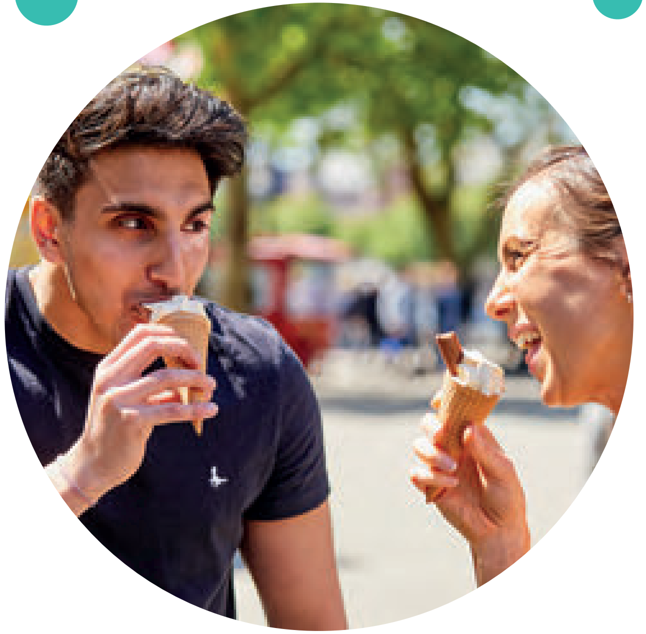
The Definitive Guide to Vitiligo

Covering diagnosis, treatments, children, emotional support & much more.

VITILIGO SOCIETY
EST 1985

Contents



Revisions

At The Vitiligo Society, we are committed to keeping this ebook as an up-to-date, reliable source of information for you to access freely.

As such, we'll continue to make revisions based on our own research and your feedback.

If you want to know when an updated version of this ebook arrives, please sign up ***here.***

If you have feedback or suggestions, we'd love to hear from you. Email us at **ebook@vitiligosociety.org**

DATE	REVISION	COMMENTS
25.06.2020	v1.0	eBook launch
09.02.2021	v1.1	Updated guidance on depigmentation treatment

About The Vitiligo Society

For over 30 years, The Vitiligo Society charity has been the go-to resource for both those living with the condition and medical professionals.

Raising global awareness, whilst aiding research to discover more about vitiligo is at the heart of everything we do.

It is thanks to your support through donations that we are able to produce independent, informative information using the advice of medical and scientific experts.

With the help of funding, generous donations, dedicated staff and volunteers we are able to distribute information on all things vitiligo, such as the latest research, self-care and new treatments.

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The Vitiligo Society has four primary goals:

Educate: provide information, raise awareness and promote acceptance of vitiligo.

Support: through online community support groups and face-to-face events.

Inspire: through storytelling and sharing personal experiences.

Partner: with local and global vitiligo medical professionals.

Support is given through the following:

- The Vitiligo Society website.
- Our online vitiligo lifestyle magazine The VitLife, which includes the latest research, treatments and other stories from your vitiligo community.
- Events where people have the opportunity to meet others with vitiligo.
- Campaigning for a better understanding of vitiligo within the medical profession.

The Vitiligo Society HQ is in London, but our reach is global. We are a unique charity as well as an accessible platform to support everyone affected by this condition.

So whether you have vitiligo or support someone with the condition, you'll always be welcome in The Vitiligo Society community.

A Message From Our Chairperson

I was diagnosed with vitiligo over 20 years ago, when I was just 13 years old. I still remember the doctor not knowing how to identify the white patches and rubbing my hands to see if the white would come off.

Two consultations later, and with the help of a very large dermatology book, my doctor was able to diagnose the skin condition as vitiligo. Reading verbatim from the book she said, *“Aha, it's vitiligo! There is no cure, it will probably get worse but don't worry, it's not contagious.”*

My experience may not be unique, but the good news is that many doctors and dermatologists are now better educated about the condition.

The rise of fashion models, actors and other celebrities with vitiligo in mainstream media has dramatically improved awareness of the condition.

It has been great to see this change over the last few years and has given inspiration to many. That being said, there is more work to do and our mission at The Vitiligo Society continues to be the same as it has been for over 30 years – we support those dealing with vitiligo and engage with the medical profession to find effective treatments and, ultimately, a cure.

This ebook has been created to provide a trusted, accurate and definitive resource for those living with vitiligo, to educate themselves on all aspects of the skin condition. I am deeply grateful for all those who have contributed to its development and I genuinely hope you enjoy reading it as much as we did making it.

I am a volunteer, as are all my fellow Trustees at The Vitiligo Society.

As a charity, I cannot stress enough our reliance on generous membership contributions and donations to continue in our mission and service to those that need our help.

If you find value from this ebook and want to support the work we do, please consider becoming a member of The Vitiligo Society.

Enjoy the book!

Simon Parker, Chairperson
The Vitiligo Society

Becoming a Member

Want to make a difference?

There are between 78–156 million people around the world who have vitiligo; we are here to support every one of them and here's how you can help too.

Whether you have vitiligo, support somebody with the condition or you're a healthcare professional – your membership matters!

Member Benefits

It's hard to keep track of all the developments with vitiligo. When you support us and become a member, we will provide you with the following:

- Our online magazine and community, The VitLife, straight to your inbox.
- Downloadable resources to guide you through each step of your journey.
- Exclusive deals and discounts from vitiligo-related brands.
- Early bird registration for conferences and events with members-only pricing.

As a charity, we rely on your help through donations and membership. You can be confident that your generosity directly enables us to:

- **Be a primary resource for information:** We'll provide the latest accurate advice on research, treatments and coping mechanisms when dealing with vitiligo.
- **Help to find a cure and new treatments:** The Society has strong relationships with medical professionals around the globe. We work hand in hand on the latest research and continue to support the efforts to find a cure.
- **Increase public awareness:** We engage, educate and tackle the stigma surrounding the condition.
- **Provide support groups and grow a community:** We provide a safe community for those with vitiligo to support each other, including a dedicated group for parents and children.

If you have any questions when signing up for a membership, please don't hesitate to contact **help@vitiligosociey.org** so we can assist you.

Your community is waiting for you…

Become a Member Today

Disclaimer

If you require any more information or have any questions about our site's disclaimer, please feel free to email us at hello@vitiligosociety.org

Disclaimers for this ebook

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Any information provided by The Vitiligo Society is NOT a replacement for seeking advice from certified medical authorities, such as a doctor or dermatologist.

The Vitiligo Society does not make any warranties about the completeness, reliability and accuracy of this information.

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Take the time to grow, evolve and enjoy the uniqueness of being.

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There are times when there are no words. So, let there be silence. Sometimes you may look in the mirror and not know who you see. That is when it’s time to look into your heart. Those times when you feel lost, let a loved one guide you.

With time, patience, education and positivity, those tough times can lead to a better version of oneself.

I have had vitiligo for over 25 years and people continue to ask me about the struggle. Yes, there have been challenging moments but they are only moments. Life is a journey that is much bigger than fleeting moments.

The toughest times and the most joyous triumphs in my life have nothing to do with vitiligo.

The man that I have become was forged through the reaction of the world looking at me for being different. I grew stronger, patient and more loving and ready to share with each encounter.

If I could give you one piece of advice; define yourself beyond what people see and that beautiful self-definition will be unshakable.

Life isn’t about the pursuit of happiness, but finding your happiness in the pursuit.

Lee Thomas
Author, vitiligo spokesperson,
The Vitiligo Society Patron & Emmy award winning
entertainment reporter for WJBK Fox 2 News

Chapter 1

What Is Vitiligo?

What Is Vitiligo?

Before this point, had you ever heard of vitiligo?

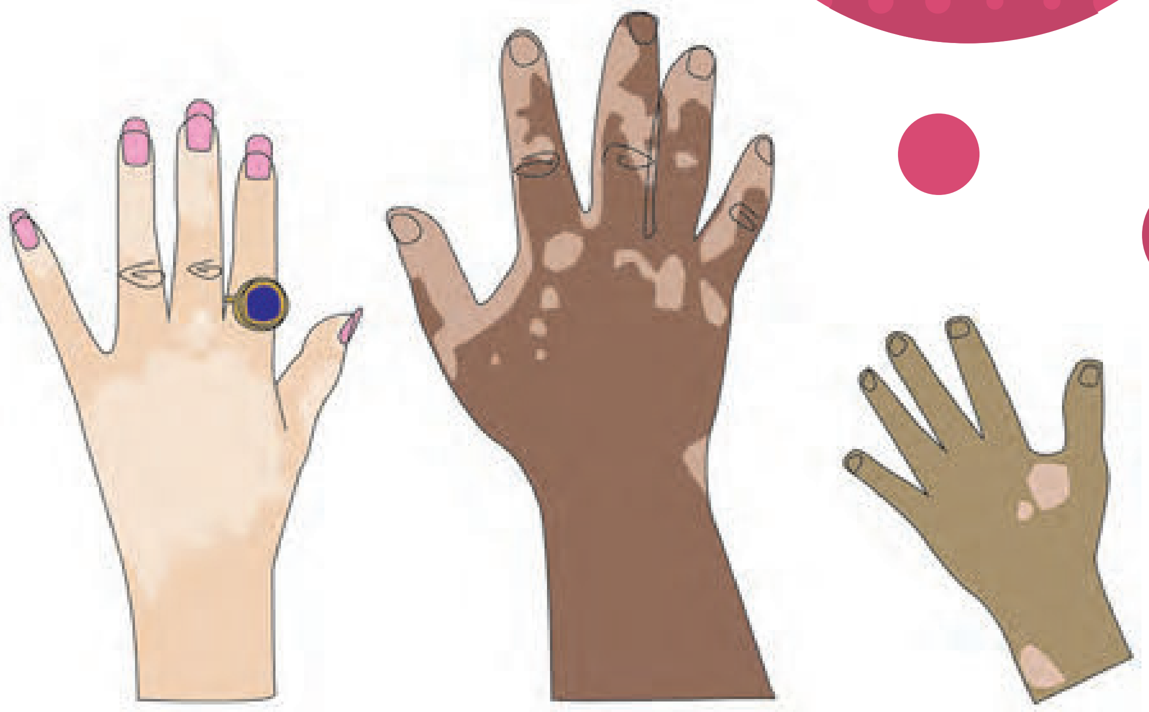
Well, you may be surprised to know that it’s more common than you might think. In fact, it is believed that between 1 and 2% of the world's population are living with the condition right now. That's over 78 million people.

Vitiligo, also called 'leucoderma', is a long-term skin condition that makes the skin, and sometimes the hair, turn white in patches. This is because melanocytes, the cells which give the skin its colour, have been damaged.

Vitiligo can actually appear anywhere on the body, but it's more likely to develop in some of the following areas:

- Eyes, nostrils, belly button, elbows and genital areas.
- Inside of the mouth (although rarely).
- Parts of the body that have folds, such as the knees and elbows.

The condition is caused by damaged melanocyte cells.



Types of Vitiligo

There are three known types of vitiligo; they are defined by how many patches someone has and where they might present on the body:

1. Focal vitiligo: Found in patients with a few vitiligo spots in a single area.

2. Generalised vitiligo (aka non-segmental vitiligo): Found in patients with many patches all over the body. The patches tend to affect the right and left sides of the body in a symmetrical pattern, almost like a mirror image. This is the most common type of vitiligo and is also known as ‘universal’ or ‘complete’ vitiligo.

3. Segmental vitiligo: The most unusual form, where patches are generally found on one side of the body and nowhere else.

Vitiligo Myth-Busting

To be clear, you can’t catch vitiligo and you certainly can’t pass it on by touching someone – the condition is not infectious.

Still have concerns? Well, here are a couple of other myths that need busting:

Vitiligo is NOT:

- Linked to cancer.
- Linked to albinism or leprosy.
- A physically harmful condition.

Now that we have addressed the myths surrounding vitiligo, let's move on to some more facts.

You cannot pass vitiligo on to someone else. It is NOT infectious.

What Causes Vitiligo?

Vitiligo is considered to be an autoimmune condition, in which the immune system attacks the body’s own tissues.

The causes are not completely understood, but they seem to be a mixture of genetic and environmental factors. People with a particular combination of genes are more likely than others to develop vitiligo, but it is not only due to heredity factors.

The development of vitiligo may be triggered by many different things, including the following:

- Hormonal changes in the body, for example during adolescence.
- Damage to the skin, for example from a cut or sunburn.
- Extreme stress.
- Contact with certain chemicals.

Can Anyone Get Vitiligo?

Anyone can develop vitiligo, whatever their skin colour or ethnic origin. It affects at least one person in every hundred throughout the world. Vitiligo can begin at any age, but about 50% of people develop it before the age of twenty.

Is Vitiligo Hereditary?

The tendency to develop vitiligo is inherited, but this does not mean that if you have vitiligo your children will definitely get it.

