

Tips to help you get the diagnosis or treatment you need

By Bridget from the BSSA Helpline and the BSSA Office.

Most of us are lucky and have excellent GPs, but we talk to quite a number of people on the Helpline whose G.P. either knows very little about Sjögren's Syndrome or who do not take it seriously. Many people have problems getting a diagnosis or referral to a specialist when they have a reluctant doctor, this also means they do not get access to the various treatments available to help with this condition. Sadly we talk to a lot of people who have been dismissed as neurotic or depressed when their true problems lie elsewhere.

This is a tricky situation; after all, it is hard enough living with a chronic (long-term) condition without feeling unsupported as well. Having a good working relationship with your G.P. is vital in this situation, so with this problem in mind we have put together a few tips to help you make the most of an appointment with your G.P. or specialist; after all the average time it takes for someone to get diagnosed with Sjögren's Syndrome is thought to be around 20 years.....we must be able to improve on that!

It is usual for a person with Sjögren's to see a Rheumatologist preferably one with a special interest in Sjögren's. You may also need to see an Ophthalmologist about your eyes or an oral specialist about your mouth. The specialist can then write to your G.P. with their findings and any requests for your treatment.

Before the appointment

1. A week in advance of you going to your appointment make a list of all your symptoms, in roughly the order in which they occurred and mark each one 1, 2 or 3 depending on their severity. Also make a list of questions you wish to ask. Review the list the day before the appointment.
2. If you have a lot of issues to raise with your G.P., book a double appointment.
3. Do research online (but don't believe everything you read online). Bring printouts with you if you want to. Be respectful, but ask about any points you think your doctor may have missed.
4. Speak with your G.P. discuss referral to a specialist.

Making the most of your G.P. or specialist appointment

1. Make sure you know where you are going, how you are getting there and if driving where you are going to park (make sure you take change for parking).
2. Leave in plenty of time so you do not arrive late and flustered.
3. Take your list with you and any other information that you think is important.
4. Stay calm and make sure to relax and breathe before your doctor's visit. It's important to get over any butterflies prior to the visit.



5. Be polite, patient, but also determined. Not every doctor has the best bedside manner. Avoid raising your voice or expressing anger at the doctor during your visit.
6. Listen carefully to the replies to your questions, making notes if needed.
7. Don't let yourself feel rushed! Doctors are often busy and their body language can make it hard for you to get through everything you wanted to. Remain steadfast and get your questions answered, even if it means keeping the doctor standing in the door jamb for a couple of extra minutes (we've been there!).
8. Take another person with you: your husband or wife, a son or daughter or a trusted friend.
9. Talk to friends and family. They can be invaluable if you have to make a difficult decision about treatment.

If your G.P. is not taking you seriously or will not refer you to a specialist, what can you do then?

1. You can try making an appointment with another partner in your practice, sometimes a locum or a trainee G.P. will have a fresh view on things.

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2. Take the BSSA literature with you, including our website address.

3. Your Ophthalmologist or Dentist can refer you directly to rheumatology without going through your G.P.

4. Consider changing to another G.P. practice.

5. If all this fails then make contact with your local P.A.L.S. service (Patient Advice and Liason Service) or your local Primary Care Trust. Search for your local PALS through your web browser, there is a pals team for each primary care trust and the telephone number should be available in each G.P.s surgery. But we are afraid this service is only available in England and unfortunately not Ireland or Scotland.

6. And finally....Good Luck!

Reliable sources for on line information

NHS website - www.nhs.uk

BSSA website – www.bssa.uk.net

NHS Direct – www.nhsdirect.nhs.uk

What is PALS (Patient Advice Liason Service)

PALS offers confidential advice, support and information on health-related matters to:

- Patients
- Their families
- Their careers

Officers from PALS are available in all hospitals.

How can PALS help?

PALS provides help in many ways. For example, it can:

- Help you with health-related questions
- Help resolve concerns or problems when you're using the NHS
- Tell you how to get more involved in your own healthcare

PALS can give you information about:

- The NHS
- The NHS complaints procedure, including how to get independent help if you want to make a complaint
- Support groups outside the NHS

How do I contact my nearest PALS?

PALS also helps to improve the NHS by listening to your concerns and suggestions. For more information, see the PALS website www.pals.nhs.uk. You can also ask your GP surgery or hospital for details of your nearest PALS. Or you can phone NHS Direct on 0845 4647.