

A view from the physio room Sjögren's Syndrome in elite sport

By Adam Rattenberry MCSP SRP, Senior Physiotherapist Cardiff City Football Club



Primary Sjögren's Syndrome and Cardiovascular risk

How do you treat an elite professional footballer diagnosed with Sjögren's Syndrome? As I have come to learn, it is not a case of treatment, but prudent daily management. With approximately 3-4% of UK adults affected by Sjögren's Syndrome and 90% of these

estimated 500,000 sufferers being female, with an average age of 50 years, for me to be in this situation is rare enough in itself with Stephen McPhail. Stephen is a professional footballer plying his trade with Cardiff City Football Club at the top end of the English Championship. Aged only 30 when diagnosed, and presenting with symptoms in reverse, Stephen breaks the mould of the classical Sjögren's sufferer.



Stephen McPhail

The last 24 months from diagnosis to date has been an enlightening journey into the unknown, breaking down the traditional barriers of physiotherapy and venturing across disciplines encompassing Radiology, ENT, Nephrology, Ophthalmology, Endocrinology, Cardiology, Rheumatology, and Sports Science. With many training sessions and games having been replaced by considerable visits to various waiting rooms and clinics, this is our journey in tackling Sjögren's Syndrome head on, and returning Stephen to playing at the top of his game once again. As hard as it sounds, it has been achieved, and should give hope to every Sjögren's sufferer out there.

Our journey started 3 years ago. Most of you reading this will have experienced initial symptoms of dryness of the eyes or mouth, gland symptoms or fatigue and sought advice. Not Stephen. When Stephen's Stage 1 MALT lymphoma was widely publicised in 2009, neither of us had heard of Sjögren's Syndrome, let alone have a diagnosis of it. This initial hurdle was a big one and presented itself prior to any other symptom. Following successful surgery and subsequent radiotherapy, we sought an answer to one of the most frequently asked questions - why? The answer did not come quickly or easily.

Many consultations and investigations later we landed at the door of a local Rheumatologist. After several further investigations and another set of blood tests we were introduced to Sjögren's Syndrome. The blank expressions displayed by Stephen and myself were quickly changed when we were informed the gentleman on the other side of the desk had a special interest in Lupus and Sjögren's Syndrome. Even with many patients under his care, he had never met a Sjögren's

patient presenting lymphoma first, with the more classical symptoms occurring at intervals later down the line.

One obvious consequence of surgery was a reduction in saliva. This coupled with the fact that dryness of the mouth is a frequent complaint in Sjögren's Syndrome meant we had to investigate ways in which to improve this. One easy step was to chew gum during training to promote continuous saliva production. Chewing gum with antibacterial ingredients provides a level of protection within the mouth usually created by saliva. We have also trialed several supplements - both artificial tears and saliva substitutes and stimulants. These have proven to be very useful and should be trialed individually to find the preferred product.

Raynaud's phenomenon is a common symptom experienced by Sjögren's sufferers. Anyone who has experienced this as the blood drains from your cold hands and feet during the winter months knows how painful this can be. Through trial and error, clinical examination gloves worn under normal fleece gloves during training has proven to be the best way of preventing this - unfortunately this doesn't work as well for the feet!

It would be remiss of me to discuss specific medications in this piece, but for those of you who get nauseous at the thought of the number of tablets awaiting you every morning, Stephen has not been exempt from this. Unfortunately medications are synonymous with autoimmune conditions such as Sjögren's Syndrome, some work well for certain individuals and some don't. It has been a gradual process tailoring Stephen's medication to suit him without having any adverse side effects, all the while remaining vigilant to adhere to World Anti-doping Regulations. Unfortunately there have been some untoward side effects along the way, as some of you will be aware, happily these are now a distant memory.

One of the more recent battles we have fought and overcome is the infiltration of Sjögren's cells into Stephen's kidneys. The kidneys are very sensitive organs and did not respond well to these foreign cells, giving rise to a condition called interstitial nephritis. The initial suspicion that something untoward was happening was picked up when we noticed a steady rise in Stephen's daily blood pressure. Several more visits to the specialist and several more investigations for Stephen found his heart was in good working order. Asking the age old question again of - why? lead us to the local Nephrology department, where a kidney biopsy answered our questions.

One symptom I haven't mentioned is fatigue, which I know so many of you experience. This in an elite footballer as you can imagine with the demands of training and performing could be very detrimental. This is one symptom that hasn't presented itself along our journey - this doesn't mean that it won't, but as we stand it is something we haven't had to contend with. For

Continued next page

this I am very grateful, as this could well be a very different story should this have been an obstacle in our path.

Of the lifestyle changes Stephen has adopted, the most significant was a change in diet, to become gluten free. It is widely publicised that gluten free diets have been adopted in those suffering with an auto immune disorder, due to the reduction in inflammatory response within the digestive tract, this with supplementations of cherry extract, beetroot juice and wheat grass have lead to Stephen feeling less bloated with increased levels of energy. This may not work for everyone, but it is certainly worth a try.

Stephen has often joked to others 'he knows me inside out' - and I do! I know all of his blood results, his scan results, the size of his glands on ultrasound, his daily medication, his training routine and sometimes how he is feeling before he says anything of a morning. I think this is one of the factors that has contributed to Stephens positive outcome. There have been many different specialties involved over the past 3 years, however, the daily monitoring and collation of all fields of information is vital in detecting small daily differences that can be acted on rapidly.

One major influence that everyone can take on board, that costs nothing but can have remarkable effects on managing your syndrome is strength of mind. Everyone has down days, and Sjögrens' sufferers have more reason than most to have down days. But too many of these days can pile up and cause you to loose sight. One remarkable quality Stephen has possessed throughout all this is the resolve to carry on, whether that is the competitive sportsman inside him or down to his innate character I don't know, but if I could bottle it and sell it I would be a very rich man.

The age old saying of "a problem shared, is a problem halved", was all too evident one afternoon when Stephen received a call from Tennis ace, Venus Williams. Venus had recently been diagnosed with Sjögrens Syndrome and had heard of Stephens plight. After a tentative start, conversation flowed and their mutual ability to put each other at ease resulted in an open sharing of symptoms and various treatment options. Not only is there great variation in diagnostic ability and management strategy here in the UK, but even greater variance across the water. An hour and a half later, experiences had been shared and a feeling of relief could be seen on Stephens face. He was not the only high profile athlete treading this path. You are no different, if you have not already done so, I would urge you to sign up to the British Sjögrens Syndrome Association website where there are thousands of others like yourself.

We can't change the fact that Stephen or yourselves have Sjögrens Syndrome, but I like to think that we can help you to deal with it every day, possibly change your outlook and work as a team to develop our understanding of just how this syndrome works. I hope this has given you an insight into some of the challenges we have faced, some of which you will have been through yourselves. I am sure there are many more waiting rooms with our name on them, however, none are daunting anymore. Just like Stephen, with the right attitude, the right team and a determination not to be beaten, daily life can continue. Since Stephen's initial diagnosis of MALT lymphoma and Sjögrens Syndrome, he has made 98 competitive appearances in the last 3 years, compared to 161 appearances in the 3 years preceding his diagnosis. A reduction - yes, but proof of not giving in - absolutely!