Children inherit a number of genes from each parent, passed on randomly. These genes can combine in many different ways and only a particular combination will give children the potential to develop vitiligo.

Even if they do inherit all the vitiligo genes, it's not inevitable that your children will develop the condition. Chance, environment and possibly other factors not yet identified can influence whether vitiligo develops.

Is There a Cure for Vitiligo?

At present, there is no cure. In some cases, the white patches can regain their colour (spontaneous repigmentation) without any treatment – this is more likely in children. However, it is rare for the condition to disappear completely.

Although at present there is no cure, research is currently being carried out in order to discover more about the condition as well as how to treat it. There are several treatment options currently available, and these have been shown to repigment the skin with varying levels of success.

We'll be exploring this later in the ebook.

It is not inevitable that children will develop the condition.

Chapter 2

Getting Diagnosed

Getting Diagnosed

Going to your doctor may feel daunting, but if you notice white patches of skin, it's important to get a medical diagnosis. There are other conditions which can be mistaken for vitiligo, so it's best to seek confirmation to be sure. In order to get the most out of your appointment, try to prepare.

It may be helpful to do the following:

- Review your family medical history.
- Make notes concerning any stressful events that have occurred in your life.
- Make a list of chemicals you may have come into contact with.
- Consider taking a friend or family member with you for emotional support.
- Prepare a list of questions to ask your doctor.
- Ask for information to take away with you. You may want to find out more about vitiligo before making any decisions.
- Arrange another appointment to discuss treatment options. Do not feel you have to commit yourself to a course of action if you're not ready to do this yet

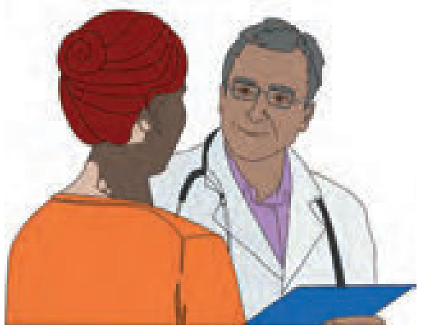
What to Expect

During your visit, your doctor will ask several questions concerning various areas of your life, including family history and whether you have had any injuries.

If available, your patches may be examined using a Wood's Lamp (ultraviolet lamp), which will assist in eliminating the possibility of it being another skin condition.

The Wood's Lamp uses long-wave ultraviolet light to diagnose various conditions, such as bacterial or fungal skin amongst others. In terms of vitiligo diagnosis, it can highlight the decrease and increase in skin pigmentation, which will change colour under the light.

It is important to go to your doctor for a diagnosis.



The Emotional Impact of Vitiligo

How you feel about having a diagnosis of vitiligo depends on a number of factors: where the patches are on your body, how noticeable they are, your support network and so on.

It may be that your vitiligo isn’t very noticeable and as such you might be able to live comfortably with the condition without further concerns.

On the other hand, the diagnosis may come as a shock and feel scary. This can be a major change and with the unpredictable nature of the condition, it can make you feel out of control.

Everyone has their own way of managing such situations, and the truth is – there is no right way.

Vitiligo is not a physically harmful condition, so you may find that the doctor's approach is to reassure you. You may find this reassurance helpful. However, as suggested previously, people have different reactions to hearing that they have vitiligo.

You may feel that focusing on the physical aspect of the condition does not take account of the emotional impact vitiligo can have. A change in appearance can be very distressing for some people – if this is how you feel, it is an understandable and normal reaction.

‘Why me?’ is an obvious question, especially if you don’t have any relatives with vitiligo. But as outlined in Chapter 1, why particular individuals develop the condition and others do not isn’t fully understood yet.

How Bad Will It Get?

Vitiligo is unpredictable, so it is difficult to tell how the condition will develop. Not knowing whether, or how much, your vitiligo patches will spread can be distressing. You may find yourself monitoring changes frequently, perhaps even obsessively. While this is a natural response, try not to make yourself more anxious by worrying about what may happen.

There is no right way to manage situations such as this

What Can I Do After Diagnosis?

Inform yourself: Get information about vitiligo. This will help you to make treatment decisions and may give you a better sense of control.

Share experiences with others: It can be reassuring to know that you are not alone in dealing with vitiligo. As well as giving support, other people can also be a significant source of information.

Reduce stress: Are there immediate changes you can make in your life that would decrease stress for you? Do you need more support from family or friends? Or, are there new hobbies and activities you could take up, such as meditation or yoga?

Talk about your feelings: This may be with your family and friends. If you find this difficult, a 'neutral person' like a counsellor may be able to help.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Chapter 3

Treatment Decisions

Treatment Decisions

There are no reliable cures for vitiligo as of yet. Available treatments focus on slowing its progress, concealing the white patches or trying to bring about repigmentation. Although this may sound glum, this is merely the situation now and does not mean it will always be the case – research into new treatments and a cure continues.

What you do after your diagnosis depends on how you feel about your condition. This is a very personal choice, and a number of factors may influence the decisions you make, such as:

- How you feel about your vitiligo.
- How it's affecting your life.
- Feedback from your family or partner.
- What your skin colour means to you.
- How your immediate community responds to your vitiligo.
- Medical risks and side effects of treatments.
- Availability of non-medical solutions that could help you manage your situation more easily.

What you do after your diagnosis depends on how you feel about your condition.

What Are My Options if I Have Vitiligo?

There are a number of different avenues you can explore in regard to your next steps:

- Decide that you can live with vitiligo and treatments are not necessary for you.
- Ask your doctor about available treatments.
- Use camouflage products to conceal the white patches.
- Seek counselling or psychological support if you are very distressed.

We'll be exploring these options further in this ebook.

Carry out Research

You need accurate information in order to make decisions about your vitiligo. There are a range of options for treating the condition, so it is important that you fully understand what treatments are available and how they may affect you.

Your doctor or dermatologist may be a reliable source of information. However, if they are not experienced with the condition do come to The Vitiligo Society for further information, or review the ***Resources*** section of this ebook.

If you find it difficult to speak to your health professional, perhaps from lack of confidence, consider writing questions down before your appointment as this will help you get the information you need.

Taking someone with you to the appointment can also help – they can support you and remind you of anything you forget to ask.

Dealing With ‘Fake News’

Not everything you read on the internet is true, and ‘fake news’ is especially dangerous when it comes to the medical field.

Unfortunately, anyone is able to publish anything on the internet without fact-checking. Coupled with the rise of social media, false information, whether intentional or not, can become viral with a single tweet or share.

There are ways you can try and minimise being misled by those offering to sell you a ‘100% cure for vitiligo’ or provide details on treatments that are not based on medical facts.

- Check the source. Who was it published by?
- Check the language and images. Are they full of sensationalism? An image of a celebrity with a quote can be very convincing, but did they actually say it?
- Bot accounts are fake social media accounts set up to spread information that is generally misleading or to push a specific agenda. Check the account’s handle and bio information. If the information is limited and the handle consists of letters and numbers in succession, it could mean it was generated by an algorithm.
- Take a look at the website's URL. Does it look odd? You generally see legit websites ending with .co.uk, .org or .com.

The best sources to go to for health information about vitiligo are The Vitiligo Society, government health websites, such as the UK's National Health Service (NHS), and the World Health Organization. Primary sources are generally better than news articles

Treatments

Treatment success may depend on the area of the body you are treating. Also, bear in mind that there is a possibility of patches returning after successfully being treated but there is no guarantee and results may not be permanent.

Recent research suggests that the effectiveness of treatments depends less on a person's age than where the vitiligo is and when it started.

- Treating vitiligo on the face seems to be particularly effective.
- Children are more likely to be responsive to treatment.
- Using treatments when vitiligo first develops is more effective than doing so later on.
- Small areas are easier to treat than large ones.

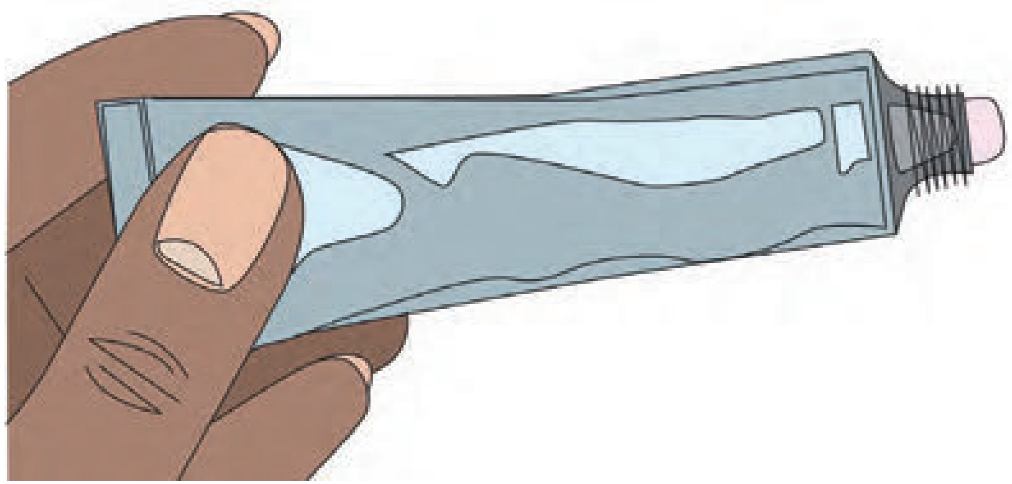
Treatment Options

Some of these treatments will be available in your country via doctors/dermatologists and others may not. **Please consult your doctor before pursuing any treatment method.**

Creams

There are two types of creams, which can both be prescribed by your doctor: steroid creams and calcineurin inhibitors (Protopic and Elidel).

Please consult your doctor before pursuing any treatment method.



Steroid Creams

Steroid creams are the most common treatment offered for vitiligo.

These creams are used to treat localised vitiligo and/or the inflammatory elements of the condition. It is worth noting that these are not the same steroids used to build muscles.

Vitiligo is considered to be an autoimmune condition, in which the immune system attacks the body's own tissues. Steroid creams can prevent this from happening for some by reducing the activity of the immune system.

Topical (medication that is applied directly to a particular area of the body) steroids come in many different formulations, such as creams, ointments and gels. Different formulations are suitable for different areas of the skin.

Topical steroids are measured in 'fingertip units' (FTU). This is the amount of topical steroid squeezed from a normal 5mm nozzle from your first crease to the tip of your finger.

They are classified as mild, moderately potent, potent or very potent.

Advantages & Disadvantages

- Steroid creams are simple to use and a treatment you can do at home.
- Creams are quite safe, so long as you follow the instructions.
- Steroid creams can be quite effective, especially with new areas of vitiligo, but they do not work for everyone.
- Overuse can lead to side effects such as skin shrinkage or stretch marks.

Doctors will prescribe the most appropriate cream to treat your condition.

You will probably have a trial period of up to eight weeks. This is to make sure that there are no side effects from using the cream. The usual procedure is to use the cream for six to eight weeks and then start the cream again after a break. It may be used for longer under close supervision.

The cream or ointment must only be applied thinly to the white patches of your skin. It is important that you follow the instructions you have been given carefully. You also need to continue with the treatment for some time (at least 12 weeks) before any results are likely to be seen.

Protopic Ointment (Tacrolimus) and Elidel (Pimecrolimus)

Protopic ointment (tacrolimus) and Elidel (pimecrolimus) are calcineurin inhibitors generally used to treat eczema.

Protopic appears to have unique qualities in suppressing the immune response in vitiligo patches. It has a similar effect to steroid treatment but without the side effects.

Elidel is a similar product to Protopic, but in a cream.

The most common advice is to apply the ointment or cream twice a day. Some doctors also recommend that their patients expose themselves to natural sunlight several times a week for 15–30 minutes.

Protopic can be prescribed by doctors for vitiligo, although it is not licensed. Often a dermatologist may recommend it, but do speak with your doctor about a prescription.

Protopic ointment has proved quite effective on the faces of some people with vitiligo when the loss of pigment is relatively recent and still active.

Unfortunately, like steroid creams, Protopic does not work for everyone.

Advantages & Disadvantages

- It is an alternative to steroid creams and can also be used at home.
- It does not have the potential side effects of steroid creams.
- Protopic does not seem to be readily absorbed into the bloodstream, so the treatment is quite localised.
- It takes a long time for results to show. It is not unusual for it to take 12–24 weeks before there are any improvements.
- Even when white patches have repigmented, they may relapse later. The usual procedure is to use the cream for six to eight weeks and then start the cream again after a break.

Further Possibilities Using Protopic

Investigations are going on to find out the effectiveness of using Protopic with Narrow Band UVB light treatment (more information on light treatments is below).

In some studies, this combination has resulted in enhanced pigmentation, but further work is needed to establish safety standards for this treatment.

Topical Vitamin D Analogues

Topical vitamin D analogues such as calcipotriol, calcitriol and tacalcitol are often used in the treatment of vitiligo as a supplemental therapy to Narrow Band UVB, PUVA (see below) or as a standalone treatment. Vitamin D analogues work by suppressing the various proteins that destroy melanin-producing cells.

