions and starts attacking melanocytes, the cells that produce skin pigment. As a result, the melanocytes are destroyed, leading to a loss of skin pigmentation, which manifests itself as white or pale pink patches on your skin.

General physiological and pathophysiological significance of Janus kinases (JAKs, JAK1/2/3 and TYK2)

In the human body, JAKs convey the signal transmissions of numerous growth factors and certain inflammation signaling proteins (e.g., cytokines such as interferon gamma). They thus play a key role in critical processes such as the formation of blood cells or in the defence against pathogens or cancer cells. Pathophysiologically, JAKs are involved in the inflammatory reactions that occur in many autoimmune diseases.

Vitiligo: the central role of Janus kinases in the destruction of the skin's pigment-producing cells (melanocytes)

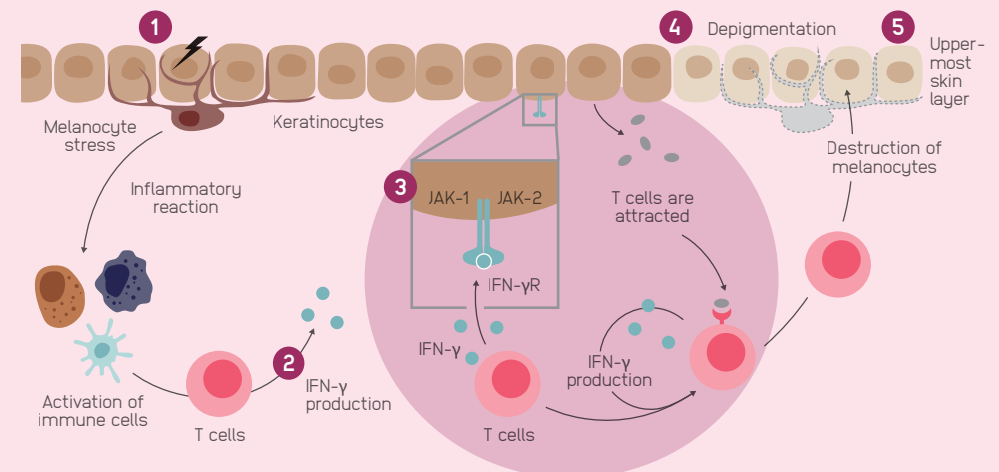
In skin affected by vitiligo, autoimmune inflammatory reactions cause JAK1/JAK2 to recruit and activate disease-specific inflammatory cells, the melanocyte-specific, cytotoxic T cells. These destroy the melanocytes, which leads to the patchy loss of skin pigmentation. In the chronic course of vitiligo, regeneration of the melanocytes is blocked by memory T cells, whose function is dependent on JAK1/JAK3.

T cells are immune cells that normally identify and destroy infected, modified, or damaged cells. There are various types of T cells that each play different roles. Some T cells, for example, develop into so-called memory T cells that permanently remember "who" they have attacked and can keep re-attacking this target.

For those who want more DETAILS ...

From melanocyte stress to depigmentation

- 1 In research, it is assumed that the damage to melanocytes is caused by a trigger ("melanocyte stress") that in turn triggers an inflammatory reaction.
- 2 This inflammatory reaction activates T cells, which attack and destroy the melanocytes. They also release the interferon gamma (IFN- γ) signaling protein, which activates the JAK-STAT signalling pathway.
- 3 This sets a process in motion in the cells of the uppermost layer of skin (keratinocytes), which attracts even more T cells.
- 4 Thus a vicious circle occurs, which drives the destruction of the melanocytes and leads to larger depigmented patches.
- 5 Memory T cells develop that remain in the skin and ensure the continued destruction of melanocytes (see diagram).



Non-segmental vitiligo is an autoimmune disease whose development is caused by a number of simultaneous, intrinsic, and extrinsic factors. At first, the reduced ability of the melanocytes to adapt to stressors leads to structural cell damage, which triggers an inflammatory reaction targeted against the melanocytes. In the chronic course of the disease, a vicious circle occurs in which keratinocytes and auto-aggressive T cells mutually reinforce each other in the destruction of melanocytes with the help of IFN- γ and the JAK-STAT signalling pathway. This leads to a gradual depigmentation of the skin, causing the white or pale pink patches characteristic of vitiligo.

