

Dealing with Doctors

The ISG Medical Advisory Board receives many different questions and comments from members. Some are factual questions about diagnosis or treatment, but a lot are about doctors. Many people with ichthyosis find visits to the doctor unsatisfactory unhelpful, bewildering, exasperating, even humiliating. Some issues are about GPs (“Primary care doctors”) and some about dermatologists (“secondary care doctors”). Here is a selection of complaints, and some suggestions about how to deal with them.

“My GP doesn't know anything about ichthyosis”

Ichthyosis is a rare condition. Most GPs have heard about it at medical school but have never seen a case. In the general medical textbooks, ichthyosis hardly gets a mention. GPs have to know about all medical conditions, particularly how to diagnose and manage common and serious disorders, so don't expect them to know all the “small print”. But do expect them to acknowledge their ignorance, and to be prepared to refer you to a specialist (dermatologist).

“My GP says it's incurable and I've just got to live with it”

Incurable is not the same as untreatable. The suffering caused by ichthyosis can be alleviated to some extent by correct treatment and advice. Many patients find that learning about their condition is empowering and even therapeutic. Explain to your doctor that you are not seeking a cure, but you want the benefit of up-to-date advice, not only about creams and ointments, but also about related health and lifestyle issues.

“My GP won't refer me to a specialist”

Some GPs have a very low threshold for referral to hospital, and send even the most trivial conditions for a second opinion. Others, often very good GPs, pride themselves on their low referral rate. They may even have read up about ichthyosis and decided that there is nothing you would get from hospital that your GP cannot provide. In modern NHS jargon, the GP is a “purchaser” and the hospital a “provider”. Your GP may be constrained by rules about referrals to “secondary care” (i.e. hospital) set by the Primary Care Trust (PCT) which commissions purchasing by your GP practice. Just remind your GP that “patient choice” is an important concept in the modern NHS, and you are entitled to request a second opinion.

“I saw a dermatologist years ago, so my GP says there's no point referring me back to hospital”

Some dermatologists keep patients with ichthyosis on the books, and follow them up annually. Others will follow up patients as long as both the specialist and the patient feel it is useful, but discharge as soon as the appointment begins to feel like a waste of time. But most dermatologists will invite the GP to refer you back if necessary. Explain to your GP that there has been a lot of recent research into ichthyosis, and you would like to be referred back for an update.

“My dermatologist doesn't know anything about ichthyosis”

This is a tricky one! Your dermatologist should know about ichthyosis, but some know more than others, and some are more interested in ichthyosis than others. Dermatology is not as broad as general

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practice, but even within this specialty there are many subspecialties, of which “the genodermatoses” (which covers ichthyosis) is only one. Your GP may, unknowingly, have referred you to a dermatologist whose particular area of expertise is occupational dermatitis or skin cancer, or to a very busy general dermatologist who has not had the opportunity to develop a specialist interest. In that case the dermatologist will usually seek advice or refer you on to a colleague with an interest in ichthyosis. Again, you are entitled to request a second opinion. The ISG Medical Advisory Board may be able to suggest a dermatologist in your area to whom you can request a referral.

“I never get to see the consultant”

In most clinics, the work is shared out between the consultant and junior doctors. Specialist Registrars (SpRs) are consultants in training: in some cases their knowledge may be more up to date than the consultant's! Associate Specialists and Clinical Assistants are usually GPs with a special interest in dermatology who work alongside the consultant for part of the week. They are generally very experienced. Senior House Officers are the most junior. Usually the junior doctor will discuss your case with the consultant. Certainly if you have a question they cannot answer you should ask to be seen by the consultant. If you particularly want to see the consultant and never do, speak to the receptionist or clinic nurse as soon as you arrive. If this doesn't work, write a letter directly to your consultant.

“My dermatologist doesn't listen to me”

Sometimes patients leave the consultation feeling dissatisfied. You may feel that the dermatologist doesn't understand what you are suffering, or has not helped you, or that you simply didn't “hit it off”. I hope this is not the case with my patients, but if it is I really want to know. In the past, no-one felt able to challenge consultants who were difficult, unhelpful or downright rude. In the modern NHS such behaviour is not tolerated: consultants are appraised annually and complaints are aired and dealt with. If you are unhappy about the way you have been treated, put down your thoughts on paper and write a letter directly to your consultant. If necessary contact your hospital's Patient Advice and Liaison Service (see below). You should also discuss the problem with your GP.

“I hate going to hospital because I am made to feel like a freak”

The doctor may ask other people to examine your skin for various reasons. Sometime this is for your benefit, the consultant may be seeking opinions and advice from colleagues. Sometimes it is for educational purposes, the consultant has a duty to teach junior doctors and medical students. But I know that patients find this experience embarrassing and humiliating. Even well-meant sympathetic comments may feel hurtful. Children probably suffer most because they are least able to understand the reasons and express their views. Sadly, many patients feel psychologically scarred by the regular mortifying ordeal of stripping off and exposing their skin to a roomful of strangers. How can I make this better for you?

First of all, if your doctor seems insensitive to the way you or your child feels, please tell him or her we really do need this feedback from you. Either explain before the examination takes place that you find it embarrassing, or write a letter afterwards and ask for it to be placed in your file. The doctor should always ask permission, even of a child, to carry out an examination. It is perfectly acceptable to say that you prefer to be examined only by one doctor.

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People who care about ichthyosis

Secondly, make sure there is a reason for getting undressed, and if necessary ask what it is. Usually it is to judge the effect of treatment, or to look at particularly troublesome areas. If your condition is stable, and the medication has not been changed, your doctor may still need to remind him or herself of what your skin is like. But if there is no good reason, feel free to decline.

Thirdly, I hope you will agree that we want as many doctors to know as much as possible about ichthyosis. So it might help if you can see the experience as your personal contribution to medical education. If you are somebody who feels embarrassed about your skin, take the opportunity to explain this, and how it affects your life. You are the expert. Learning from a real patient is much more effective than learning from a text-book.

“At the hospital I always have to wait for hours”

Complaints about the hospital service don't usually come to the ISG, but I know everybody has them. Dermatology outpatient clinics are usually very busy, often overbooked, and sometimes frankly disorganised. Appointments may be changed more than once, and your records may even be unavailable when you come to clinic. These organisational problems irritate the doctors just as much as the patients. We do our best to prevent them but most are beyond our control. But please do voice your opinion. Most hospitals have a Patient Advice and Liaison Service (PALS) who will encourage you to submit a complaint. They should make public the complaints received and their response. If you are interested, key “PALS” and your hospital name into an internet search engine.

The bottom line is, if you are unhappy about something, say so. Nothing will change if you don't. Consultants really do want to help you, and need to know if you are unhappy with the service. You may find writing a letter easier and more effective: always keep a copy in case you need to take things further. Patient choice and patient satisfaction are higher on the NHS agenda than ever before. Finally, remember that your Medical Advisory Board is here to help. Keep sending us your questions and concerns, and we will do our best to advise you.

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