Side effects can include skin irritation, burning, itching, dry skin, peeling skin or a rash. In rare cases, too much vitamin D can be absorbed into the body, which can lead to increased levels of calcium.

Too much calcium in your blood can weaken your bones, create kidney stones, and interfere with how your heart and brain work.

Azathioprine

Azathioprine is an immunosuppressive agent that has been widely used in the treatment of vitiligo and has proved effective. Azathioprine is used to halt the progression of vitiligo and also induce repigmentation. It can be used on its own or in combination with other treatments such as oral PUVA treatment.

There have been negligible side effects, such as nausea and anaemia, recorded in patients using the azathioprine group of drugs.

Vitamin D analogues suppress proteins that destroy melanin-producing cells.

Light Treatments

Light treatments can be very effective, but people can react differently, as with the creams.

To get light treatment, you will need to be referred by your doctor to a hospital dermatologist.

Factors to Consider When Deciding Whether to Have Light Treatment

- It is most suitable for people who have large patches of vitiligo.
- Response to light treatment is variable. It is usually stopped after three months if there has been no improvement.
- If there is an improvement, a course of treatment is likely to be long, often lasting for a year or more.
- It may be difficult to fit hospital visits in with your other commitments.
- Some people dislike the feeling of being shut in the light cubicle (although most get used to it).
- Treatments may bring about repigmentation, but this may not be permanent.

What Does it Involve?

Light treatment is given by a machine that looks rather like a shower cubicle lined with fluorescent tubes. The amount of time you spend inside the cubicle is built up gradually in order to avoid burning.

Treatment is usually given two or three times a week because it is not safe to give it more often. Any redness (burning) can take up to 24 hours to appear and needs to be protected from further exposure. During the treatment, you must wear wraparound goggles to protect your eyes. You should also avoid looking directly at the rays of light.

There are two types of light treatment.

PUVA Treatment

PUVA (Psoralen and Ultraviolet A) is an effective treatment for vitiligo and other skin conditions. It involves taking medication as well as light treatment. This is an older treatment that has been replaced by many dermatologists with Narrowband UVB.

Psoralens are chemicals found in plants, which make the skin more sensitive to light (either natural sunlight or UVA rays). Psoralen may be given as capsules to swallow, one or two hours before treatment.

It may also be given as a lotion to paint on the white skin patches or to dissolve into bathwater (in which you have to soak for a short period before UVA treatment). You should not take psoralens if you are pregnant.

Because psoralen makes your eyes sensitive to sunlight, you need to wear dark glasses to protect your eyes for at least eight hours after taking the capsule.

You also need to be careful that you are not taking or using other substances that are making your skin more sensitive to the UVA rays. These include some medicines, including complementary or herbal medicines, coal tar or disinfectant soap and some deodorants, perfumes and aftershaves.

Narrowband UVB Treatment

Narrowband UVB is now the most common type of light treatment for vitiligo.

It uses the light of a specific UVB wavelength, which has proved to be more effective than using standard UVB.

There are a number of advantages over PUVA:

- It does not require additional medication, so you do not need to take special precautions before and after treatment.
- Areas of skin with pigmentation do not develop the deep tan as is usual with PUVA treatment, so the contrast between pigmented skin and the treated vitiligo skin is less obvious.
- Exposure to the light is for much shorter periods.
- The different light source reduces the risk of skin cancer.
- UVB treatment does not tend to damage the skin as much as PUVA can.
- This treatment is safe enough that it is used for children, as well as pregnant and nursing mothers.
- Studies suggest that it is a more effective treatment than PUVA.

Bleaching (Depigmentation Treatment)

Bleaching the skin is a non-reversible permanent treatment for vitiligo. It results in a total lack of skin colour.

During this process a hydroquinone-based medicine is continually applied to the pigmented areas of skin, bleaching them to match the tone of the white patches. The pigment cells are destroyed, which means that no further repigmentation is possible on the bleached areas.

The NHS and British Skin Association recommend that this treatment should only be considered if 50% of your skin has lost its pigment or in cases where no other treatment has worked.

You would need to bear in mind the following:

- Bleached skin will almost always be more sensitive to sunlight.
- Bleaching can lead to a profoundly disorienting loss of identity.
- You would not be able to use new treatments in future because they might repigment your vitiligo skin patches.
- Possible risks include redness, itching and stinging (from the hydroquinone).
- Should the skin repigment it may be a different tone from the original colour.

Skin Grafting

In this procedure, a small section of your healthy, pigmented skin is transferred to areas that have lost pigment. This procedure is generally used if you have small patches of vitiligo.

This treatment is only suitable for people who have very stable vitiligo (where new patches have not developed and old patches have not spread for at least two years).
It is rarely used in the UK because of the disadvantages:

- Trauma to the skin can cause a vitiligo patch to develop in the area the graft was taken from.
- Treatment can cause scarring, infection and a cobblestone appearance.
- The colour from the grafted skin is lost eventually.

Alternative Treatments

The following treatments are not generally recommended by mainstream doctors or dermatologists.

You may feel that they are worth investigating if conventional treatments have not worked for you. However, The Vitiligo Society cannot recommend using any of these treatments, due to the lack of clinical trials to prove their effectiveness.

DISCLAIMER: We suggest that you check the qualifications and experience of private practitioners very carefully before paying for their procedures or products.

Recell®

This is quite a new procedure that involves the practitioner taking a small sample of pigmented skin. The skin is then placed in a heated enzyme solution for 15–20 minutes so that the cells begin to separate. The pigment cells are then carefully collected. The recipient skin area is prepared by removing the top layers using a laser, dermabrasion or deep peeling. The pigment cells are then sprayed onto the skin, which is then covered with a special dressing for five to seven days.

This procedure takes approximately 30–45 minutes. It is not as intrusive as skin grafting, but the repigmentation process can take time to be effective.

Most patients will see some improvement within 24 weeks and can continue to improve for up to a year after treatment. The results are permanent and usually, just one treatment is needed.

The Recell® procedure is still in its infancy so it is not known how successful it will be in the long term.

We suggest checking the qualifications of any private practitioners very carefully

Climatotherapy

Climatotherapy involves using natural resources in the environment to treat a medical condition.

For example, people have been travelling to clinics in Jordan or Israel for decades to treat various ailments by bathing in the Dead Sea.

The high saturation of minerals such as sodium, magnesium and potassium in the Dead Sea, as well as the clean, dry air and lower UV rays in its vicinity can encourage repigmentation on affected vitiligo patches. They can also help with a number of other ailments, including skin conditions such as psoriasis and eczema.

In relation to vitiligo, the magnesium in the water brings down the hydrogen peroxide levels of your skin. This is something that is supposed to happen naturally but research has pointed to this not happening as it should in those with vitiligo.

Bromine is another mineral responsible for relaxing your body and emotional state. This is important as stress is thought to trigger the condition, and a happier relaxed state can aid in the healing of pigmentation.

Although the treatment, which includes sunbathing and swimming in the Dead Sea, may seem like the perfect holiday, it is actually quite a rigorous treatment regime.

Patients will generally be required to wake early to bathe in the Dead Sea before showering and sunbathing in the solarium – increasing their sunbathing duration each time until it is a full hour. This regime is repeated twice a day.

At a clinic, consultants are on hand to provide patients with check-ups, supplements and additional treatments, such as ointments.

For in-depth information on this treatment click ***here.*** You can watch a conference talk by Simon Parker, Chairperson of The Vitiligo Society, about his experience of treating his vitiligo at the Dead Sea.

Laser Treatment

There is conflicting evidence about the effectiveness of laser treatments, so these are only available privately and can be very expensive.

Excimer Laser

Excimer Laser therapy is used to treat localised vitiligo as well as other skin conditions. Using a cool beam high-energy laser at the specific wavelength of 308nm, (similar to the one used for eye treatments) repigmentation can be induced in a shorter time and there is no global exposure to radiation.

It is often combined with topical therapies to enhance response, such as calcineurin inhibitors and topical steroids.

Complementary Medicines

Some complementary medicine products are heavily advertised on the internet, but there is no reliable evidence of their safety or effectiveness.

Current evidence indicates that most complementary medicine products to treat vitiligo are ineffective and expensive. The Vitiligo Society continues to monitor vitiligo research and treatments and will advise on any proven product or treatment.

New Treatments in the Pipeline

There is evidence that some classes of biologic drugs can help stop or reverse vitiligo by acting as an immunosuppressant. Clinical trials are underway of Jak-1 inhibitors and anti-IL15 biologics. These are suppressants usually used in the treatment of arthritis to tamp down an overactive immune system that causes inflammation of the joints. It is anticipated that one or more drugs will be approved for use in some countries, in selected patients with vitiligo, possibly within the next 5 years or so, if the clinical trials show benefit.

Making the Decision to Stop Medical Treatment

It can take up to 12 weeks before treatments start to work and some people find this wait for repigmentation very distressing.

As mentioned previously, treatments are not effective for everyone. You may decide that treatment is too upsetting emotionally and stop. It may be more appropriate for you to use camouflage products, or just try to focus on developing other aspects of your life and your appearance. Vitiligo is just one part of who you are.

Getting Professional, Emotional or Psychological Support

Having vitiligo can be very stressful, particularly if it is visible on your face and hands. Talking to friends and family members about anxieties and fears may be enough to help you cope with the condition. If this does not help, you should go to your doctor to discuss your concerns. You might be referred to a specialist for counselling or psychological support.

Talking to a counsellor, who is neutral and non-judgemental, could be an effective way to help you develop ways of managing emotions such as anxiety and grief, as well as difficult social situations, like other people's reactions.

Counselling can support you through grief and help you manage anxiety.

Chapter 4

Diagnosis & Treatment of Vitiligo: UK Guidelines

Diagnosis and Treatment of Vitiligo: UK Guidelines

Giving diagnoses and prescribing treatments are clearly the responsibility of doctors. Doctors have been trained and provided with the necessary guidelines in order to diagnose and treat vitiligo.

Although patients cannot instruct their doctor as to which direction to take, it is still useful for patients to know what doctors (and other medical professionals) are advised to do for patients with vitiligo.

This section includes the following details based on guidance provided to UK doctors:

- Making a definitive diagnosis.
- Suggesting supportive treatments, such as the use of camouflage.
- Considering treatment options.
- Offering psychological support.

Making a Definitive Diagnosis

To start with a diagnosis of vitiligo has to be confirmed. Diagnosis is more straightforward with the symmetrical type of vitiligo than with the less common segmental form (where patches are not the same on both sides of the body).

If patients have irregular patterns of vitiligo, doctors are advised to refer patients for expert assessment by a dermatologist.

Three main skin conditions can be mistaken for vitiligo:

- **Tinea versicolor:** a superficial yeast infection that can cause a loss of pigment on the upper trunk and chest.
- **Piebaldism:** a condition which results in white patches of skin. There is also usually a forelock of white hair, which can be present at birth.
- **Idiopathic guttate hypomelanosis:** in which many small, white patches are found, mostly on the trunk or on sun-exposed parts of the limbs.

Initial Assessment

The doctor's examination should include looking at:

- How the white patches are distributed
- How big they are and whether depigmentation is total or partial.

Your doctor will note whether the affected areas are symmetrical and whether they are around the nose and mouth, etc.

With adults, your doctor may ask for a blood test to check if the thyroid is working properly, as vitiligo patients can be prone to thyroid conditions. Your doctor should also ask about the effects of vitiligo on your quality of life, which may include personal questions about how your skin condition is affecting your relationships and emotional wellbeing.

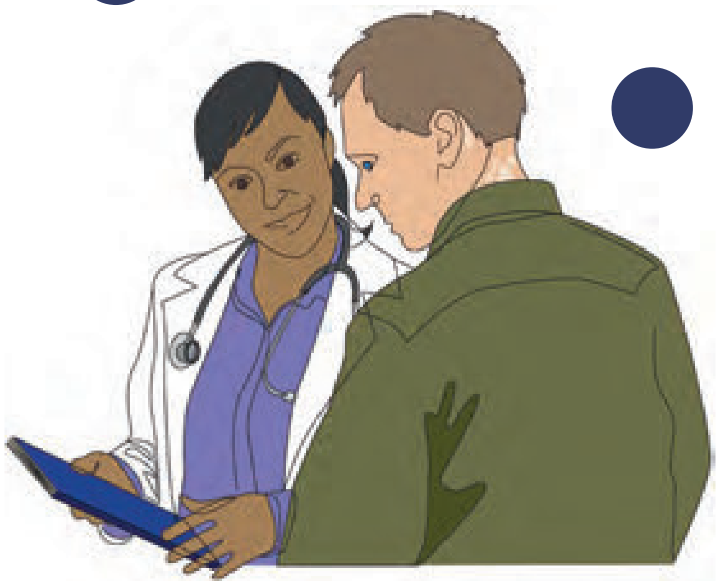
Doctors are advised that, for some people, vitiligo can be devastating; it can have a significant impact on the patient's quality of life and self-esteem. It may cause social isolation and significant depression, create difficulties in sexual relationships and result in stigmatisation.

