

*Highlighted words are explained in Common Terms and Definitions sheet*

### Introduction

Pain is a very common feature in people with Behçet's **syndrome** (or Behçet's **disease**). It can affect many different parts of the body and is not just associated with ulcers. This leaflet covers aspects of pain in the musculoskeletal system and chronic widespread pain. The management of pain from ulcers, headaches and eye problems are discussed in other documents.

There are three main potential causes for musculoskeletal and generalised pain in Behçet's: arthritis (sore joints), enthesitis (inflammation where tendons join bones) and chronic widespread pain.

### Arthritis

Patients with Behçet's are prone to get arthritis, just as anybody else. There is, however, an extra potential in some patients to have a specific form of arthritis linked to Behçet's, where inflammation develops in joints (inflammatory arthritis). This results in joints, more likely large ones such as knees, becoming swollen, sore and stiff, especially in the morning.

If you have Behçet's and you have developed sore, swollen, stiff joints it is important to discuss this with your GP, who may refer you on to a rheumatologist, the type of specialist most equipped to diagnose and treat this problem. If you attend one of the Behçet's Centres for Excellence you will be able to access the care of a rheumatologist directly. Your rheumatologist will want to hear more about your symptoms, examine you (looking for signs of inflammation in joints), check some blood tests (to look for other possible causes of arthritis and inflammation) and may request x-rays or an MRI scan.

If you have been diagnosed to have arthritis linked to Behçet's the good news is that this is not a form of arthritis that tends to damage joints and produce deformities, but one that can be helped! There are many different treatments that may help. Draining the inflamed joint of fluid and injecting cortisone can be extremely helpful and not as painful as you might fear – but this is only a short term solution. Reviewing your overall treatment will be important, because you may need more intensive therapy. This varies from standard tablets such as colchicine or azathioprine to biologic anti TNF $\alpha$  drugs (such as infliximab, adalimumab, or etanercept). Your rheumatologist should be able to find a treatment that will help your sore joints and then keep an eye on you, to make sure everything goes well.

### Enthesitis

The other form of joint problems often reported in Behçet's is that of enthesitis. Here, inflammation and pain occurs where tendons join bones. This can be a particular problem in the legs, with soreness around their ankle (where the Achilles tendon joins the heel), or around the knee cap. If you are getting these symptoms it is again important to discuss them with a doctor who can refer you to a rheumatologist if required. In this situation, the rheumatologist may wish to examine you by an ultrasound scan of the sore area or an MRI scan – in addition to straightforward x-rays and, of course, relevant blood tests.

The treatment for Enthesitis again focuses on controlling the Behçet's in general. Often, simple painkillers such as brufen, naproxen or celecoxib are all that is needed – but a review of your medicines will be important and, occasionally, a change to a biologic drug might be required.

Sometimes, people with Behçet's can develop inflammation in their back. This leads to symptoms of stiffness in the lower back, first thing in the morning, that can take at least an hour to wear off. This problem tends

to come on slowly, and not overnight. Your doctor or rheumatologist will want to check you out by X rays or, ideally, an MRI scan of your lower back, focusing on the sacroiliac joints at the bottom. Treatment for this comprises physiotherapy, to help keep your back mobile, through anti-inflammatory drugs (which help most people) to biologics (when the other drugs don't work).

## Chronic Widespread Pain

For reasons that we still don't fully understand, many patients with Behçet's get chronic pain all over, with many areas of the body sensitive to pain even when touched lightly. This is both disturbing for patients and frustrating for doctors - since it is often hard to treat. In situations of chronic widespread pain in Behçet's the picture is very similar (if not identical) to fibromyalgia – a cause of chronic pain in the general population. Here people experience severe pain in many areas, but there is no obvious reason as to why that should be the case. For example, there is no evidence of arthritis or enthesitis.

This is a miserable and frustrating problem to have. However, it can be helped. Unfortunately, not everyone responds to treatment. The key thing is to have a proper assessment by an appropriate doctor, either an experienced GP or a rheumatologist, who can rule out other conditions and be experienced in the management of related conditions, such as fibromyalgia. Getting a diagnosis is an important first step to getting help. Having a doctor who can understand the problem can often make a big difference, irrespective of the treatment! There are a number of options to help. Unfortunately, whilst many problems in Behçet's get better when treating the underlying disease, pain sadly does not normally resolve as the rest of the Behçet's improves. Doctors therefore rely on a combination of three approaches, independent of the Behçet's itself, which have been proven to help in fibromyalgia and which also appear to help many people with Behçet's:

First, consider medication. Medicines, such as very low dose amitriptyline or pregabalin (or gabapentin) can help many people. The key thing is to start with a very low dose and for your doctor to gradually increase it until either it works or it causes side effects that are not acceptable. This can help dramatically many people but not all.

Second, a course of physiotherapy in the form of a "graded exercise programme". Exercising in a controlled and supervised way can help many people to overcome the pain and, by exercising, help normalise sleep patterns which are often all skewed in this condition.

Finally, cognitive behavioural therapy. This involves speaking to a professional clinical psychologist or counsellor, who can talk through the various strategies to help pace yourself and cope with the pain. In an ideal situation accessing a pain management programme, which runs in many hospitals, is the optimal way to achieve this. If you are suitable and able to access the programme it is very unusual if you don't get at least some degree of help.

In summary, arthritis and enthesitis in Behçet's can cause much pain, but are typically amenable to treatment, with the help of a rheumatologist. Chronic widespread pain, unfortunately, is often hard to treat with our current limited understanding of disease and therapies available today. This remains an unmet need and highlights the requirement for more research here, to help us understand this better and to ensure that, when this information sheet is revised in the future, more effective advice and help can be provided!

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