



# Making decisions about available treatments

The aim of this eBooklet is to help you think through the choices that are available to you. It includes:

- the factors which might influence your decisions.
- information about conventional treatments available on the NHS (creams and light treatments) and less common ones, bleaching and skin grafts.
- information about treatments available privately – recell, laser and ‘complementary’ medicines.
- when you might consider counselling.

# Making treatment decisions

There is no reliable cure for vitiligo yet. Available treatments focus on slowing its progress, concealing the white patches or trying to bring about repigmentation, which is unlikely to be complete or permanent. Vitiligo may even get better by itself in up to 50% of affected individuals.

This uncertainty about what may happen with vitiligo leaves you with a range of choices about what to do. This is a very personal decision, informed by a number of different issues, such as:

- What you feel about your vitiligo.
- How it is affecting your life.
- What your family/partner thinks about your condition.
- What your skin colour means to you.
- How your community responds to your vitiligo, and what would be their reaction to a total change in skin colour?
- Medical risks and side-effects of treatments.
- Availability of non-medical solutions which could help you manage more easily.

WHAT ARE MY  
**my options?**

- Decide that you can live with it as it is.
- Ask your doctor about available treatments.
- Use camouflage products to conceal the white patches.
- Seek counselling or psychological support if you are very distressed.

## Getting good information

You need good information to make decisions about your vitiligo. There is a range of options for treating the condition; it is important that you fully understand what treatments are and how they might affect you.

Some people find speaking to health professionals about their condition very difficult, especially if their confidence is low. Possibly writing things down before your appointment 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.

We hope that the information from the Vitiligo Society will also help you to make choices about how you want to manage your vitiligo.

## Treatments

No complete cure for vitiligo has been discovered yet, but there are treatments which can slow down or stop its progress. In some cases, treatment can bring about complete repigmentation.

They may not work on all areas of the body and treatments do not work for everyone. If colour does return to the white patches, there is still a risk of the vitiligo coming back at a later date. 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 more responsive to treatment.
- Using treatments when vitiligo first develops is more effective than later on.
- Small areas are easier to treat than larger ones.

# WHAT DOES THE **treatment** INVOLVE?

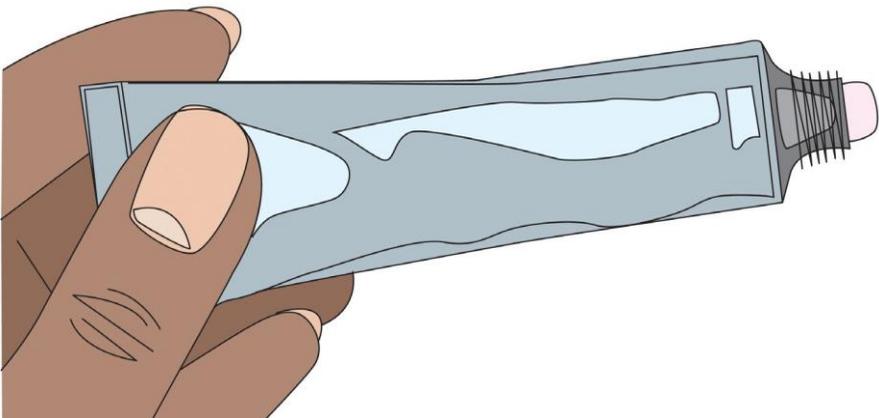
## **Creams**

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

### ***Steroid creams***

Steroid creams are the most common treatment offered on the NHS for vitiligo. These are creams which are used to treat inflammatory conditions of the skin.

Vitiligo is considered to be an 'autoimmune' condition, in which the immune system attacks the body's own tissues. Steroid creams can stop this happening and therefore stop the progress of vitiligo. They are classified as mild, moderately potent, potent or very potent. The doctor will generally prescribe the most appropriate cream that will treat the condition.



You will probably have a trial period of using the cream of up to two months. This is to make sure that there are no side effects. 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 be applied to the white patches of your skin thinly. 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 three months) before any results are likely to be seen.

## The advantages and disadvantages of steroid creams

- Steroid creams are simple to use and a treatment you can do at home.
- Creams are quite safe, so long as instructions are followed.
- 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.

## *Protopic ointment*

**Protopic** (also known as **tacrolimus**) **ointment** is a treatment that has mainly been used for eczema. Recently, protopic has also been used in clinical studies for the treatment of vitiligo. It is made from a rare soil bacterium found only in Japan.