These questions, although personal, help your doctor to build a bigger picture and determine any additional services you may need.

It is suggested that patients are given information about The Vitiligo Society.

Patients should also be offered advice about sunscreens and cosmetic camouflage, including fake tanning products.

Personal questions, help your doctor to build a bigger picture.



Deciding on Appropriate Treatment

Doctors are advised that for adults and children with fair skin types it may be appropriate to consider not giving any treatments, except sunscreens and camouflage cosmetics. Obviously, this would be discussed with you.

Treatment of vitiligo can be viewed in two phases: the first is to halt the progression of the disease; the second is to encourage repigmentation. Some treatments can achieve both.

Research indicates that the effectiveness of treatments depends not so much on a person's age, but more on where the vitiligo is situated and when it started. It is most effective in treating the face, in childhood, in the early stages of the condition and when patches are small.**

Treatments Available to Non-Specialists (i.e. Doctors & General Practitioners)

Topical Steroids

The use of topical steroids (creams that are used on the white patches) is generally the first line of treatment.

Keep in mind that the recommended treatments for adults and children are slightly different.

Recommended treatments for adults & children are slightly different.

For adults with recently developed vitiligo, and for children, it is recommended that treatment with a potent (betamethasone valerate) or very potent (clobetasol propionate) topical steroid should be considered.

These can repigment vitiligo, but only in a small proportion of cases. A trial period of no more than eight weeks is advised because these creams can have side effects over a longer period, such as inflammation and thinning of the skin.

*** Information about this research, conducted in Japan, is taken from a poster presentation, Evaluation of our recent therapies of vitiligo vulgaris by Shibata, T. et al, at the 21st International Pigment Cell Conference, 20–24 Sept. 2011 Bordeaux, France.*

Specialist Treatments

Phototherapy

Phototherapy is appropriate for extensive vitiligo, especially if the vitiligo is active. It has been a mainstay of treatment for several years.There is evidence that some vitiligo patients respond well to phototherapy with Narrowband UVB (NB-UVB). Also, research indicates that NB-UVB is more effective than PUVA (Psoralen in combination with UVA).

Phototherapy treatments should be considered only in specialist dermatology units.

Depigmentation

Depigmentation treatments should be reserved for severely affected adults and should be undertaken only by specialist dermatologists.
Where a patient has extensive vitiligo with a dark skin tone, especially on cosmetically sensitive areas such as the hands or face, it is worthwhile considering whether complete depigmentation of the affected areas might be beneficial.

The profound effect that this may have culturally needs to be taken into account and fully understood by the patient.

Surgery

If light therapy and medications aren’t successful, some people may be viable candidates for surgery. Surgical treatment of vitiligo is appropriate for cosmetically sensitive sites, such as the face or back of the hands, but only if the condition has been inactive for 6 –12 months.

Surgical treatments are not recommended in children and should be considered only in specialist dermatology or plastic surgery units.

Systemic Treatments

Since vitiligo is viewed as an autoimmune condition, it is natural to wonder whether systemic treatments (drugs or therapies that potentially affect the entire body rather than a local area) might have something to offer. At present, the use of oral dexamethasone to halt the progression of vitiligo cannot be recommended due to an unacceptable risk of side effects.

Psychological Support

Vitiligo can have profound psychological effects. When patients are severely affected by vitiligo, psychological support should be offered as a way of improving their ability to manage the condition. This support may be counselling or cognitive behavioural therapy (CBT). Parents of children with vitiligo should be offered psychological counselling where needed.

Chapter 5

A Positive Approach

A Positive Approach

This chapter aims to help you take a positive approach to coping with vitiligo and managing the reactions of other people, whilst recognising that living with the condition can be challenging.

The Social Context

We live in a consumer society that often values physical appearance. It is difficult not to be influenced by media images of models and celebrities who seem to have ‘perfect’ skin, as well as slim bodies and designer clothes. However, in recent times there has been some change, as slow as it is; celebrities, sports personalities, musicians with vitiligo are becoming more visible. There are also a number of vitiligo models included in big brand campaigns.

Despite these positive changes, having vitiligo might still make you feel embarrassed about your appearance and anxious about how other people may see your condition. The distress caused by these negative feelings may make you react in a number of ways, such as the following:

- Avoiding/escaping social situations and activities you would otherwise enjoy, e.g. swimming.
- Hiding white patches by using camouflage or wearing clothing you would not otherwise wear.
- Becoming hypersensitive to the reactions of other people.
- Unfavourably comparing yourself to others.

These reactions are not only understandable but natural. However, they can damage your confidence and prevent you from leading a happy and fulfilled life.

A Positive Approach

The approach suggested here involves challenging negative thoughts and feelings and replacing them with more positive ones. By doing this, it is possible to change how you see yourself and how you relate to other people. Using the following method should help you develop a more positive way of coping with your skin condition.

Helping you take a positive approach to coping with vitiligo.

Thinking Positively

Focus on the Positives

Try to identify your negative thoughts and challenge them by asking yourself questions.

“Is it really true that all people judge me in terms of my skin?”

“Does my self-worth as a person and my abilities to cope depend on my physical appearance?”

“Would I ever choose a friend solely on the way they look?”

Become more conscious of other aspects of your appearance and your personality.

Focus your attention on your strengths and the good things in your life as opposed to your vitiligo. Make statements to yourself, such as:

“I am worried that I won’t be loved/accepted because of my vitiligo. Actually there are people in my life (e.g. family, friends, colleagues) who do love/accept me because...”

“I am going to stop worrying about my skin and concentrate on the positives in my life.”

“Beauty is in the eye of the beholder. There are people who find me attractive because... [insert positive attributes of your appearance or your personality].”

Have a self-affirmation

Create your own positive statement about yourself, which you can repeat in your head when you are in a difficult situation, such as:

“I am competent, efficient, caring, passionate, courageous and considerate.”

“Anyone who really knows me thinks I’m witty, wonderful and good company.”

Affirmations are a powerful tool and can help counter long-term belief systems about yourself.

They are messages absorbed at a subconscious level and have been shown to create a positive impact.

“I am competent, efficient, caring, passionate, courageous and considerate!”

Divert your attention

When you realise that you are thinking about your appearance and what other people might think about your looks, redirect your thoughts. Focus your attention away from negative thoughts and on to something else.

You could do this by:

- Using your self-affirmation
- Thinking of something you have to do or are looking forward to doing.

Stop making comparisons

Try monitoring the times of day, activities and situations in which you tend to compare yourself with others. It can increase your awareness of this habit and help you to stop. Concentrate on self-care and wellbeing to increase your self-confidence.

Stop checking

Also, try to stop the habit of checking your skin too frequently in a way that causes distress. If you check yourself, you need to do it in an objective way. That means looking at your body and observing your appearance without judging it.

Behaving Positively

Reduce your own anxieties by acting positively.

Make your appearance as good as possible. If you are happy with your clothes, shoes and hairstyle, you will feel more confident and able to act positively. Remember, people are not just looking at the vitiligo, they are looking at the rest of you too.

Be aware of your body language. We communicate how we feel by the way we stand, sit or walk. Having your head up, making good eye contact, smiling and having a strong voice gives the message that you are confident, friendly and worth getting to know.

Making eye contact can feel intrusive or cause anxiety for someone with vitiligo, but it should help to think of it as a 'normal' part of the communication process.

Arrange for friends or family members to go with you to places that are difficult or new. This will give you someone familiar to talk to and someone who can give you more confidence to make contact with new people. They can also be there to aid you if a difficult situation arises.

Reduce other people's anxieties by talking positively about vitiligo. Remember that they might also feel self-conscious. Perhaps they have never met anyone with vitiligo. They may be unsure of where to look for fear of making you feel uncomfortable, or they may just be feeling your anxiety.

Here are some examples of how you can talk positively about your vitiligo.

Explain your condition, using words you feel comfortable with, such as,

"It's called vitiligo; it causes my skin and/or hair to turn white in patches"

or, *"My skin has patches that are different colours."*

Mention it if the other person looks concerned, even if they do not directly ask you about it. Try to keep your explanations short; this will inform people but keep some of your privacy as well.

People don't really need to know any more than you want to tell them.

People don't need to know any more than you want to tell them

Reassure other people that vitiligo does not hurt, if they seem to be concerned about this.

Reassure them, if necessary that they cannot catch vitiligo. All you need to say is, *"It's called vitiligo, it's not catching."*

Use **humour** if you can, where appropriate.

Keep **relaxed**; try not to talk about your anxieties unless you know the other person is going to be interested and sympathetic.

If you don't feel like talking about your condition, or you don't like the way someone is asking you about vitiligo, you can try the following:

- **Distracting** people away from your condition by changing the subject. Asking the other person a question about themselves, or about an interest you have in common.
- **Being assertive**, without being aggressive or rude. You can just say something like, "I don't really feel like talking about it now." Then make an excuse to move on to something else or some other activity.

Dealing With Difficult Situations

People with vitiligo frequently have to deal with uncomfortable situations, such as when other people are staring or making intrusive comments.

These can be very challenging and make you feel awkward. If this applies to you, it may help to make a list of the situations that cause you distress. Start by working out ways to tackle the least intimidating ones before dealing with the situations that cause the most distress.

Taking a gradual approach can help build your confidence. For example, you could try the following:

- If you think someone is staring at you, give them a quick smile. This will let them know that you have noticed their stare. Hopefully, they will be embarrassed and stop staring at you. Remember, they are probably just curious about your condition and are not necessarily being rude or intentionally insensitive.
- If you are asked about your vitiligo, look straight back and smile at the person and decide whether you want to reply or not. Use the Explaining, Reassuring, Distracting and Being Assertive methods described above.
- Think about the situations you have tackled, learning from anything you could have done better, but particularly noting what went well. Praise and reward yourself for your achievements in overcoming your difficulties.

Feeling Positive

Expressing Your Feelings

Remember the following:

- Everyone who has vitiligo experiences negative feelings at some stage. This is normal and you are not alone.
- It usually helps to express your feelings, rather than to suppress them.
- Sharing how you feel with other people close to you will probably help them as well as you. They will better understand how to support you.

Accepting the Condition

If you think and behave positively in the ways suggested, you may get to the stage of accepting your condition.

You should not feel guilty in any way, either for having vitiligo in the first place, or for having difficulties managing it. Look after yourself and try to see that your appearance is only one aspect of who you are.

Statements like the following may help you to accept your skin condition and assist in self-care:

“I still have healthy skin.”

“I am different, but everybody is different in some way.”

“I may not like my vitiligo but it’s part of me. Everybody has something that they may not like or worry about.”

Being positive and accepting the condition can be hard for those who live within communities that hold negative beliefs about vitiligo.

You may benefit from getting further help and support to cope with your skin condition.

Chapter 6

Emotional Support

Emotional Support

This chapter has been created to assist if you are feeling any anguish as a result of having vitiligo.

The information is based on the experiences of other people with the condition, to help you understand your reactions and to reassure you that you are not alone in facing the challenges that vitiligo can present.

You're not alone

Different Reactions

Vitiligo can be difficult to live with emotionally – it involves a change in appearance that is unpredictable and outside of your control. How severe your vitiligo is will not necessarily determine how you will react.

How individuals respond to having vitiligo depends on many other life factors, such as:

- when the vitiligo develops
- the importance of your appearance to your identity
- how supported you feel in your life
- significant life events and losses you have experienced
- how you have coped with challenges in the past.

If You Developed Vitiligo During Childhood...

Your sense of self and identity was still being formed, so your experience of vitiligo was part of this process.

Your family would have more than likely influenced whether you saw the condition as an acceptable aspect of you, or whether there was shame and pressure to conceal the white patches. During your childhood, your parents may have made treatment decisions which you did not choose or fully understand.

Your self-esteem and confidence may have also been affected by the reaction of other people to your vitiligo, especially your peers at school.

If You Developed Vitiligo as an Adult...

Your sense of self and identity will be more fully formed, with established personality traits and coping skills. Thinking back on how you overcame other difficulties in your past may help you to work out ways of coping with vitiligo.

However, if you have placed a lot of value on your appearance or experienced low self-esteem for some reason, adjusting to the changes brought by vitiligo may take time.

Making Sense of Your Emotions

People who tell their story of vitiligo often refer to it as a journey that people have to travel through, trying out different treatment options and experiencing changing emotions.

Hopefully, like many others, your journey will enable you to accept the condition as just one aspect of your appearance.

Here are some of the feelings that you may experience on your vitiligo journey. Remember that we are all different and there is no particular order to how you should feel at any stage of your journey.

The Grief Process

Having vitiligo may give you a profound sense of loss over your previous appearance or your identity.

