

Coping with Sjögren's Syndrome

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Background:

If you look at any bookshop, the therapy/psychology/self-care section overflows with self-help books on any imaginable topic (and a few unimaginable ones). Look at the books though, and you will find that somewhere between a tenth and a quarter of them is actually useful. Why is this? Mainly, this is because everyone is different – their problems are different, their perceptions are different, their lives are different and their personalities are different.

You get the idea. Anything I say about coping with Sjögren's Syndrome will only apply to a few of you. I cannot tell you how to deal with Sjögren's Syndrome. For a start, I don't have it, so I don't know how it feels. More importantly, I don't know you, so I can't very well tell you what to do.

However, you will be relieved to know that us psychologists are not completely helpless. Over the years, researchers and clinicians have come up with some ideas to help people cope with chronic diseases, and this is what I shall write about. Rather than see my comments as wisdom that needs to be followed to the letter, I suggest that you think about them as ideas that can be experimented with and adapted until you find something that 'works for you'.

1. Coping can be difficult and requires persistence.

For some time we have lived in an era where former smokers outnumber current smokers. Now, anyone who smokes will wonder at this. Most smokers have tried to quit, but failed. Many smokers who are trying to quit have found quitting to be so difficult that they can't understand how they could possibly achieve it. But, statistics tell us that they probably will – provided that they keep trying.

Why is this? One explanation is that people change a lot over time, and don't even realise it. Thus, things that don't work well for you this year might do next year (and vice versa). Another explanation is that it sometimes takes time for strategies to work. A good example might be someone who learns relaxation techniques to deal with stress. The techniques take time to learn, and people often find it difficult to use them when they are under pressure. However, once they get better at this, the techniques start to become helpful. Thus, it sometimes helps to be persistent with things that don't work immediately.

The same applies to coping with Sjögren's Syndrome. If you are persistent and try new ways of coping, you may find that you are more successful at it. Take artificial saliva. It takes a while to work out how to use it, to remember to use it and the amount that will be helpful. Artificial saliva will not work for everyone, but it's worth remembering that the more you practice with it, the more chance that you will get the best out of the product.



2. Stop, Think, Act and Evaluate.

Now, I'm not saying that you should try anything that comes into your mind. Far from it. You are the person who knows yourself and your problems best. This knowledge may help you to figure out what sort of approach is likely to work for you. When people start to find their problems are getting on top of them we ask them to Stop, Think, Act and Evaluate.

Stop means stopping what you are doing. It can also mean clearing your thoughts. This is particularly useful if you find yourself either trying lots of solutions or feel that you are getting confused.

Think, means trying to understand exactly what the problem is. If you feel worried, frustrated or upset, can you work out why? If you are upset because something that has worked for a long time no longer works, can you work out what has changed? Sometimes you might be upset, and have trouble thinking calmly. It helps to get a friend, partner or relative to help you to work through these things. Your doctor or dentist might also be able to help. The next stage is to work out what solutions might work for the problem you have identified. Try to think widely about this. Your doctor or dentist might be helpful, and there are several websites available (try to avoid the temptation to diagnose yourself though – if you think that your condition has changed, it's really best to get a professional opinion). You might even want to make a list of alternatives.

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Act means trying to implement your solution. If the solution is complicated, it is worth taking the time to work out exactly what to do and to adapt it to your needs. For example, if you do choose to learn relaxation to deal with stress, it's worth taking the time to learn the techniques and experiment with them to ensure that they work in a way that is best for you.

Evaluate means trying to work out whether your solution really works or not. There are two things I recommend. First, allow some time for the effects to show. Also, try to work out what success really means. Be realistic. Sometimes people become disappointed because they expect the problem to either be cured or to go away. This is common, for example, in people who try new medicines. The second thing is to try one solution at a time (if you can). If you try too many solutions by 'throwing the kitchen sink' at the problem, you might get a good result. However, the problem is that you won't know which of them worked. You get what I mean here. The key thing about Stop, Think, Act and Evaluate is that you try to learn and understand as much as you can about your condition and yourself.

3. Feeling better

At this point, I usually get the 'yes-but' response. In other words, people say to me 'yes, I can see the point of all this, but I feel miserable and I want solutions now'. And it's true that people sometimes get overwhelmed when they encounter new problems or old problems get worse.

One solution to this is to try to identify problems before they get on top of you. It's easier to think about things and be persistent when you don't feel bad. This, of course doesn't always work. What a lot of people do is to talk to others about it. Many people

talk to their partners and friends, others talk to professionals and some use message boards. Some talk to their pets. All are legitimate (although don't expect too much from your dog). You might just want a rant or some attention (dogs are great for this) or you might want someone to help you straighten out your thinking (note: dogs have their limits here). It might be an idea to think about who is available and able to fill these roles.

A final point. If you feel that things are getting on top of you, that you are too upset to carry on with your normal life or you feel bad for a long time, don't leave it. This can create problems that are best dealt with early. Have a chat with your doctor.

