



# CONCERNS ABOUT INFESTATION

## WHAT ARE THE AIMS OF THIS LEAFLET?

This leaflet has been written to help you understand more about your concerns of infestation. It covers what might be contributing to your symptoms, and what can be done to help you manage them.

## WHAT ARE CONCERNS ABOUT INFESTATION?

You have been given this leaflet as you have expressed considerable concern that your skin or other parts of your body are infested with some form of living organism or other material. You may have been worrying about this for some time or you may have only recently started to have these concerns. It is likely that you have already seen several healthcare professionals who have not been able to confirm that you have an infestation. Understandably, people in this situation often feel extremely frustrated and upset or angry. However, it is important to remember that your healthcare team are there to help you and will do everything they can to try and make things better.

## WHAT CAUSES CONCERNS ABOUT INFESTATION?

It can be difficult to quickly find a cause for your symptoms. Infestation may feel like the most logical explanation for the sensations of crawling and biting that you feel. There are however many other possible explanations for these symptoms, including internal disorders such as coeliac and thyroid disease, recreational drug use, and medication reactions. Regardless of the cause, these symptoms can cause significant psychological distress and have

a negative impact on many aspects of life. This in turn can lead to poor sleep, anxiety, low self-esteem or feeling low, which can make any physical symptoms feel worse.

## ARE CONCERNS ABOUT INFESTATION HEREDITARY?

No, there is no evidence that this condition is passed on genetically. However, some people who are affected are worried that other members of their family, friends or even pets might be affected because of them. It is important that you inform your healthcare team about any such concerns so that professional help can be offered before trying to address this yourself.

## WHAT ARE THE SYMPTOMS ASSOCIATED WITH CONCERNS ABOUT INFESTATION?

People with this condition commonly describe itching, crawling, moving or biting skin sensations. This may be just on the scalp or may be somewhere else on the body. Some people also report seeing black specks, particles, fibres, worms or small insects coming from their skin that others may be unable to see. Some people say that they come from the nose, around the eyes, or from the gut.

## WHAT ARE THE SKIN CHANGES SEEN IN CONCERNS ABOUT INFESTATION?

Visible skin changes may or may not be present in this condition. Common changes seen include redness, scrapes or scratches, open wounds, increased or decreased areas of skin colour, scarring, and sometimes an eczema-like rash. These changes are often triggered or worsened by scratching, picking at the skin, applying



chemicals or heat to treat the perceived infestation area. We recognise that it may be very difficult, but advise that you resist using such methods, since this typically leads to worsening of the symptoms.

## **HOW ARE CONCERNS ABOUT INFESTATION TYPICALLY INVESTIGATED?**

It is likely that you will already have had a thorough examination of your skin, but if not, this will take place in the clinic. Skin infestations are easily identified with a skin examination, which may involve the use of magnifying equipment (a dermatoscope). If you have taken photographs, these will be examined by your healthcare professional. You may also have provided a self-collected specimen from your skin, which can be sent to the laboratory for formal assessment. Blood and urine tests are also usually carried out to explore all the potential causes for your distressing skin sensations.

Concerns about infestation can be very worrying and may trigger feelings of stress or anxiety. You may be asked to fill in some questionnaires about this side of things to see if supporting you to manage the associated stress would be beneficial for you.

In some people, despite a thorough assessment and lots of tests, no cause is found. While this may feel very frustrating, healthcare professionals understand the physical sensations of crawling and biting that you feel are very real, not imagined, and are still treatable.

## **UNDERSTANDING THE LINK BETWEEN MIND AND SKIN**

We know that problems affecting the skin have an impact on mental health and mood. It is also clear that conditions affecting the mind can significantly worsen skin conditions or even cause them in some cases. There is increasing evidence that multiple systems in the body interact with and influence each other to cause illness, including the skin, gut, nervous,

hormone and immune systems. It may seem strange if your healthcare team offers you treatment to help improve your psychological wellbeing when you are primarily concerned about your skin, however this is a recommended treatment approach that has been shown to be highly effective.

## **HOW CAN CONCERNS ABOUT INFESTATION BE TREATED?**

If your doctor or healthcare professional is able to find evidence of a specific infestation, they will proceed to treat it accordingly. When they are unable to find an infestation, it is difficult to justify the use of treatments specifically for insects, bugs, or parasites. Such treatments may have unpleasant side-effects including skin irritation, which can make symptoms worse. Your doctor will continue to keep an open mind on what may be causing your symptoms and will re-examine you and review any further specimens you may bring to clinic.

Sometimes you may be offered a referral to a specialist clinic where there are a range of different specialists (including a psychologist and a psychiatrist) with expertise in working with more complex skin conditions. This does not mean that your symptoms are not real. It simply means that healthcare professionals recognise that living with these symptoms can have a huge impact on your life and may require several different treatment approaches.

In many cases people with concerns about infestation where no identified cause has been found will be offered medications such as neuroleptics (also known as antipsychotics). These are used in very low doses, much lower than those used to treat some other conditions and are generally well tolerated and safe. Research shows that neuroleptics can help with the itching / biting / moving sensations in the skin (or elsewhere in the body). Having started such medication, people usually



report a reduction in their symptoms, and an improvement in their mood and quality of life. More importantly, they often report no longer having concerns about infestation. It is important to note that these medications need to be taken for several weeks before improvements are noticed, and they are continued for at least one year. They should be taken regularly and as prescribed to avoid side-effects or the risk of not working.

It is important to treat every aspect of the problem in people with concerns about infestation. Treatment is therefore offered to help with any feelings of stress, anxiety, or depression. You may also be offered an appointment to see a psychologist. They will be able to listen to your concerns and take a full history of the impact these feelings are having on you. If needed, they will offer you evidence-based talking therapy to help reduce the distress related to your condition.

### **SELF-CARE (WHAT CAN I DO?)**

Having concerns about infestation can impact on many areas of daily life. It is common for people in this situation to start avoiding leaving the house, not socialising or meeting with family or friends, for fear of passing on the perceived infestation. Sleep is often disturbed, and some people may drink more alcohol or turn to recreational drugs to try and make things feel better. Although it may feel uncomfortable at first, it helps to get out of the house each day, engage in regular physical activity, maintain regular social contact, eat as healthily as possible, focus on getting good sleep, and avoid excessive alcohol or any recreational drugs. Distracting yourself when feeling the physical sensations of infestation will also help, such as by going for a walk, listening to the radio, or phoning a friend or family member.

### **WHERE CAN I GET MORE INFORMATION ABOUT THIS CONDITION?**

Information about this type of condition available on the internet has been found to be unreliable. It is very tempting to spend a lot of time searching online for information about the condition and possible solutions, but this more often than not leads to more worry, anxiety and distress, and is best avoided. Consequently, you are strongly advised to discuss your concerns and symptoms directly with the healthcare professionals, who are able to guide you towards an accurate diagnosis and effective treatment.

If you are feeling overwhelmed or vulnerable at any point and it is not possible to contact your general practitioner (GP) or another healthcare professional, please consider contacting the Samaritans for support on 116 123 or online (<https://www.samaritans.org>). You could also contact your local mental health crisis service, whose number can be obtained by searching online, from your GP surgery, or by calling your local Accident and Emergency department.

**This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Association of Dermatologists: individual patient circumstances may differ, which might alter both the advice and course of therapy given to you by your doctor.**

*This leaflet has been assessed for readability by the British Association of Dermatologists' Patient Information Lay Review Panel*

**BRITISH ASSOCIATION OF DERMATOLOGISTS**

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