

British Sjögren's Syndrome Association Helpline

The BSSA helpline is available to everyone but if you are not a member and find the service helpful please consider becoming a member, because without the income from our members the service would not be available to help you and other sufferers.

BSSA Helpline 0121 478 1133

- Available 9.30am and 4pm, Monday to Friday
- Friendly, listening ear
- Very informed staff
- Practical advice
- Supported by the BSSA Medical Council
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The helpline is manned by two ladies whose knowledge and expertise in Sjögren's is vast. As they both suffer from Sjögren's Syndrome it gives them not only first hand knowledge of what is required but also a firm understanding of the needs and frustrations of fellow sufferers. They both also have a medical background. Members of the Medical Council support the helpline when further advice is needed.

Tips from other members

When you become a member of the BSSA you will receive a quarterly newsletter, which contains a lot more members tips and advice.

- I would like to share the following with other members, like all SS sufferers I have tried a lot of things to help my dry mouth at night. For the past six months I have been using Salivix Pastilles and I have found them very good, you just suck one when needed.
- Like many people with SS I have stomach problems, gastritis, irritation of the stomach, in particular has made my life miserable at times. Although I cannot drink orange or apple juice, tea, coffee or alcohol because they all aggravate it, surprisingly grapefruit juice, pink or ordinary, is extremely soothing. I drink it every day, it's like medicine!
- I use a pair of slightly tinted pair of ordinary glasses, the optician will do this for you. It takes away the glare of overhead lights and you look fashionable enough without wearing dark glasses indoors.
- For cracked lips try using petroleum Jelly (e.g. Vaseline).
- Due to my dry mouth I keep licking my lips, because of this I found that my lipstick kept coming off. I recently started using "Lip infinity" from Max Factor, and have found it is brilliant.
- As I constantly use eye drops I can't use mascara, but now I attend a beautician every six weeks and have my eyelashes dyed. It does cause discomfort for an hour or two but that is all.
- Homemade mouth wash, mix together:
One teaspoon of salt
One teaspoon of baking powder
One litre of cooled boiled water.
The mouthwash needs to be kept in the fridge and made from fresh daily.

Questions and Answers

Below are some questions which have previously been asked in the quarterly newsletter or on the helpline, the newsletter also contains articles written by a medical experts.

- Q In the past 12 months I have spent in excess of £500 on dentist treatment, I now have abscess under another tooth and I cannot afford to spend any more money on my teeth, do you have any advice?
A Speak to your GP about being referred to your local dental hospital for extra help with the tooth problems.
- Q I had a lip biopsy two weeks ago and the test has come back inconclusive – what happens next?
A You still need to speak to your rheumatologist about treatments for symptoms you are suffering.
- Q I have recently been discharged from my Ophthalmologist, but I would feel happier if I still saw someone regarding my SS. Who would I be best to see?
A Ask your GP to refer you to a rheumatologist. Contact PALS (Patient Advice Liaison Service) to see if they can advise a specialist in your area.
- Q I have been advised to take Hydroxychloroquine, how would I benefit from it?
A Many people with SS find using Plaqueril very useful for the fatigue aches and pains, extreme tiredness and general inflammation associated with SS.
- Q My GP will not prescribe bioxtra toothpaste even though I have been advised to use it, do you have any other suggestions.
A Bioxtra is available on the NHS and it is less expensive than the mouth gel so most GPs are likely to prescribe it. Biotene toothpaste is very good, and worth trying.
- Q I have IBS and for the last two days I have been using fibro gel, how long does it take before there is a significant improvement?
A I suggest you use the fibro gel for a week or two to give it time to help.
- Q I have heard that HRT can help improve SS, is this true?
A HRT may help but it does depend on each individual case and needs to be discussed with your GP or consultant.
- Q My glands in my neck are swollen and my GP is sending me for an ultrasound, is this normal in SS to have enlarged glands?
A Yes unfortunately it is a common problem with SS both in the face and the neck area. When the face is affected it is usually around the jaw line.
- Q Currently I am using hyperomellose 0.3% eye drops (bottle) and find that my eyes are still sore for up to an hour afterwards.
A Try using preservative free eye drops and ask your GP if you could try Viscotears gel as a longer lasting eye drop.
- Q My nose is very dry, what suggestions do you have?
A Nozil is very good for a dry nose and it lasts for most of the day and when used at bedtime it will last through the night. There is also a sea salt nasal spray called Sterimar which is worth trying.
- Q I get a photo sensitive rash on my arms, do you have any suggestions on creams for sun blocks.
A Try baby sun creams with at least factor 30, as other people have found these very good.