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. Protopic ointment has proved quite effective on the faces of some people who have vitiligo, when the loss of pigment is relatively recent and still active. Like steroid creams, unfortunately protopic does not work for everyone.

Protopic can be prescribed by GPs for vitiligo, although it is not licensed. Often a dermatologist may recommend it but ask the GP to actually prescribe it.

**Elidel** (also known as **pimecrolimus**) is a similar product to protopic, but it is in a cream form.

WHAT DOES THE  
**treatment**  
INVOLVE?

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

## **The advantages and disadvantages of protopic / elidel**

- 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 three to six months before there is any improvement.
- Even when white patches have re-pigmented, 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 below). In some studies, this combination has shown enhanced pigmentation but further work is needed to establish safety standards for this treatment.

## Light treatments

Light treatments can be very effective, but people react differently to these treatments, 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 improvement, a course of treatment is likely to be long; often it can last 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 THE **treatment** INVOLVE?

Light treatment is given by a machine which 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 wrap-around goggles to protect your eyes. You should also avoid looking directly at the rays of light.

**There are two types of light treatment:**

### ***1. PUVA treatment***

This treatment is used in some hospitals. It involves taking medication as well as light treatment. The letters PUVA stand for Psoralen and Ultra Violet light A. 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 substances include some medicines, including complementary or herbal medicines. They also include coal tar or disinfectant soap and some deodorants, perfumes and aftershaves.

## **2. Narrowband UVB treatment**

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

- Does not require additional medication, so you do not need to take special precautions before and after treatment.
- The normal skin does not develop the deep tan usual with PUVA treatment, so the contrast between normal skin and the treated vitiligo skin is less obvious.
- Exposure to the light is for much shorter periods.
- The different light source reduces the possible risk of skin cancer.
- UVB treatment does not tend to damage the skin nearly as much as PUVA can.
- It is a safer treatment for children than PUVA.
- Treatment 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. The pigment cells are destroyed, which means that no further repigmentation is possible on the bleached areas. This treatment should only be considered if your vitiligo is extremely severe (at least 75-80% of your skin has lost its pigment). You would need to consider the following:

- Bleached skin will almost always be more sensitive to sunlight.
- Bleaching can lead to a profoundly disorienting loss of identity, so it is rarely used.
- You would not be able to use new treatments in future which might repigment your vitiligo skin patches.

## Skin grafting

It is possible to graft some normal skin into vitiligo skin, so that the pigment cells spread into the white patches. 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 make a vitiligo patch develop in the site the graft was taken from.
- Treatment can cause scarring.
- The colour from the grafted skin is lost eventually.

## Alternative Treatments

The following treatments are not available on the NHS. 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.

**We would 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 normal skin. The skin cells are separated out and then sprayed onto the white vitiligo patches, so that the pigment cells can develop. The re-pigmentation process takes several months.

Although less intrusive than skin grafts, the procedure involves some skin trauma. Further research is required to find out how effective this treatment is, in the short-term and long-term.

## ***Laser treatment***

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

## ***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.

## **Making the decision to stop trying medical treatments**

It can take up to three months before treatments start to work and some people find this waiting for repigmentation very distressing. As suggested before, treatments are not effective for everyone. You may decide that treatment is too upsetting emotionally and stop the treatments. It may be more appropriate for you to use camouflage products, and/or just try to focus on developing other aspects of your life and your appearance. Vitiligo is just one part of who you are.

There is further information about camouflage and other products in the eBooklets

*Managing vitiligo – Camouflage and*

*Managing vitiligo – Other products and processes.*

## Getting professional emotional/ psychological support

Having vitiligo can be very stressful, particularly for people who have it on their face and hands. Talking to friends and family members about anxieties and fears may be enough to help cope with the condition. If this does not help, you should go to your doctor to discuss your concerns. You may be referred to a specialist for counselling or psychological support. You may find it easier to talk to a counsellor, who is neutral and non-judgemental.

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

It can also help you develop ways of managing difficult social situations, like other people's reactions. You may also want support to think about treatment decisions and how you can manage your skin condition most easily.



There is further information about dealing with the emotional aspects of vitiligo in the eBooklets

*Living with vitiligo – A positive approach and*

*Living with vitiligo – Emotional support*

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