Signs of vitiligo

The characteristic symptom of vitiligo is clearly defined, depigmented white or pale pink patches on the skin. These patches can occur on any part of the body, but normally on the hands and feet as well as on the arms and face. Even head and beard hair, eyelashes, or eyebrows within white patches can become "decoloured". Sometimes the loss of pigmentation even affects mucous membranes. The skin changes do not normally cause any complaints other than a possible, occasional itching.

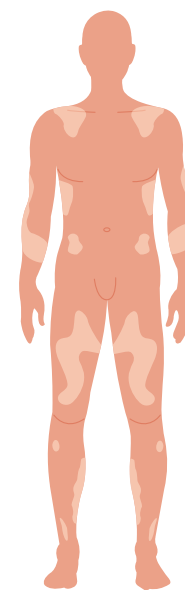


Vitiligo occurs in various forms

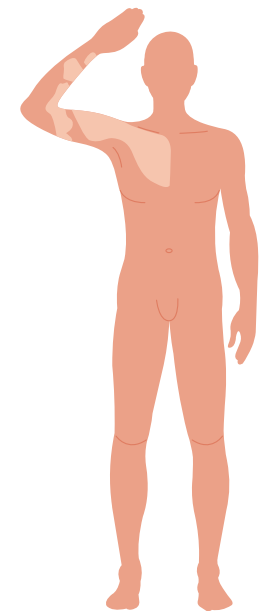
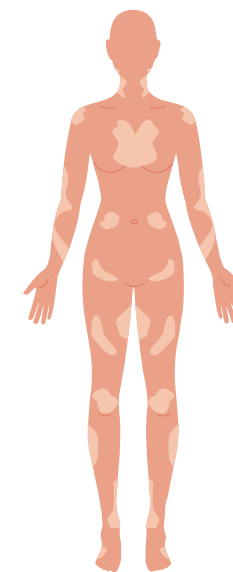
Vitiligo is classified according to the two main forms, **non-segmental vitiligo** and segmental vitiligo. There is also a **mixed form**, which has the characteristics of both main forms.

In the **far more common non-segmental vitiligo (NSV)**, which affects around 85% of patients, the depigmented patches are usually symmetrically distributed on the face, neck, the arms and legs, as well as around orifices. Body hair is usually unaffected. If left untreated, NSV progresses and the patches expand.

Segmental vitiligo (SV) is far less common. It accounts for only a small fraction of all vitiligo cases. Often, it starts earlier than NSV, and the depigmented patches are usually found only on one side of the body. According to current understanding, SV is not an autoimmune disease. It normally progresses faster than NSV, but often stops within a year.



Non-segmental vitiligo



Segmental vitiligo

Vitiligo – not just a *CosMETIC* problem

The visible skin changes that occur with vitiligo, and the stigmatisation that sufferers often experience, can cause stress for sufferers and greatly impact their quality of life, day-to-day life, and social life.

Guidelines help doctors and patients decide on the best course of treatment for the disease. They are based on the latest scientific research and proven methods.

The guideline "Diagnosis and Treatment of Vitiligo" makes it very clear that vitiligo is more than just a cosmetic problem. It doesn't just affect the patient's skin, but also their mental well-being. Many sufferers feel their joy in life and day-to-day living is greatly impacted as a result of the permanently visible depigmentation to their skin.

"Very often in my life, I feel people are only looking at me because of my skin patches. I interpret every look negatively."



Career

Partnership

Sex life

Going to the hairdresser

Arranging free time

Choosing clothes



Vitiligo can burden the *Soul*

Although vitiligo is neither dangerous nor contagious, it can massively impact patients' lives. Many sufferers report that the disease has greatly impacted their lives: from training and career, arranging their free time, having a partnership and sex life, to daily activities like going to the hairdresser, choosing clothes, or deciding whether or not to go swimming. It's no wonder, then, that vitiligo patients are more likely to suffer mental problems such as depression and anxiety. They also often feel misunderstood by others and discriminated and marginalised because of their appearance. They want more understanding and more support from their doctors, friends, or family. Perhaps you also wish that the people around you thought of vitiligo not just as a cosmetic problem, but as a disease that has a massive impact on your life.

