



Emotional Support

This eBooklet is aimed at people who are experiencing distress 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. It is intended to be read with the other eBooklet which gives practical advice about how to live with the condition, *Living with vitiligo - a positive approach*.

Introduction – different reactions

Vitiligo can be very difficult to live with emotionally - it involves a change in appearance which is unpredictable and outside of our control. The severity of the vitiligo is not necessarily a predictor of how distressing it can be. 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,
- other 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 forming, so your experience of vitiligo was part of this process. You will have been influenced by the response to your condition of your family: whether it was seen as an acceptable aspect of you, or possibly 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 more 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 which 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 and of your life generally.

Here are some of the emotions that you may experience on your vitiligo 'journey'. Remember that we are all different and there is no particular order to the emotions that people can feel.

The grief process

Having vitiligo may give you a profound sense of loss, of 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.

As vitiligo is an unpredictable condition 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 might have been different if you did not have the condition. You should not feel guilty about having these feelings. It is important to give yourself time to feel hurt and cry if you want to, rather than feeling you have to be brave all the time.

The grieving process may be particularly difficult for people who experience a feeling of loss of 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 and identity. As vitiligo is more pronounced with dark skin tones, your own and other people's awareness of your appearance will 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.



Anxiety

The changing nature of vitiligo means that you can experience a range of emotions. This can be difficult to manage. You may become overly vigilant, waiting and watching for small changes to the white patches of skin, checking your appearance in the mirror, and becoming increasingly anxious if patches increase. Sometimes skin can repigment, but anxiety about the patches reappearing can remain.

Feeling anxious is a natural response to having vitiligo, but you need to consider ways of reducing your anxiety. For some people, using skin camouflage to conceal visible vitiligo patches can give a feeling of safety, comfort and perhaps confidence, especially in social situations. You may find it helpful to look at the strategies suggested in the eBooklet *Living with vitiligo – a positive approach*.

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. Someone with vitiligo may feel judged as less valued than others because of their appearance. Experiencing unwanted attention through 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 that they must be to blame in some way. The idea that vitiligo is something to be ashamed of is linked to people feeling they have to conceal their vitiligo patches.

By understanding more about vitiligo and meeting with 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, a 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) to help reconnect you to others.

Seeing vitiligo as 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 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.

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 an individual, something to celebrate and in which to find value.

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