This sense of loss can trigger a range of emotions that are part of the natural process of grieving. These include shock, denial, anger and depression.

Vitiligo is an unpredictable condition and these emotions can appear at any time in its progression.

Grief may be expressed in terms of thinking about how you might have looked without vitiligo, or imagining how your life may have been different if you did not have the condition.

Don’t feel guilty about having these feelings. It is important to give yourself time to acknowledge any hurt and cry if you need to, rather than feeling you have to be brave at all times.

The grieving process may be particularly difficult if you are experiencing the feelings of loss of your racial and cultural identity as a result of developing vitiligo.

Your skin tone can define you as belonging to a particular community, and losing that skin tone may affect your feelings of belonging. As vitiligo is more pronounced with dark skin tones, your own and other people’s awareness of your appearance may also be heightened.

Coping with feelings of loss should become easier with time, especially if you are able to talk to your family or friends about your feelings, fears and anxieties.

Shame

Feelings of shame about having vitiligo are often accompanied by a lack of confidence and low self-esteem.

Looking different can lead to feelings of inferiority in relation to other people. You may feel judged and less valued than others because of your appearance.

Experiencing unwanted attention such as staring or unkind comments can increase these feelings. Some people may hold culturally informed beliefs that vitiligo is bad or a curse of some kind. Such beliefs are likely to create feelings of shame, leading to people with the condition feeling like they are to blame.

By understanding more about vitiligo and meeting other people who also have the condition, feelings of shame can be reduced. This will help you realise that vitiligo is not something to be ashamed of, and it is not your fault if you have developed the condition.

Social Avoidance

Some people respond to having vitiligo by increasingly isolating themselves from others. This may be out of shame, fear of ridicule, or as a result of a negative incident in the past. It is important to seek help and support if you feel yourself becoming isolated from other people. You can:

- get support (from family, friends or professionals)
- contact other people who have vitiligo (through The Vitiligo Society).

Seeing Vitiligo as Just One Aspect of Who You Are

Your vitiligo journey can become more manageable when you recognise that vitiligo is just one aspect of your appearance. Body image is also about our body language and how we choose to present ourselves through our choice of clothes, hairstyle and so on.

Engaging with these different aspects of your appearance can give you a sense of control over what you look like – to yourself and other people.

Furthermore, your appearance is also only one aspect of who you are as a person. How you develop relationships with others, use your talents and take up opportunities in life are arguably more important than your appearance.

With time, you may be able to think of your skin condition as part of your own growth and development as a person, something to celebrate and in which to find value.

Chapter 7

Nutrition

Nutrition

You may have questions around diet and whether this could make any difference to your vitiligo.

Whilst things may feel a little out of your control, choosing the foods you eat is something you can manage. So, having a good diet is something practical you can do to help yourself.

A good diet is something practical we can do to help ourselves.

Are There Any Foods That Should Be Eaten or Avoided?

In short...no. The body is complex, requiring a wide, balanced range of nutrients to maintain its healthy state.

These nutrients need each other to function effectively. That’s why picking out one type of food, vitamin or mineral to take as a supplement is not usually helpful.

Avoiding particular food groups will not help either. For example, it has been suggested in some forums that avoiding certain foods, such as white foods can lead to an improvement in your vitiligo. White foods include dairy products, tofu, cauliflower, beans are a good source of vitamins and minerals, and are an essential part of a well balanced healthy diet.

So again, you need a varied diet, including the nutrients that are involved in the pigmentation process and those that promote healthy skin generally. If you are unsure, speak with your healthcare advisor for information on healthy eating.

What Nutrients Should Be Included in a Balanced Diet for Someone With Vitiligo?

Scientists have been working on the connection between diet and vitiligo. Although no one nutrient has been identified as a ‘cure’, it is evident that the following nutrients are involved in pigmentation, maintaining healthy skin and supporting your immune system.

Speak with your healthcare advisor for information on healthy eating.

Vitamin B12 and Folic Acid

Vitamin B12 and folic acid work closely together and it seems we need a balance of these nutrients as they are highly important in keeping our nervous system healthy.

Folic acid contains substances which play a role in the pigmentation process and also supports healthy cell division.

Tyrosinase is an enzyme found in the human tissue that helps drive the production of melanin. Homocysteine is a common amino acid in your blood derived from eating meat. High levels of homocysteine in the system slows down the activity of tyrosinase and in turn slows down melanin production.

Therefore B12 works in tandem with folic acid to inhibit the production of homocysteine.

Folic acid can be found in these foods:

- Spinach
- Kale
- Beans
- Peas
- Lentils
- Broccoli
- Some citrus fruits, such as oranges, grapefruit, lemons, and limes
- Fortified grains, such as bread and pasta

Evidence suggests that low levels of vitamin B12 could be a factor in vitiligo for a few people.

This is because there seems to be some association between vitiligo and pernicious anaemia, a condition in which people cannot absorb vitamin B12.

Vitamin B12 is found in most animal products, such as milk and egg yolks, as well as breakfast cereals fortified with it.

If you’re vegan you’ll need to take care that there’s enough of this vitamin in your diet. Fortified foods and supplements are the only proven reliable sources for vegans.

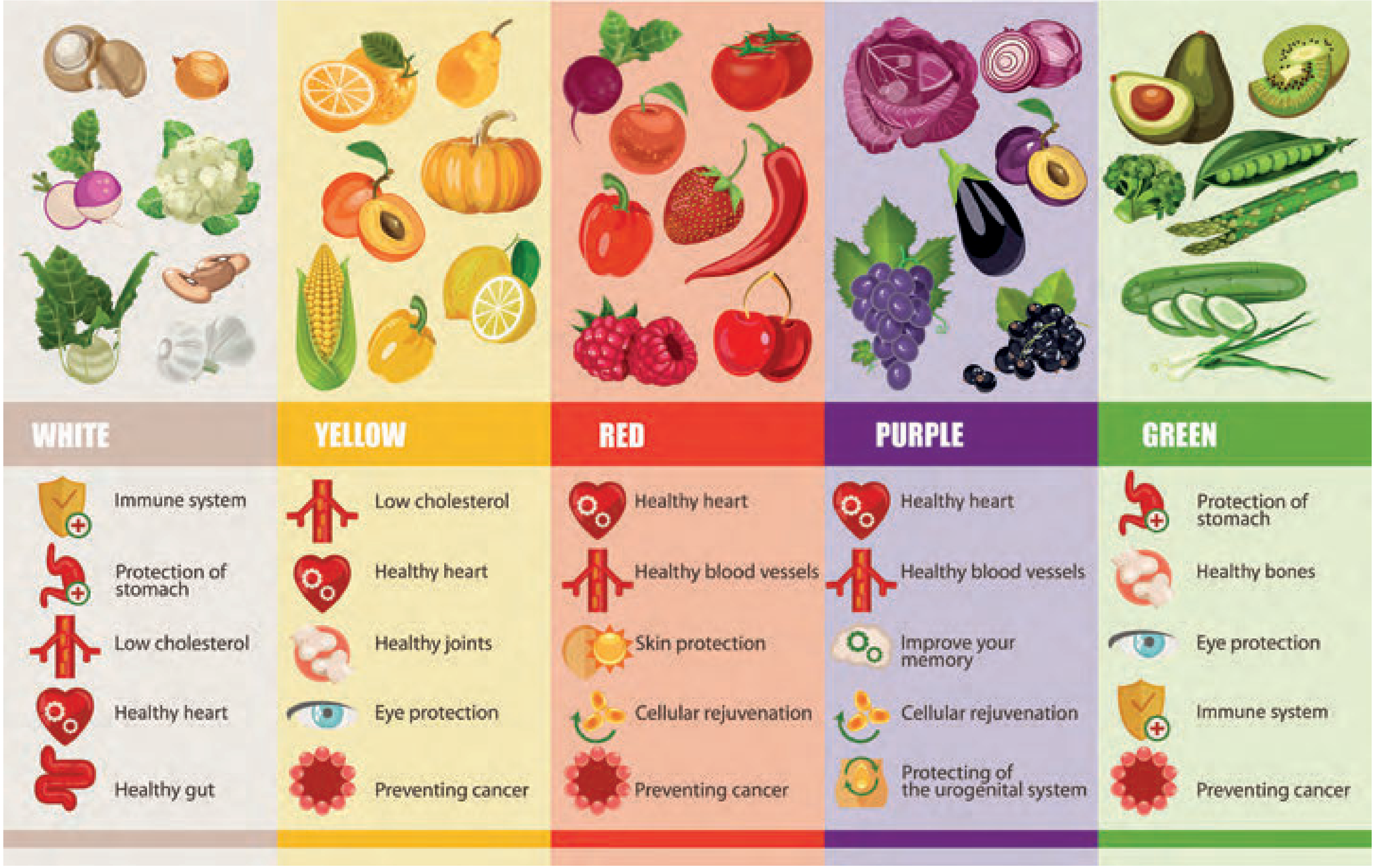
Vitamin C

Vitamin C is needed to keep skin healthy, and it is also needed for some of the enzymes which are involved in skin pigmentation.

Foods that have a high level of vitamin C include these fruits and vegetables:

- Broccoli
- Bell peppers
- Leafy green vegetables
- Tomatoes
- Citrus fruits

You need at least five portions of vegetables and fruit a day. It is better to include more vegetables than fruit, as fruit can be high in sugar. Vitamin C is also an antioxidant. This means that it helps to maintain the body's immune system by controlling agents called free radicals (unstable atoms that can cause damage to cells and lead to illnesses and the aging process) that are the result of metabolic activity. Other antioxidants include vitamins A and E, beta carotene and minerals such as selenium, copper and zinc.
In order to take in high levels of antioxidants to help with free radicals, it is best to 'eat the rainbow'. This entails eating as many different colours of vegetables and fruit as possible, as the different coloured vegetables and fruit contain different levels of certain antioxidants. In fact, there are certain studies suggesting a link between oxidative stress and vitiligo.



WHITE	YELLOW	RED	PURPLE	GREEN
Immune system	Low cholesterol	Healthy heart	Healthy heart	Protection of stomach
Protection of stomach	Healthy heart	Healthy blood vessels	Healthy blood vessels	Healthy bones
Low cholesterol	Healthy joints	Skin protection	Improve your memory	Eye protection
Healthy heart	Eye protection	Cellular rejuvenation	Cellular rejuvenation	Immune system
Healthy gut	Preventing cancer	Preventing cancer	Protecting of the urogenital system	Preventing cancer

Vitamin D

Vitamin D is a hormone that helps the body absorb calcium and phosphates which are vital in the maintenance of healthy bones and, importantly, the immune system.

Low levels of Vitamin D in the body can adversely impact our immune system and there are many studies suggesting a link between low levels of vitamin D and autoimmune diseases such as vitiligo. There is also growing evidence that low levels of Vitamin D may be linked to a number of diseases such as some cancers, diabetes, MS and Alzheimer’s.

The level of pigmentation in our skin can affect vitamin D levels in our body. The cells that produce our skin pigments are called melanocytes and these cells are where vitamin D is produced (or synthesised) when exposed to sunlight.

More than 80% of the vitamin D needed by humans comes through exposure to sunlight. Due to the reliance on the sun, it is common for people to suffer from vitamin D deficiency in climates where the sun is weaker.

In terms of sun exposure, you only need 20–30 minutes a day (two to three times a week) during the summer. The body then can go on to store vitamin D for the winter months. See Chapter 9 Suncare.

If you have darker skin you may also be at risk of vitamin D deficiency because the pigment (melanin) in dark skin doesn't absorb as much UV radiation.

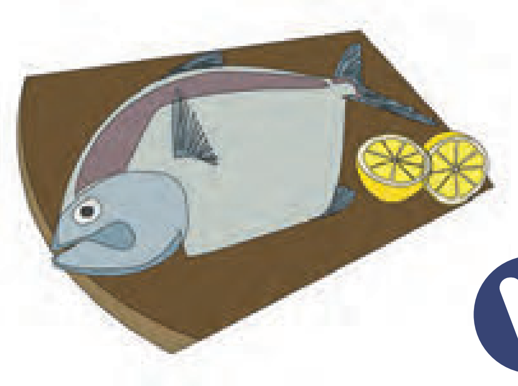
In which case, a supplement may be required to top up.

Here are some other factors that can put you are risk of vitamin D deficiency:

- Obesity
- Old age
- Overusing sunscreen
- Wearing clothes that cover every part of your body

The following foods can supply vitamin D:

- Oily fish (e.g. mackerel, herring, salmon, sardines)
- Cod liver oil
- Liver
- Milk
- Eggs
- Fortified foods, e.g. margarine, some milk powders, yoghurts and some cereals



Beta Carotene

Beta carotene is an antioxidant that converts to vitamin A in the body. Therefore, it is an essential nutrient responsible for keeping the skin healthy. Its antioxidant qualities also help to protect our cells from damage.