Negative feelings and mental strain are completely understandable in the case of stressful diseases. Nobody should feel ashamed about that. However, there is now increasing understanding and support for sufferers.

Support from friends and family

Family and friends can support sufferers by showing them empathy, encouraging medical care, informing themselves about vitiligo, and showing understanding. They can also help support a healthy lifestyle and raise awareness for the disease. Showing sufferers that they are valued and loved just as they are can also be helpful.

Speak with a specialist

Treatment options need to be improved for people with vitiligo. This includes extensive education and advice, as well as psychological support in some cases. Effective treatment strategies that lead to even and lasting repigmentation and thus reduce the stress of the disease are particularly important. There has been intensive research in this area in recent years, and new options are now available that may help you. Make an appointment with a specialist to discuss the best treatment options for you.

Scan the QR code and find a specialist near you:

Jameda



Bundesverband der Deutschen Dermatologen [German Society of Dermatologists] (BVDD)



The extent to which quality of life is impacted by vitiligo depends on factors such as the extent of the skin changes and which areas are affected. The mental burden can be higher if the disease affects highly visible areas like the face and the hands.

The gender and age of sufferers also play a role: younger people feel more impacted than older people, and women generally suffer the impacts of visible changes more than men.





DiAGNOSIS of vitiligo

Your GP can generally make a diagnosis of vitiligo just by looking. The clearly defined white or pale pink patches are typical. However, with light skin tones, it may help to observe the vitiligo patches under UV light (Wood's light), under which the lesions glow a whitish yellow. A tissue sample is only required in very rare cases.

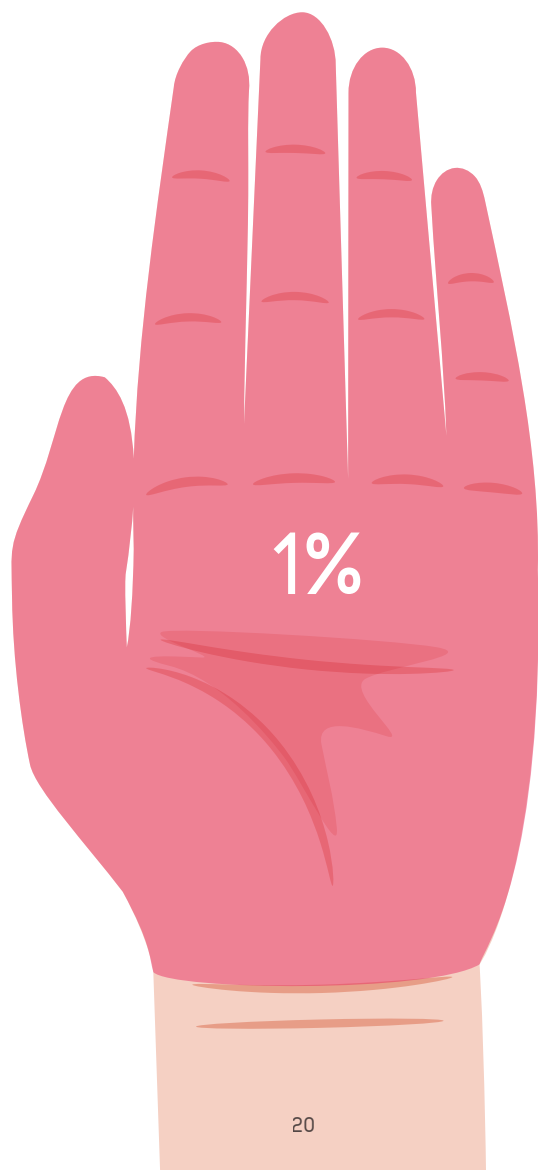
Other tests such as blood tests may be helpful to identify any concomitant diseases early, particularly thyroid disorders.



How your vitiligo is Measured

It is important to establish the nature of your vitiligo, as the choice of treatment depends on the extent of the disease.

The **affected body surface area (BSA)** is often used to assess the nature and extent of the vitiligo. The extent of the vitiligo is expressed as a percentage of the body surface area.

