

Support groups for hidradenitis suppurativa

BY CATHY MALCOLM, MUHAMMAD UMAIR JAVED AND WILLIAM DICKSON

Hidradenitis suppurativa (HS) is an inflammatory condition characterised by painful inflamed nodules in the apocrine regions of the body. It follows a chronic relapsing clinical course and is a very difficult condition to treat. It has an estimated prevalence of 1-4% worldwide [1]. HS has a wide array of clinical presentations and can involve different sites of the body [2]. There are no specific tests for its diagnosis, hence any inflammatory abscesses in the apocrine bearing skin should trigger a possible diagnosis of HS. HS is not curable, however, several treatment options are available which include preventive, medical, surgical and psychological strategies.

Medical treatment may involve general measures such as weight control, wearing loose clothing and antiseptic soaps. Antibiotics in the form of clindamycin and tetracycline can also be used. Other medical treatment options include use of hormonal therapy, immunosuppression and retinoids [3,4]. Radiotherapy has also been used for treatment with variable success. Depending upon the severity and extent of the disease different surgical options can be used and may involve simple drainage, limited excision, sinus tract surgery and radical excision in combination with healing with secondary intention, skin grafting or flap surgery [4].

HS has a high degree of morbidity including pain and malodorous discharge, which can have a significant impact on the quality of life of patients [5,6]. Due to the chronic and relapsing nature of the disease, patients frequently require long-term support. Online support groups have been proven to be useful for several clinical conditions. Similarly, for HS, online support groups can potentially allow patient education, counselling, sharing of experiences and exchange of knowledge. This article reviews the online support groups available for HS patients.

The Hidradenitis Suppurativa Trust www.hstrust.org

Formed in 2007 by a HS patient, this registered UK charity is dedicated to the raising of awareness, understanding and support for patients with HS. Funded from charitable donations via a programme of active fundraising events, an expanding range of branded awareness items and a weekly lottery, the HS Trust has also instigated HS Awareness Week 2015, which ran 8-14 June.

It also started a programme called the HS support team, which is a network of medical professionals from around the UK who have a particular interest and experience in treating HS. Thus, patients who are struggling to find the necessary expertise locally have recourse to a database of interested medical professionals. This link with medical experts also ensures that all information provided on the website is up to date and medically correct.

Their website provides information for patients on the disease, diagnosis and treatment options with a useful frequently asked Q&A page. It also has links to various other sources of information which is helpfully split into sources of technical information and sources of support. Additionally, the HS Trust runs two free support groups at two venues in the UK.

Patient UK www.patient.co.uk

This website was first launched in 1997 to offer comprehensive, free, up-to-date health information for both patients and doctors and is accredited by The Information Standard and National Health Service (NHS) England quality mark.

The website provides information for patients in the form of condition leaflets which employ simple language and 'PatientPlus' articles as a professional resource which are written by UK doctors

and are based on research evidence, UK and European Guidelines. The 'PatientPlus' article on HS has clear and systematic information on all aspects of hidradenitis including prevention, drugs used in acute and chronic stages and surgical indications for the three main stages of this disease. The language used here is more technical than the condition leaflets reflecting its professional application.

This site also offers a single external link to the Hidradenitis Suppurativa Trust for further information and support. Personal experiences of sufferers can be posted on this website allowing them to share their views and opinions with others in an online forum.

British Skin Foundation www.britishskinfoundation.org.uk

This UK registered charity was founded in 1996 and relies entirely on donations to fund their research into common skin conditions and skin cancers.

The site provides limited information on HS via a question and answer style article with no images. It also has external links to the British Association of Dermatology internet page.

The site also provides an online forum where HS sufferers can ask questions, find out tips from other people and generally share their experiences of living with skin disease. The foundation also produces a free, regular newsletter covering aspects of skin disease.

British Association of Dermatologists www.bad.org.uk

The British Association of Dermatologists is a registered charity which was established in 1920, and is funded by the activities of its members.

The site provides information about HS in the form of a patient information leaflet, written in a question and answer type format. It covers the main topics

using non-technical language, provides references, and has limited links to other information websites and self-help groups. The information is fairly basic and suffers from a lack of graphics or photographs of the condition.

NHS Choices

www.nhs.uk/conditions/hidradenitis-suppurativa/Pages/Introduction

NHS Choices offers a wide range of resources that can support health and care professionals in their work with patients and clients. Via the Health A-Z index they offer information on numerous conditions and their treatments including HS. The article on HS is clearly laid out, covering aetiology, diagnosis, treatment options and lifestyle tips with numerous illustrations.

The site offers external links to the HS Trust and BAD and also allows readers to comment on the article so that patients can comment and share their experiences, although this is entirely unregulated.

Primary Care Dermatology Society
www.pcids.org.uk/clinical-guidance/hidradenitis-suppurativa

The Primary Care Dermatology Society (PCDS) was formed in 1994 by a group of GPs with an interest in dermatology to provide a forum for the exchange of views on primary care dermatology, and to develop skills and progress clinical research in this field of medicine.

It is supported by sponsorship from pharmaceutical companies and by annual subscriptions, which allow the society to subsidise and develop educational meetings all over the UK.

The site provides a single clinical guidance article on HS which is clearly laid out and comprehensively covers aetiology, history, clinical findings and management with excellent images to aid diagnosis.

The technical language used within this article reflects that it is aimed at GPs. The site contains no links to other sources of information specific to HS, although does have links to other dermatological websites.

HS Friends

<http://hsf-uk.find-forum.net>

This UK-based support website for people with hidradenitis suppurativa provides a free online discussion forum which supports the Hidradenitis Suppurativa Trust. The site offers no patient information but merely provides a platform for online discussion amongst members.

Conclusion

Online support groups can provide valuable psychosocial support for HS patients. Hence, where possible, physicians and plastic surgeons should make patients suffering from HS aware of the available online support groups.

References

1. Dufour DN, Emtestam L, Jemec GB. Hidradenitis suppurativa: a common and burdensome, yet under-recognised, inflammatory skin disease. *Postgrad Med J* 2014;**90**(1062):216-21.
2. Alikhan A, Lynch PJ, Eisen DB. Hidradenitis suppurativa: a comprehensive review. *J Am Acad Dermatol* 2009;**60**(4):539-61; quiz 562-3.
3. Shah N. Hidradenitis suppurativa: a treatment challenge. *Am Fam Physician* 2005;**72**(8):1547-52.
4. Slade DE, Powell BW, Mortimer PS. Hidradenitis suppurativa: pathogenesis and management. *Br J Plast Surg* 2003;**56**(5):451-61.
5. Alavi A, Anooshirvani N, Kim WB, et al. Quality-of-life impairment in patients with hidradenitis suppurativa: a Canadian study. *Am J Clin Dermatol* 2015;**16**(1):61-5.
6. Von der Werth JM, Jemec GB. Morbidity in patients with hidradenitis suppurativa. *Br J Dermatol* 2001;**144**(4):809-13.



Muhammad Umair Javed,

Welsh Centre for Burns and Plastic Surgery, Morriston Hospital, Swansea, UK.

E: umair.dr@gmail.com

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Cathy Malcolm,

Welsh Centre for Burns and Plastic Surgery, Morriston Hospital, Swansea, UK.

William Dickson,

MBE, Welsh Centre for Burns and Plastic Surgery, Morriston Hospital, Swansea, UK.