Beta carotene can be found in these foods:

- Carrots
- Sweet potatoes
- Dark leafy greens, such as kale and spinach
- Romaine lettuce
- Squashes
- Cantaloupes
- Red and yellow peppers
- Apricots
- Peas
- Broccoli

Do keep in mind that too much beta carotene is not very good for your liver!

Minerals

Minerals such as copper, iron and zinc are all common in the pigmentation process, so they may be an important aspect to consider when it comes to your diet.

If these minerals are lacking in your diet you may run the risk of these deficiencies making the condition worse.
Most foods provide some copper, but it can also be found in the following:

- Nuts
- Offal
- Wheat
- Bran
- Shellfish

Iron is found naturally in these foods:

- Red meat (especially liver)
- Oily fish
- Pulses
- Dark green vegetables
- Dried fruit (especially apricots)

Please note that iron from vegetable sources is better absorbed if eaten with a source of vitamin C. Iron is also added to many breads and cereals. These foods are the best sources of zinc:

- Seafood
- Meat and poultry
- Dairy products
- Eggs
- Nuts
- Pulses
- Vegetables

Are Supplements a Good Idea?

If you have a healthy, balanced diet it shouldn't be necessary to take supplements. Supplements may be a good idea if you have a restricted diet, or if it is found that you have a specific deficiency. You should never take more than the recommended dose.

Some vitamins, notably vitamins A and D, are stored in the body. If you take too much of them, they can be toxic and cause you to feel ill.

Water

Water is a key part of our diet and it is essential that we drink it regularly. It's an important factor in helping the body run efficiently and aiding nutrients to reach the skin through proper blood flow. However, there is no evidence to show that drinking lots of water influences skin hydration or its overall appearance.

To be Clear

Unfortunately, current research suggests that changing the food you eat is not going to cure your vitiligo. However, this may well help if you are not eating a healthy, balanced diet. Such a diet is needed to give you a good supply of the nutrients described above.

You need to eat plenty of fruit and vegetables (at least five servings per day), as well as a variety of starchy foods and proteins. Try to cut down on fatty, rich foods and processed foods, which have fewer nutrients.

A healthy diet, including drinking plenty of water, is good for you generally, not just your skin!

If you have a healthy, balanced diet it shouldn't be necessary to take supplements.

Chapter 8

Skin Camouflage

Skin Camouflage

People cope with and respond to vitiligo in a variety of ways. Many people use camouflage to cover their vitiligo, so that they can get on with their lives without feeling self-conscious in public. However, skin camouflage does not suit everyone.

This chapter aims to give you the facts about camouflage, to help you decide whether it may be an option for you.

Remember skin camouflage does not suit everyone.

What is Skin Camouflage?

Skin camouflage is not ‘make-up’, they are specialist creams and powders that are highly pigmented – used to cover up your vitiligo patches as well as other skin conditions. Camouflages are made in a wide range of skin colours so that they can be matched to your natural skin tone, otherwise known as ‘skin tone matching’.

Camouflages cannot alter the texture of the skin, nor can it cure vitiligo. What it can do is to make the white patches seem less noticeable. Even when the camouflage is not an accurate skin colour match, it can help stop people staring, making comments or asking questions.

The range of camouflage products can be used by men, women and children, irrespective of age, religion, nationality and skin classification group. Although it is not usually recommended for babies or very young children unless suggested by their doctor.

The products are suitable for you to use yourself; however, initial training is advisable in order to apply them properly. You can visit ***The Vitiligo Society website*** to find out more about organisations offering training as well as tips on applying skin camouflage.

For some people, using camouflage is a long-term lifeline. You may want to wear it all the time, especially when you start to develop vitiligo and are adjusting to having the condition.

Alternatively, you may want to use camouflage only on special occasions.

Whether you wish to try this technique is entirely up to you – how you wear it or indeed if you wear it is your choice.

How you wear Skin Camouflage or indeed if you wear it is your choice

What Is Special About Skin Camouflage Products?

Some make-up products can be very effective in masking the white patches, but they do not have all the necessary properties of skin camouflage.

When correctly applied, skin camouflage is waterproof, which means you can go swimming, take a shower or have a bath without it coming off.

The products have sun screening properties, although no skin camouflage should be considered a full sunblock. They certainly should not be relied upon as sun protection for the whole day. Non-greasy sun protection can be applied underneath the camouflage and reapplied over it throughout the day.
For those who like to wear make-up, it can be applied over the camouflage.

Depending upon the brand chosen, an application of skin camouflage should stay in place for up to four days on the body and 12 to 18 hours on the face.

Can Skin Camouflage Damage the Skin?

For hygienic reasons, it is recommended that camouflage is removed daily and the skin is cleansed, but camouflage products can be immediately reapplied.
There is no current evidence that skin camouflage creams encourage spots, damage the skin or encourage vitiligo.

How Do I Get Skin Camouflage Products?

Skin camouflage involves applying a cream, which is fixed by a setting powder. There are currently four brands available from the UK's National Health Service (NHS) prescription, at doctor’s discretion, all with similar ingredients:

- Covermark
- Dermacolor
- Keromask
- Veil

These brands can also be ordered without a prescription directly from the supplier. The creams and powders cost a little more than the average cosmetic, but a small amount covers a large area of skin, which makes skin camouflage cost-effective

Outside of prescription, there are other brands of skin camouflage products available on the internet and over the counter in some shops. These may give an identical outcome to those listed above, but you really need to see the colours on your skin to achieve an acceptable skin match. This can be difficult in your local department store or pharmacy.

Remember too that products available in the UK have to be licensed for sale and must comply with EU legislation and regulations; not all products available elsewhere carry such a safety standard.

If you don't live in the UK, check with your local vitiligo charity or support organisation to seek suggestions on camouflage options.

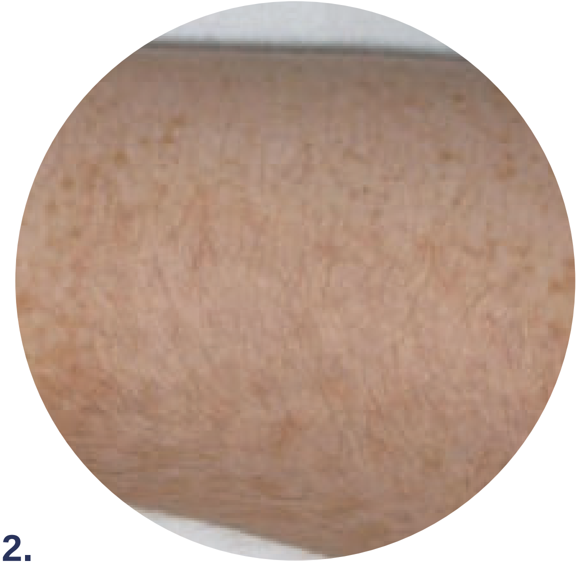
Getting Advice About Skin Camouflage

It is recommended you seek the advice of someone trained in skin camouflage in order to help you with the following:

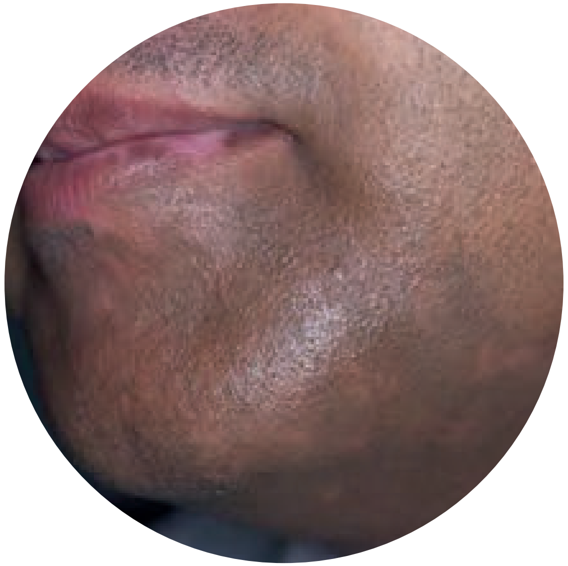
- Choose the best product for your skin and lifestyle.
- Obtain an acceptable skin colour match for your skin. Ideally, one cream and one powder should be all you need. If your skin changes colour with the seasons, then it is better to see the consultant during the height of summer for a skin match. The consultant will then give you an additional colour to the skin tone for you to mix and create the autumn, winter and spring skin colour. An extra colour will also be needed if your vitiligo spans skin that is two-toned, for example to the inner and outer side of your arm.
- You may need an additional colour if you have multiple freckles (photos 1 & 2), or beard shadow (photos 3 & 4).
- Learn how to apply camouflage. Most people find the quickest and easiest way to apply their camouflage is with their fingertips (photo 5) but you can use a brush or cosmetic sponge if you prefer. You then need to use a powder puff to apply the setting powder (photo 6), as this will ensure that you press and roll the powder into the cream. A cosmetic brush is a useful tool to dust off excess powder (photo 7). Using a fixing spray (photo 8) will make the camouflage application more secure. This can be an important part of the application routine when the camouflage is used on very personal areas of the body. Once you have learnt the technique of applying camouflage, it should become quicker and easier to do (photo 9), adding just a few minutes to your usual hygiene routine.
- Learn how to maintain and remove the camouflage quickly. You will need to know how to maintain the camouflaged area during wear, what might accidentally remove the camouflage and how to remove the products quickly and effectively.

Camouflage is difficult to remove from head hair, so care needs to be taken when working close to the hairline. It is easily brushed off from eyebrows and fine hairs from your limbs and body.

Before (1) and After (2) applying multiple freckles



Before (3) and After (4) applying beard shadow



Application using fingertips (5)

Powdering (6)

Brushing off excess (7)
Applying fixing spray (8)

finished result (9)

“I’ve lived with vitiligo for most of my life. In fact, I lost 100% of my skin’s pigment to the condition. Growing up, I put on a courageous smile but inside, I was struggling – battling the bully in my mind and an ever-shrinking self-esteem. I wanted nothing more than to be ‘normal’.

Today, more than two decades after that first spot appeared, it’s a different story. I’ve finally found happiness. It started by taking one small step towards loving my skin (an accidental trip to the grocery store without makeup) and snowballed into a desire to face my fears head-on.

Here’s what I learned: You can’t skip the hard parts. But if you’re seeking a better way of living with vitiligo, you can have faith that your strength and desire for ‘more’ is going to get you there”.

Erika Page
Founder & Editor-in-Chief
Living Dappled
https://livingdappled.com

Top left © Rachael Laurin / top right & bottom © Shawna Simmons

G-SHOCK

Chapter 9

Suncare

Suncare

Most people with vitiligo need to take extra care of their skin in warmer weather because they are particularly vulnerable to sunburn.

How the Sun Affects Vitiligo

People with vitiligo are more vulnerable to sunburn because their white skin patches have no natural protection against the sun's rays. 'Normal' skin is protected by melanin (skin pigment); the effect of the sun is to increase melanin production and to turn the skin brown to protect it from burning. This does not happen in vitiligo patches, where melanin is either absent or inactive.

If you do not protect your patches, it is likely to burn quickly. The areas most at risk are those where the skin is thinnest, for example, eyelids, nose, neck, the upper part of the torso such as the neck, shoulders, back, and the backs of the hands. Not only is sunburn painful, but it may also stimulate the vitiligo to spread in some. Sunburn also increases the risk of skin cancer.

It may not be practical or necessary to avoid sun exposure completely. Also, some sunlight is needed to keep healthy as it is your main source of vitamin D. So you should spend short times in the morning or late afternoon outside when the sun is not so strong (no more than 20–30 mins).

The solution is to take precautions to protect the skin from sun damage. Having vitiligo should not stop you from taking outdoor holidays in warmer climates.

Effective Sun Protection

Sunblock or Sunscreen Products

You need to choose a sunblock or sunscreen product that protects you from the ultraviolet light in the sun's rays.

There are two types of rays:

UVA are long rays which penetrate deep into the skin and can cause dryness and wrinkles, as well as contributing to burning. On sun protection products, the extent of protection against UVA rays is indicated by stars. Vitiligo skin requires at least four stars UVA protection (****).

UVB are medium length rays which are mainly absorbed in the upper layers of the skin. They are the main cause of sunburn. On sun protection products, the extent of protection against UVB rays is indicated by the Skin Protection Factor (SPF) number, which ranges from 2 to 50+. Vitiligo skin requires at least SPF 30. There is little evidence that SPFs of over 30 provide any additional benefit.

You also need to make sure that your sun protection product is water-resistant or preferably waterproof if you are going in the water. Waterproof products give longer protection than water-resistant ones. Also, remember that the sun can penetrate water to a depth of 10 metres.

Some brands of sunblock are classified by The UK's National Health Service (NHS) as substances which can be obtained through a prescription from your doctor.

Applying Sunblock or Sunscreen Products

The effectiveness of any product depends on it being applied correctly, so it is imperative that you follow application direction on whatever product you use. This will tell you the amount to use and when to apply before exposure to the sun.