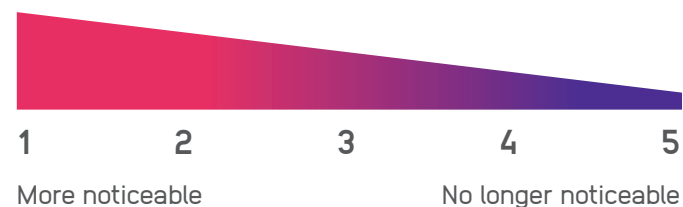


1% of your body surface area roughly corresponds to your hands, including the fingers.

If up to 3% of your skin is affected by vitiligo, it is considered as a limited case. Between 3% and 10%, the vitiligo is regarded as a mild case. A moderate case is when 10% to 30% of the skin is affected by vitiligo, and a severe case is when more than 30% of the body is affected.

If your vitiligo is already being treated, doctors use the **Vitiligo Noticeability Scale (VNS)** for a simple assessment of treatment success. On a scale of 1 to 5, you can indicate how your vitiligo has changed compared to the last measurement.

How extensive is the vitiligo now compared to before treatment?



In addition to this simple scale, doctors have other ways of assessing your vitiligo.

These include various questionnaires and scales that your doctor can use to measure the impact of vitiligo on your quality of life.

TREATMENT of vitiligo

The aim of vitiligo treatment is to stop the spread of the disease, trigger repigmentation, and prevent relapses.

Vitiligo treatments have been researched for a long time, and various treatment options are now available to doctors. According to a recent study, vitiligo patients across Europe are currently trialling an average of 6 different treatments. Around two-thirds hope that a new and effective treatment option will be available for them one day.

The majority of current treatment methods either target the immune system (corticosteroids, calcineurin inhibitors) or seek to encourage the regeneration of the melanocytes (phototherapies):



Topical (applied externally) medications (ointments, creams, lotions)

Corticosteroids (cortisone) block inflammatory reactions. These can be used with limited vitiligo. They are particularly effective on darker skin types and around the face and neck region. Due to the various side effects of cortisone, however, such as thinning of the skin or the formation of dilated veins, they should only be used on the body.

So-called **calcineurin inhibitors** can be used for vitiligo on the face. These are also anti-inflammatory and work particularly well in the face and neck area. They are also suitable as maintenance therapy once repigmentation has been achieved. Possible side effects include burning and itching as well as skin rashes.

Currently, available topical medications should only be used for limited conditions (up to 3% body surface area).



Systemic medications (for internal use)

Oral corticosteroids (cortisone tablets) can be used with rapidly progressing vitiligo to stabilise the condition. Since they have to be taken over a period of months, typical cortisone side effects can be expected.



Phototherapy and light therapy

Phototherapies using UV light are used if the spread of vitiligo is too great for topical treatment or the vitiligo is rapidly progressing. **Light therapies using a laser** are used to specifically target vitiligo lesions. Phototherapy using UV light as well as laser therapies need to be applied several times a week over a long period, sometimes in combination with other medications.

What all of these treatment approaches have in common is that they do not target the underlying mechanism of the autoimmune disease vitiligo. In addition to that, they are also time-intensive.



However, there has been some progress in recent years.

Following intensive research, it is now clearer how vitiligo develops (see also page 8). As a result, new options such as JAK inhibitors are available to target the disease. These are active agents that can block the overactivation of the JAK/STAT signalling pathway. These topical, cortisone-free medications can be used where the disease affects up to 10% of the body surface. It may therefore be an option to talk to a specialist if you are not satisfied with the results of your previous treatments. Together, you can decide if new treatment options are appropriate for you.

Download the Vititrack app and record your vitiligo progress!

Regularly photograph your skin changes and discuss the photos with your specialist if needed.



Things *You* can do yourself

UV protection: Since the skin is particularly sensitive in the depigmented regions, you should always use UV protection with a high sun protection factor (SPF 50 or higher). Even though vitiligo patients are not at a higher risk of skin cancer, using sunscreen products is generally a good idea to prevent sunburn.

Depigmented areas, particularly around the face, can be masked using medical **camouflage make-up**. They usually cover the areas very well and are waterproof. Some products can even remain on the skin for several days. They should be removed gently and carefully so as not to irritate the skin. Self-help groups and cosmetics institutes offer courses to learn camouflage techniques.

