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Skin and genetic haemochromatosis

February 2019

Could skin problems be one of the signifiers of what has been branded a “stealth” condition?

Haemochromatosis is a genetic condition that causes the body to absorb excessive iron from the diet. The iron is stored in organs and in turn the excess iron can give rise to a range of medical problems including but not limited to, joint pain and disease, chronic fatigue and weakness, cognitive and psychological difficulties, skin problems, sexual health issues, abnormal liver function, diabetes and cardiomyopathy.

Genetic haemochromatosis (GH) tends to be underdiagnosed, and despite many patients reporting skin conditions, the link with skin is missed due to lack of research and awareness.

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Ultimately, is there a question to be answered about links between iron and skin?

There has been a traditional link with skin bronzing and arthritis or diabetes where a GH patient was identified with a “bronze fist” or with “bronze diabetes”. Bronze pigmentation occurs because iron builds up within sweat glands. This causes an increase in iron in the epidermis. If the sweat glands are affected it can cause heavy, dark staining with a particular colour. Old scars can be highly pigmented and the conjunctive and lid of the eye can be coloured.

If the skin is heavily affected it can become a slate grey in colour. Patients also report diminished facial, pubic and axillary hair, and there can be dryness and itchiness to varying degrees.

A patient survey was carried out by [Haemochromatosis UK](#) in 2017 and the recently released report “*Living with the Impact of Iron Overload*” shows that skin discolouration is one of the most commonly occurring symptoms reported by haemochromatosis patients. In the survey, 70.4% of respondents had experienced skin problems. Within this, the most common types of issues ever experienced were “itchiness (45%), tanning or bronzing of the skin (28%) or blotchiness or rashes (24%)”.

Where the report looked at current symptoms, skin problems were noted to be a persistent problem in 28% of respondents and a painful problem in 10% of respondents.

The main treatment for genetic haemochromatosis (GH) is the regular removal of blood, a process called venesection. With the venesection process, almost 70% of those that have received treatment perceived that it had helped their skin condition.

With skin being such a prominent factor in the patient survey report, and in the experiences of patients, there needs to be more awareness and understanding of the effects of iron on the skin. There are many patients questioning the link between their skin conditions and GH, especially where those skin conditions have improved upon treatment.

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Patient Experiences

Gabrielle Clarke Talarico, haemochromatosis patient

Since menopause in 2003 I have suffered from bouts of chronic physical urticaria which have always been attributed to stress. With hindsight I now wonder if the urticaria is actually a complication of the haemochromatosis. My present attack started in February 2018 and the quality of my life and state of mind are being badly affected because of it despite a course of cortisone, constantly taking antihistamines and applying cortisone ointments.



Urticaria on Gabrielle's forearm

My first venesection was in November 2018 and I have had three more since then. When my ferritin was checked before the third it was in the upper limit of normal, the first time ever since being monitored. Previous values have always been elevated.

For the last 20 days I have stopped taking antihistamines, something which I could not do before. The urticaria is still present but much more manageable.



Urticaria on Gabrielle's abdomen

Janet Entwistle, haemochromatosis patient

I had noticed that every time I knocked myself I would bruise and bleed into my skin and that my skin was discoloured and looked tanned.

This became worse with my skin ripping very easily at the slightest knock.



A cut on Janet's arm

This was diagnosed as tissue thin skin syndrome. The consultant I saw said that this could be hereditary - my Mum had thin skin and her sister and brother.

The consultant said it had come on 20 years early for me and just advised that I cream my skin daily with moisturiser to help the skin slide easier.

I know just have to be very careful, I cannot wrap myself in cotton wool so often have skin tears that as resulted in marks all over my arms and legs.

I have now had a Squamous Cell Carcinoma removed from my right arm and at present still awaiting the result of the grading on this.

Anonymous, haemochromatosis patient

Haemochromatosis has been a long hard journey with debilitating consequences. My joints are suffering with deformed hands fingers and toes, restricted neck movement, severe back pain and muscular pain. My skin is very dry and itchy but the moist areas of my eyes, body, mouth and vagina suffer particularly. My eyes feel as though I have sticks in them, my mouth blisters and my tongue splits. I have a diagnosis of lichen sclerosus of the vulva which is treatable.

Neil Owen, haemochromatosis patient

At the first consultation, the Gastroenterologist commented that my skin had a rather 'odd'

appearance – he described it as somewhat leathery and almost rubbery to feel in places (neither I nor my wife had noticed anything odd). By luck a Consultant Dermatologist was also taking clinic and she came and had a look at me. She agreed that there was something ‘odd’ about the skin and undertook a skin biopsy to see if there were any clinical evidence of skin change (ultimately there wasn’t). Since treatment, the quality of the skin has continued to improve and the ‘waxy’ feel has long since gone.

Answering the skin question: a call for research

David Head, Chief Executive of Haemochromatosis UK says, “Iron has always been implicated as affecting the skin, even in the early days it was known as bronze diabetes. Our survey, anecdotal evidence and patient case studies leads us to strongly believe that there is a need for research into skin and haemochromatosis.”

References

[The Haemochromatosis Handbook](#)

[Living with the Impact of Iron Overload](#)

Tamana Gulati, Haemochromatosis UK

[BSF blog](#)

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Great to see this blog. I was diagnosed with haemochromatosis in 2017 after going back and forwards to GP with what I thought was a reaction to an antibiotic. I had a rash on my thighs of small dry spots which I now think was my blocked sweat glands as I had massive iron overload. The spots disappeared after a year of venesections but have started to reappear. I also had bronzing although more grey. I think I am now developing other skin issues due to low immune system and hope these will improve. I have developed lichen Planus in my mouth too. Hope this information helps to add to the anecdotal evidence. Kathy Harvey, Derbyshire

From: Kathy Harvey

Published: 08 March 2019



I have just seen a GP because of recurring Urticaria, which ony started after an infected prosthesis was removed and replaced. I was diagnosed with Haemochromatosis in 2012 and have acute arthritis as the main symptom. There are clearly many areas of this condition that need more research.

From: David Perry

Published: 07 March 2019



My diagnosis of Haemochromatosis followed investigations for an extremely itchy scalp. My GP initially was treating me for dermatitis (possibly caused by anaemia). However, following a full blood screen, I was found to have a high ferritin level - confirmed later (following DNA ysis) as Genetic Haemochromatosis.

From: Susan Mason

Published: 18 February 2019



Thank goodness. I thought I was going mad! I have unbearable itching and have had it for a long time. There has never been much emphasis on it in all the places I have googled effects of heamachromatosis. I have had just about every skin cream known to man. I have changed washing

powders, diet, recorded it in a diary and everything I can think of. At last it is recognised !!!!! I am even prepared to be a volunteer to try products out if it gives me some sort of relief!

From: Julie Holland

Published: 18 February 2019

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