You may find it easier to apply your sun protection before dressing, for example around the neckline and arms. You also need to remember to reapply your sun protection during the day, approximately once an hour, to make sure that you continue to be protected. Make sure you also use a product on your scalp, if you have thinning hair and lips.

You can keep unused sunscreen for the following year by storing it somewhere cool and dry, but ensure you keep an eye on the expiry date.

Other Measures

To avoid burning, it is important not to rely too much on sunblock.

Some UV rays will go through any sunscreen. You can also protect your skin by wearing loose cotton clothes, such as a long-sleeved shirt over a sleeveless t-shirt, which may be the most comfortable.

Try to avoid wearing uncomfortable synthetic fibres and tight tee-shirts especially in hot humid climates. Wearing a sunhat and sunglasses will also help to prevent sunburn, as well as keeping in the shade, especially at the hottest time of day (11 am to 3 pm).

This is particularly important for children, and especially babies, whose skin is so delicate.

Sunlight Facts to Consider

It is important to ensure you are prepared when living in or venturing to warmer climates. So here are some facts to consider:

- Snow, sand and water can reflect up to 85% of the sun’s rays. Even in the shade, you can be exposed to 50% of the surrounding sunlight through reflection.
- Sunlight gets stronger the nearer you get to the equator.
- Sunlight is also stronger at high altitudes, a point to remember when skiing.
- Sun rays can penetrate quite dense clouds, so it is possible to burn even when you feel cool. A cold wind will not protect you from sunlight either. Be particularly careful in the seaside climate of sun and wind as – the coolness of the wind can distract you from the power of the sun.

Snow, sand and water can reflect up to 85% of the sun’s rays.

Chapter 10

Guide for Parents and Carers

Guide for Parents and Carers

This chapter aims to help you support your child with vitiligo. Of course, all children are individuals and they will not react in exactly the same way to having the condition.

However, each child is likely to have similar problems and face similar challenges as a result of having vitiligo. You are not alone, other people are facing similar issues even if the visible differences are not exactly the same.

Some common issues are discussed here to help you in supporting your child, whatever stage of development they may have reached.

All children are individuals and they will not react in exactly the same way.

Talking to Your Child About Vitiligo

It may be difficult for you, as a parent or carer, to talk to your child about vitiligo because of your own feelings about the condition. It is also important that you recognise your own feelings towards vitiligo as this may be an emotional time for you also. So if you feel like you are struggling, do speak to a healthcare professional.

You can also join supportive groups like ***The Vitiligo Society Parents' Support Network***

The better you cope with your child having vitiligo, the easier it will be to help your child deal with it. It is important that you talk to your child in a matter of fact, confident way about their appearance. This can help ease fears before they arise and assist your child in feeling more secure and confident.

You may have found ways of discussing your child's condition if they have lived with it from an early age. However, a recent change in appearance may need a new language to talk about sensitive and painful issues in your lives.

The following tips may help you both:

- Use the medical terms to describe the conditions as it will help familiarise your child with all aspects of vitiligo.
- Describe how vitiligo does and does not affect them.
- Use words that describe the colour, shape and texture of the vitiligo patches.
- Keep it honest and simple. Always assure your child that the change in their skin colour makes absolutely no difference to the way you feel about them.
- Remind them that if their vitiligo is visible e.g on their face; people may be looking at them for a different reason, i.e to determine facial expressions.

It is important that you talk to your child in a matter of fact, confident way

Answering Questions About the Causes of Vitiligo

As your child gets older, they will probably want to know what causes vitiligo and whether the condition will be passed on to their own children. This is a very difficult question to answer and will be dependent on their understanding of genetics and how they work. It will help if your child has already learned about how children inherit genes from their parents.

Again, you will need to be honest; that at the moment no one can answer that question. You can inform them that it doesn't mean their children will definitely get vitiligo, just because they themselves have the condition.

However, how likely it is that vitiligo is passed on depends on how many family members have the condition. How children inherit genes may be best explained in terms of inheritance being like a lottery. A person has about 30,000 genes, inherited in a random fashion from both parents, rather like numbers being picked in the lottery.

These genes can result in a very large number of different combinations, only some of which will give children the potential to develop vitiligo.

Even if a child inherits all the vitiligo genes, it is not inevitable that they will develop the condition. Chance and environmental factors influence whether the vitiligo develops.

Other Siblings

Having a child with vitiligo can warrant a lot of attention and time especially when trying to manage medical appointments and juggling daily life. This can be even more demanding if you have more than one child. However, it is important to keep other children in the loop and part of the process, especially as they may have concerns of their own, such as:

- Will I get vitiligo too?
- Will people stare at us when we are out together?
- Will my brother/sister get sick?

The way you respond to answers will need to be tailored to age. The most important thing is to keep it honest and keep it simple.

The discussion around vitiligo should be ongoing and not a one-time major discussion never to be had again. The condition is unpredictable and will create new emotions if new patches develop or skin develops new pigmentation.

Helping Children Express Their Feelings About Having Vitiligo

Whether you are talking to your child who has vitiligo or their siblings there are some key methods you can follow to help navigate your way through some of the conversations or questions they may have.

- Try to remain neutral and not judge any questions or answers your child may have or give. This is a perfect opportunity to correct any misinformation.
- Allow your child to finish speaking before you correct any errors.
- Ask your child some questions about what they know about the condition.
- Compliment and praise your child for sharing their feelings and coming to you with any questions. You want to foster an environment where they feel at ease and safe to communicate with you in regards to the condition.
- Be prepared to deal with a range of emotions. These are all normal and your child is allowed to go through these feelings so try and stay calm and once again, neutral.

Helping Children Develop Their Confidence

Your child may experience doubts about their gifts and abilities. Their goals and ambitions may be hindered by thoughts of

“I can’t join in with that”

or *“I don’t think I can learn to do that.”*

You can challenge these negative thoughts by talking through a more positive approach with your child.

You can give your child and yourself a confidence boost by having something reassuring to say such as:

“I will be okay.”

“I have done this before and I can do it again.”

“I will ignore those who stare. I will smile and show them I am okay.”

“I am good at (games/music/sport etc.).”

“I am happy with myself and my family and friends love me.”

“I am amazing and my family is proud of me.”

It is important to acknowledge your child’s positive talents and personality traits to develop their self-esteem and in turn boost their confidence.

Support their talents, hopes and desires as far as possible by giving them opportunities to participate in relevant activities.

You can also help your child by:

- encouraging them to read books that celebrate being different, instead of stories which suggest that ‘beautiful’ is always good and ‘ugly’ is bad
- creating opportunities to enjoy a full social life by inviting friends around to play.

Dealing With Other People

You can help your child develop good relationships with other people by telling them yourself about your child’s vitiligo.

You cannot assume that teachers, parents and other adults will know about the condition, for example, that it is not infectious or contagious. Make sure that they understand both the physical and psychological aspects of vitiligo.

These adults will then have the information to give to their children, which will help them understand your child better.

This is easier when the children are younger, but at some point your child will be asked questions when you are not there to provide the answers.

Discussing possible situations in advance will prepare and equip your child to deal with questions about their vitiligo. Possible ways to introduce this might be:

“I’m wondering what you might want to say to children or people who ask about your vitiligo? Would you find it helpful to practise some things you could say?”

You can help your child to become familiar with simple phrases such as:

“It’s called vitiligo, you can’t catch it” or “It doesn’t hurt, it just makes me two colours instead of one.”

Try practising these simple conversations until your child feels more confident and able to manage. Also, helping them to use their own words will empower them to deal with what may be an uncomfortable situation.

When a situation arises, you can ask afterwards, *"How did that feel to you?"* If it did not go well, you can help your child find a different way of dealing with the situation next time. Suggestions as to what children may say are included in ***Chapter 11 Guide to Vitiligo for Children and Teens.***

It is always difficult to find a balance between giving your child the space to be independent and giving advice about what to do. As they get older, they need the confidence to deal with difficult situations on their own, at the same time as knowing that you are there for support and help when needed.

Bullying

An important part of any child's education is learning about and accepting differences in people.

This should go some way to reduce bullying and teasing.

Most teachers will be glad of the opportunity to include vitiligo in classroom discussions and so increase the children's awareness and understanding of the condition.

You may find it helpful to give your child's teachers a copy of this ebook, pointing out ***Chapter 12 Guide for Schools.***

You will also need to talk to them about how vitiligo affects your child in particular. Ask the school to give this information to all the adults, including meals supervisors and classroom assistants, so that they can deal with any problems that may arise.

Unfortunately, name-calling and bullying are common among children, particularly those who are different in some way. A child may be picked on simply for wearing glasses, height, hair colour or having a skin condition such as vitiligo and this can be very distressing.

You need to tell your child that bullying should not be accepted and that they should tell the nearest adult about it. If the bullying is happening in school, you should expect this to be dealt with as soon as an incident is reported.

If you are not happy with how any bullying is handled, make an appointment with the class teacher or tutor to discuss your concerns.

Playing Games and Sports

Children with extensive vitiligo may find games and sports particularly stressful. If this applies to your child, talk to the teacher concerned about how this can be managed.

Fake tans can be a very helpful way of disguising the patches so that your child does not feel self-conscious about taking off their clothes.

Getting Medical Advice

As you may know, going to the doctor or specialist with your child can be very stressful. You will probably be discussing their vitiligo in front of them, which may cause your child distress, especially if they are not fully prepared to see the doctor. It is advisable to discuss the visit beforehand and write down the questions you (or your child) want to ask before you go.

As a parent, you will naturally want to get the best treatment for your child and try every medical option open. However, you need to be aware that your efforts to find a treatment may be misunderstood by your child. It is possible that they may think that this means you are ashamed of their condition and ultimately that you don't love them. It will be beneficial to review some of the treatment options beforehand with your child and understand if they want to try any of the options. Ultimately, your child should understand that accepting vitiligo and not treating it is also an option and that they will have your support.

You can help your child cope with concerns about vitiligo by making them feel secure and loved for who they are. The more confident they are in managing any difficulties they have, the more positive they will feel about the future.

Treatment options are discussed in ***Chapter 3 Treatment Decisions.***

The more confident your child is, the more positive they will feel.

“I developed vitiligo when I was 30 years old and it now affects around 50% of my body.

Being an international DJ and Producer has naturally meant my life has been played out under the spotlight. There were occasions when I would look at my vitiligo and question how I felt about people seeing it. I wondered whether people were judging me because it was different. After feeling like this for some time, I finally came to the realisation that ‘I am who I am’ and accepting myself is the most important thing of all. It was at that moment that I started to wear my vitiligo as a badge of honour.
For me, the key is not being afraid of how people see you. I’m no longer affected by other people's opinions. How you feel about your skin is what matters and never allow it to hold you back from your ambitions in life”.

Simon Marlin
Global DJ, The Shapeshifters

Chapter 11

Guide to Vitiligo for Children and Teens

Guide to Vitiligo for Children and Teens

This chapter suggests some ways for you to deal with any difficulties you may experience. We hope it will also help you with worries or concerns that you may have about having vitiligo.

The information is based on the experiences of people with the condition, to help you understand your reactions and to reassure you that you are not alone in facing the challenges that vitiligo can present.

Lots of people have it; you are not the only one!

Vitiligo Recap

You may know the following about vitiligo:

- Vitiligo means having white patches on your skin and sometimes your hair.
- Lots of people have it; you are not the only one!
- It does not hurt you.
- It's not infectious; you cannot catch vitiligo and if you have the condition you cannot pass it on to someone else by touching them. Vitiligo can begin at any age but about 50% of people develop it before the age of twenty.
- Anyone can develop vitiligo, whatever their skin colour or ethnic origin. It affects at least one – four people in every hundred throughout the world, including in the UK.

Why Do People Have Vitiligo?

This is a difficult question to answer because scientists and doctors do not yet fully understand the causes of vitiligo. People can be born with all sorts of different conditions, or they can develop them later. To some extent, it seems to be due to the genes someone inherits from their parents, but there are also environmental factors involved.

The development of vitiligo may be triggered by several factors, including:

- Hormonal changes in the body, for example during puberty.
- Damage to the skin, for example from a cut or sunburn.
- Increase in stress levels.

There are three important things to remember:

1. Everybody is different. Just take a look around at your classmates, they all look different. They will have different hair, eyes, noses, mouths and skin. Some will be tall, others short, and so on. Apart from identical twins, no two people have the same facial features, height and build.

Very often, especially in adolescence, we are critical of our own appearance, wishing that we had blonde hair rather than brown, a smaller nose, fewer spots, etc.

But you know what... everyone else has these thoughts too.

2. How you look is only one side of you – your personality is also very important. You may usually be happy, like being with other people, be quite serious or enjoy your own company. All of these traits are just fine and make you who you are. There is no right or wrong way to be, we are just different.