Self-tanners can also make the skin appear evenly toned.



Owing to the risk of scarring, allergies, and infection, the guidelines **advise against** using **permanent make-up**.

Diet with vitiligo

There is not yet any scientific evidence that certain foods cause vitiligo or can help with repigmentation. However, it is recommended to avoid foods that you are allergic to or find hard to digest.

These can disrupt the digestive or endocrine system, thus further disrupting the immune system, to which vitiligo is connected. A balanced diet is important, and it is recommended to include vitamin D, as it supports the immune system, which is affected by vitiligo.

The strict and often imbalanced diets sometimes recommended in magazines and on social media should be avoided. These do not normally have the desired benefit and can even be harmful. Vitamin supplements are also unable to cure vitiligo. In fact, an excessive dose of certain vitamins can even make the symptoms worse.

Always consult your doctor before making any changes to your diet or taking food supplements!

SUPPORT and HELP

Many vitiligo patients feel like they've been left alone with their disease. Understanding and support is available here to anyone who needs it:

Family and friends

You can talk about your disease with your family and friends. Together, you can develop strategies to help you cope better with the disease, find new courage, and open up new perspectives.

Professional help for when the burden is too much

The mental burden that you experience with vitiligo can be very high. Vitiligo can affect your life and mental stability so much that you feel overwhelmed. In the worst cases, this can lead to depression with social withdrawal and isolation. This is where professional support can help. Don't be afraid to ask your doctor for help if you feel hopeless, alone, or overwhelmed by vitiligo. Your doctors can recommend suitable psychotherapists and prescribe psychological support that can help you manage your vitiligo better and more confidently.

Self-help – less alone with others

Self-help organisations and self-help groups for vitiligo patients have plenty of information about the disease and its treatment, specialist doctors and clinics, and topics like cost reimbursement and medical and psychosocial care.

You can also contact other sufferers directly and talk to them about their experiences. Self-help groups are generally safe spaces where you can discuss even sensitive topics confidentially like intimacy, partnerships, family life, career challenges as a result of vitiligo, and much more. Self-help groups can give you the feeling of being well-supported.

Deutscher Vitiligo-Bund e.V.
www.vitiligo-bund.de

Deutscher Vitiligo Verein e.V.
www.vitiligo-verein.de

Vitiligo Communities
on social media
#vitiligo



How to find specialists near you

Simply scan the QR code and find a specialist near you.

Jameda



Bundesverband der
Deutschen Dermatologen
[German Society of
Dermatologists] (BVDD)



Glossary

Autoimmune disease	Malfunction of the immune system where it attacks the body's own cells and organs
Chronic disease	Long-lasting disease that is difficult to cure
Depigmentation, depigmented	Reduced or lack of skin colour
Immune system	The body's defence system, which is responsible for protecting against pathogens and foreign substances
Interferon gamma (IFN-γ)	Signalling protein involved in inflammation processes
JAK/STAT signalling pathway	Specific signal transmission pathway in the organism
Janus kinases	Enzymes that activate signal transmission in the cells
Keratinocyte	Cells in the epidermis
Lesion	Damage, injury, disruption or change
Melanocyte	Cell in the skin that produces the skin pigment melanin
Repigmentation	Restoration of normal (skin) colour
SPF	Sun Protection Factor
Symptom	A sign of a disease
T cells	Defence cells of the immune system that identify and eliminate infected, modified, or damaged cells. Some T cells develop into so-called memory T cells that permanently remember "who" they have attacked and quickly respond whenever the "enemy" is detected again

We want to say *THANK You!*

We extend our warmest thanks to Sabrina, Sarah-Liv and Florian for giving us an insight into their lives with vitiligo and for being the faces of this brochure.

Vitiligo is a disease with many faces.

While some are coping well with it, others aren't. It is important to know you don't have to suffer. Lots has happened in vitiligo research, and there are new support options for you.

You now have a choice.

Follow us on
Instagram
for more
information
about vitiligo



and take
a look at
our website.



Together, we're never alone.

Your team at Incyte
Biosciences Germany GmbH



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