



ANOGENITAL GRANULOMATOSIS

WHAT ARE THE AIMS OF THIS LEAFLET?

This leaflet has been written to provide you with an overview of anogenital granulomatosis. This leaflet tells you what anogenital granulomatosis is, what can be done about it, and where you can find out more about it.

WHAT IS ANOGENITAL GRANULOMATOSIS?

This is when an inflammatory condition such as Crohn disease affects the skin around the bottom and genital skin.

- In females, this can include the vulva (the visible part of the female genitalia, around the vaginal opening).
- In males, the penis and scrotal skin can be affected.

Granulomatosis is a type of inflammation that is not caused by bacteria or other contagious substances. Instead, the inflammation results from the immune system reacting to something it recognises as harmful, even though there is no infection present. This type of inflammation is often seen in Crohn disease and [sarcoidosis](#). It can occur at any age although it tends to occur before the age of 40 in most cases.

The most common cause of granulomatosis of the genital skin is Crohn disease. Usually, this affects the digestive tract, but it can also affect the skin around the anus and genitals. When this happens, it is termed anogenital granulomatosis (AGG) or anogenital Crohn disease. It can also be known as skin/cutaneous Crohn disease or metastatic Crohn disease.

Around six out of ten people diagnosed with granulomatosis have already been diagnosed with Crohn disease. Of them, a third have intestinal Crohn disease that is visible with endoscopy (a camera test that looks at the lining of the intestine). In some people, it can be the first or only sign of Crohn disease, without

any bowel symptoms. A third of patients with Crohn disease of the bowel may develop signs of it outside of the gut, including anogenital granulomatosis.

What causes Crohn disease and why it affects the genital skin in some people is not known. This condition is not due to infection or poor hygiene.

HOW IS ANOGENITAL GRANULOMATOSIS DIAGNOSED?

Because AGG can look a lot like many other anogenital skin conditions, it may take some time and many medical investigations before Crohn disease is diagnosed. This can be even more challenging if a diagnosis of Crohn disease affecting the bowel has not been made yet.

More than one skin condition may be present and overlap with AGG. Inflammation may cause breaks in the skin, leading to secondary bacterial, viral or fungal infections. This can complicate the appearance and symptoms of AGG. Different specialties may be involved, such as gastroenterology, gynaecology, urology and dermatology. Sometimes, a skin biopsy is needed, where a small sample of skin is taken under local anaesthetic for examination under the microscope.

WHAT DOES A FLARE FEEL AND LOOK LIKE?

Anogenital granulomatosis can cause different changes to the genital skin. The most common sign is persistent swelling called lymphoedema. This is caused by inflammation that blocks the lymph fluid channels. There can also be breaks or splits in the skin (ulcers and fissures), skin thickening, skin tags and abscess ([boil](#)) formation. Often, these are painful.

The most common symptoms of an AGG flare are pain or tenderness, especially at the site of breaks or splits in the skin. This pain can make



having sex painful or difficult. Swelling of the vulva, penis or scrotum is also common, and the affected area may become itchy. If there is a secondary infection, you may have a fever, notice a tender lump (a [boil](#) or abscess) which may leak, or a spreading red rash typical of cellulitis infection.

WHAT CAN I DO TO HELP MY SKIN?

It is important to be aware of your own symptoms so that you can track them and help manage your condition through changing treatment course as necessary. With your consent, medical photography can also assist in the visual monitoring of your condition. Medical photography involves taking photos of the affected area professionally in the hospital and storing them securely in your medical records.

As a general measure, you should avoid using bubble bath, shower gel and soap to the genital skin as these can cause irritation and worsen symptoms. Washing with a plain moisturiser or cleanser which is free from soap and fragrance will clean the skin without damaging it.

- Treatment with a [steroid cream or ointment](#) often eases symptoms by reducing inflammation.
- In the case of secondary infection, washing with antiseptic cleansers containing chlorhexidine can help. Sometimes antibiotic or antifungal creams or tablets are needed.
- Tablets or injection treatments to suppress the immune system, which is driving the inflammation, are sometimes needed. These may be used to treat Crohn disease in the gut also. Examples include [oral steroids](#), [methotrexate](#) and [azathioprine](#), as well as tablet or injectable biologic therapies like [adalimumab](#) and [infliximab](#). Steroid injections can also be given into the affected area under a short general anaesthetic.
- Compression underwear, which are like body shaping underwear that squeeze the area, may help if there is genital swelling. Some are available from high street stores or online. You may be

referred to a specialist service for help, if required.

- Sometimes surgery is needed to remove excess skin. As affected skin tissue can heal poorly, this would usually be undertaken by specialist surgeons and often in liaison with skin and bowel doctors (dermatologists and gastroenterologists, respectively). This is to ensure that the inflammation following surgery is controlled as best as possible.

Even with the treatments mentioned above, pain may still be an issue for some people. If you are finding it difficult to manage your pain, there are other options that might help. These include pain relief tablets like paracetamol or short courses of nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen or aspirin.

You can also try cool gel packs on the affected area for relief; a doughnut-shaped cushion can help making sitting down feel more comfortable.

Some people find that applying a local anaesthetic, like lidocaine ointment, can be helpful. You can discuss this option with your healthcare professional. The local anaesthetic can be used up to 20 minutes before sex to reduce discomfort, or at other times during the day, or overnight, to ease the pain.

WILL IT STOP ME FROM DOING THINGS?

AGG can affect people differently. Some people can lead full and active lives, whereas others may find it difficult to manage certain symptoms. As this is a long-term condition, it requires a long-term use of creams and dressings. This may be difficult for some people. AGG can also affect a person's sexual life. It is not unusual for people to experience pain or difficult emotions such as shame and embarrassment. AGG can also have an impact on a person's mood or self-esteem. In such cases, it is important to discuss this with your healthcare professional. They can refer you to psychosexual counselling.

WILL IT EVER GO AWAY?

There is no cure for anogenital granulomatosis, only long-term management. It is a condition



where flares (which coincide with symptoms) may be spaced out by long periods where symptoms are well controlled (remission).

There are many treatments which can make a big difference to symptoms and potentially lead to remission (see 'What can I do to help my skin').

WHERE CAN I GET MORE INFORMATION ABOUT ANOGENITAL GRANULOMATOSIS?

Patient support groups providing information

Crohn's & Colitis UK

Web: www.crohnsandcolitis.org.uk

Email: helpline@crohnsandcolitis.org.uk

Tel: 0300 222 5700

Weblinks to other relevant resources

UK-based patient's account of her experience with genital Crohn disease:

www.abalancedbelly.co.uk/genitalcrohns/

For further information on biologics and other targeted medicine used in Crohn disease:

www.crohnsandcolitis.org.uk/info-support/information-about-crohns-and-colitis/all-information-about-crohns-and-colitis/treatments/biologics-and-other-targeted-medicines

DermNetNZ: dermnetnz.org/topics/genital-crohn-disease

Jargon Buster: www.skinhealthinfo.org.uk/support-resources/jargon-buster/

Please note that the British Association of Dermatologists (BAD) provides web links to additional resources to help people access a range of information about their treatment or skin condition. The views expressed in these external resources may not be shared by the BAD or its members. The BAD has no control of and does not endorse the content of external links.

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

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