3. Media images can be misleading. It can be difficult not to be influenced by the images of ‘good looking’ models and celebrities who give the impression that looking like them is the only way to feel good. However, remember that often these images are fake, altered to make people look more attractive than they actually are. It is not true either that someone is seen as ‘beautiful’ is necessarily happy. There is a lot of pressure on us to look good. But that doesn’t mean that we should all look the same.

Everyone is different and that’s OK!

Coping With Vitiligo and Dealing With Unwanted Attention

Being self-conscious or lacking confidence is something that everyone feels, especially in adolescence. The physical and emotional changes involved in changing from a child to an adult can be very difficult to deal with.

People your age, whoever they are, have concerns about their looks, their identity and what life in the future will be like.

If you have vitiligo on your face, remember that people may be looking at you for more than one reason.

They may be talking to you and looking at the expression on your face, to work out what you are thinking. Looking at someone’s face is a way of showing that you are listening to them, or it may be a way of communicating an idea to them.

However, people do look more at other people when they are different or special in some way. Often people are just being curious, maybe because they have not seen vitiligo before.

- You can tell yourself it is OK for people to look, especially if they are giving you a smile at the same time.
- Looking is OK but staring is not. However, sometimes people stare and they do not even realise they are doing it.
- If you think someone is staring at you, try giving them a quick smile. This is a way of letting them know that you have noticed their stare. They may be embarrassed and think before they meet you next time.

Help With A Positive Approach

We are here to help you change the way you think about yourself. For tips and methods on how to do this, see ***Chapter 5: A Positive Approach.***

The chapter will teach you how to do three things:

- Think positively
- Act positively
- Talk positively

What Can I Say if Someone Asks About Vitiligo?

When you look a bit different, you may be asked questions. You may find it difficult to answer questions at first, but don't worry – you are not alone.

Here are some tips for when someone asks you a question about vitiligo, and you feel like answering it.

Explain Simply What Vitiligo Is

You could say, *"It's just the way my skin is"* or *"It's called vitiligo and it affects my skin."* People don't really need to know any more unless they are a friend and you would like to continue the discussion.

Reassure them that vitiligo does not hurt. People may be concerned about you, so you could say, *"It's just a condition on my skin. Don't worry – it doesn't hurt me."*

Reassure them that they cannot catch vitiligo: To stop the person feeling worried about vitiligo, all you need to say is, *"It's called vitiligo, it's not catching."*

If Someone Is Asking Too Many Questions

Try distracting their attention. Distraction involves changing what you are talking about.

You can turn the conversation around by asking them a question about themselves. This takes the attention away from you, like this for example:

Peter: *Hi, what's your name?*
Amelie: *Amelie, what's yours?*
Peter: *It's Peter. Why does your skin look like that?*
Amelie: *It's just the way my skin is. It's called vitiligo.*
Peter: *When did it happen? Will it go away?*
Amelie: *I am not sure, but what lesson have you got next?*
Peter: *I have maths.*

Try being assertive. A strong voice and posture (shoulders back, head held up high) and firm words will help you to be assertive without being aggressive or nasty.

You could just say, *"Would it be OK if we talked about this another time? I don't really feel like answering questions today."*

What if Other Children Are Unkind About My Vitiligo or Bully Me?

You may, unfortunately, meet children who are unkind about people who are different. They are often people who feel sad about themselves for some reason. These people are bullies and may pick on other children who are different in some way – for example, because they wear glasses, or are short, not only because of having vitiligo. But there is no excuse for anybody to make you feel unhappy or upset about your vitiligo.

Bullying often happens in school and your school will have a bullying policy to deal with it. If you ever have a problem with someone making you uncomfortable or upset, you need to tell a teacher or another adult.

The adult should talk to the person who has made you unhappy, or ask someone else to do this. The bullying should be stopped, for the sake of the bully as well as yourself.

Your family will want to know if something has happened at school, so that they can help you too.

What Can I Do if I Am Feeling Sad or Worried?

Everybody feels sad or worried at times. As we are different people and deal with feelings differently.

You may be someone who likes to be on your own when you are feeling sad.

However, remember the following:

- It is usually best to talk to someone and share your feelings. This may be a friend, a parent or another adult, such as your teacher.
- There are counselling services if you find it difficult to talk to your friends and family about your feelings. Some people find it easier to talk to someone who is not directly involved in their life. Your school will know about these services.
- ***Use guided meditation to help restore a sense of calm.***
- It may help to have a self-motto, something that you can tell yourself when you are feeling sad or worried about something. You could say, *"I am great just the way I am,"* or *"I can deal with this because I know I am OK."* Use your self-motto when you find yourself in a difficult situation, maybe when you have been asked to read something out loud in class.

Chapter 12

Guide for Schools

Guide for Schools

This chapter aims to help you explain what vitiligo is to your pupils and support any child in your school who has this condition.

As education professionals, you have a very important role in making sure that children with vitiligo are fully included in the school and are given any support they need.

Of course, all children are individuals and they will not react in exactly the same way to having vitiligo. You will need to find out from the parents/carers about how the condition has affected their child.

The main problem that children with vitiligo have to face in school is the reaction of other pupils to their appearance. Once children become aware of visual differences, they are likely to stare, make comments and ask questions about anyone who looks different.

Without the intervention from school staff, this kind of attention can become quite distressing for a child with this condition.

It may even develop into bullying, impacting on a child's psychological well being.

As education professionals you have a very important role

Explaining What Vitiligo Is to Your Pupils

Giving pupils the basic facts about vitiligo should reduce the need to ask questions directly to children with the condition. It should also reduce incidents of bullying if students have more understanding about the impact vitiligo can have.

When providing your students with information about this condition you may want to refer to ***Chapter 1 What is Vitiligo?*** and ***Chapter 11 Guide to Vitiligo for Children and Teens.***

How Are People Affected by Vitiligo?

Although vitiligo does not hurt physically it is not to say children will not feel the effects in other ways. For example, children with the condition are likely to be affected psychologically, especially if they do not feel supported and valued.

Concerns and anxieties about having a different appearance can lead to symptoms of distress, such as underachievement and withdrawal from school activities.

It is also important to note that vitiligo can be brought on or made worse during stressful times, so you may want to consider this during a period such as exams etc.

Be Prepared to Talk to a Child About Vitiligo

Children may want to talk to adults at school about issues concerning their vitiligo. It is important that you acknowledge their concerns and talk to them in a matter of fact and confident way about their appearance.

A child with vitiligo may need reassurance that the change in their skin colour makes no difference to the way adults at school feel about them.

If you are concerned about the psychological wellbeing of a child with vitiligo, it may be appropriate to refer them to a counselling service, after consulting their parent/carer.

Including a Child With Vitiligo

As with any child with difficulties, emphasising their strengths and making sure that they are included in school activities will build up confidence and self-esteem. If they seem withdrawn, it may be appropriate to create opportunities for a child with vitiligo to socialise with the other children.

Depending on the age of the children, working on challenging stereotypes of beauty will be a valuable way of including a child with vitiligo. It is helpful to encourage the class to look at materials that celebrate being different, in contrast to those which suggest that ‘beautiful’ is always good and ‘ugly’ is bad.

PE Activities

Be aware that there may be particular issues in PE. A child with vitiligo may be reluctant to change their clothes in front of other children, or they might not want to participate in an activity like swimming.

You will need to discuss strategies for managing these difficulties with the child’s parent/carer.

Skincare in Hot Weather

You need to be aware that a child with vitiligo will probably need to take extra care when their skin is exposed to sunlight.

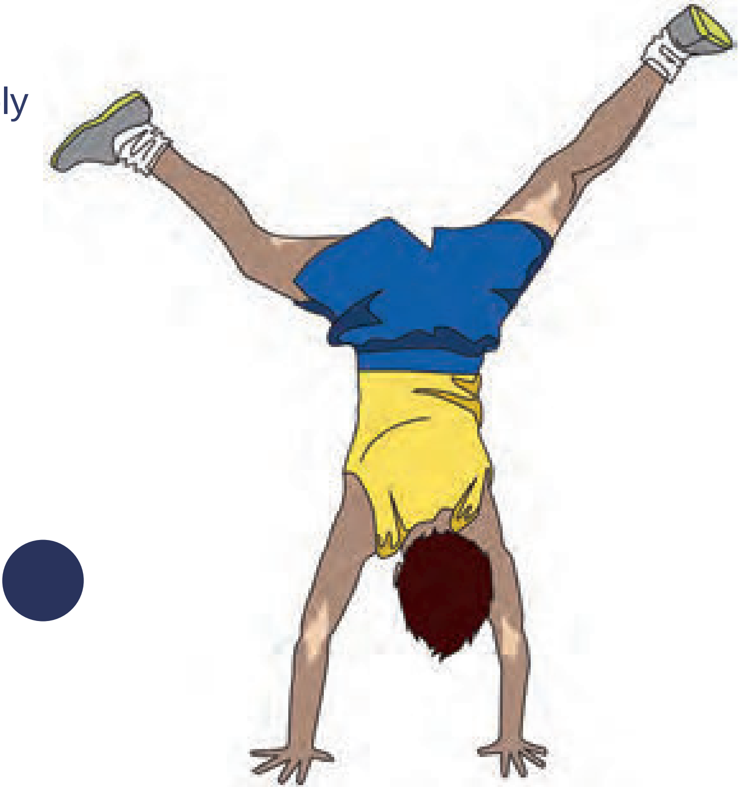
Most people with vitiligo are particularly vulnerable to sunburn. Not only is sunburn painful but it might stimulate the vitiligo to spread in some people.

It is therefore important to make sure that children with vitiligo:

- wear a sunhat
- use sun protection creams or lotions
- are encouraged to keep in the shade, particularly at the hottest time of day.

Dealing With Bullying

The school’s bullying policy will apply to all instances where children are picked on by their peers. It will be useful if all staff, including meals supervisors and classroom assistants, have information about vitiligo to help them deal with problems arising from a child living with this condition.



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Resources

Vitiligo Research Foundation

British Skin Foundation

Changing Faces UK

Living Dappled

The American Vitiligo Foundation

VSTRONG Detroit

Vitiligo Support International - USA

VitFriends

ARIV Onlus - Italy

Association Française du Vitiligo - France

Asociación de Pacientes de VITILIGO de España

Deutscher Vitiligo-Bund e.V. - Germany

LVVP - Holland

SPVG - Switzerland

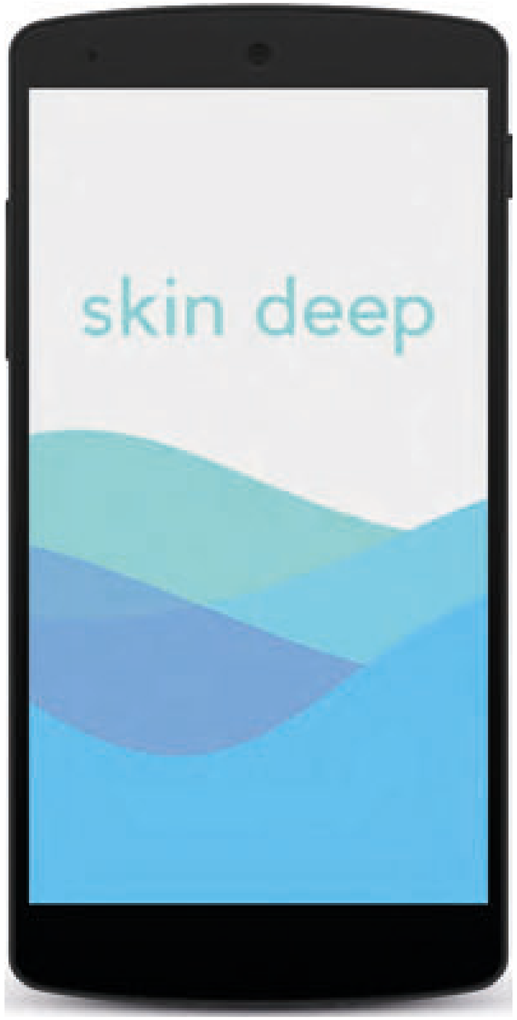
Svenska Vitiligoförbundet - Sweden

Vitiligo Association of Australia

Vitiligo Society of South Africa

Vitiligo Norge - Norway

To have your organisation added to this resources list, please email **ebook@vitiligosociety.org**



you are more than Skin Deep

We, The Vitiligo Society, are currently developing an Android and iOS mobile app to provide emotional support to those living with skin conditions including vitiligo. Research has shown that meditation can supplement the skin treatment process, reduce stress and anxiety and decrease depression by improving self-image.

Skin Deep will provide:

- Therapeutic support for dealing with difficult emotions
- Professionally scripted meditations by certified Psychologists
- Choice of male or female voice and accent to suit your taste
- Reminders notifications to build a regular meditation practice

Price? Totally Free.

Be the first to download Skin Deep upon release, by signing up ***here***

Further Information

If you would like further information about vitiligo, please look at The Vitiligo Society website:
https://vitiligosociety.org

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