

# DIRECTOR'S REPORT

## The symptoms we don't often talk about

As part of having a chronic illness, many symptoms are suffered in noble silence. This may be motivated by a tendency to feel that such problems are trivial and hence not worth mentioning to others, or there may be a component of shame attached to other symptoms. The 6 key issues that often arise and are absent from discussion are the following.

Fatigue is almost universal in autoimmune conditions. Because it is so non-specific, it is often neglected and is not a subject of great discussion because it is so universal at various levels. Nevertheless, the symptoms of fatigue in autoimmunity are often profound and may be aggravated by coexisting problems including thyroid pathology and other forms of autoimmunity such as coeliac or nutritional deficiency. Fatigue is often amenable to a structured approach involving pacing and the adjustment of expectations and lifestyle. This involves setting targets that are achievable rather than setting oneself up for failure.

The second commonly undisclosed symptom is dryness. Dryness of the eyes and mouth are frequent accompaniments of autoimmune problems such as lupus and Sjögren's as well as scleroderma. Dryness can cause difficulty with chewing, impairment of speech quality and changes in taste as well as dental pathology. There is often a degree of self-consciousness associated with dryness and the irritation of the eyes can sometimes impart a redness to the eyes that is distressing. Often sunglasses are worn as a combined measure to hide the reddened eyes and to guard the eyes against light which is

often a source of some distress. Cognitive clouding is a third feature that is commonly experienced in the autoimmune conditions. There is a wooliness to thinking, much like that experienced in the setting of a common cold, but experienced more continually associated with word finding and conceptual difficulties and reduced concentration. Again, such problems are amenable to intervention with the assistance of reminder and mnemonic systems to improve recollection and to assist with planning.

The impaired thinking must not be attributed to an isolated event without first considering the possibility that it may reflect or be a manifestation of an underlying depressive condition. Depression and anxiety is our fourth feature that is not always raised. Depression is often heralded by a loss of interest in usual activities and a lack of motivation as well as a tendency to see the future in darker terms than are realistic. Such symptoms should prompt discussion with health professions as assistance can readily be secured but the first step is to talk about these issues.

A fifth feature is the symptoms of incontinence, both urinary and faecal. Symptoms of incontinence can be a result of many things including muscle and nerve damage, learnt behaviour or a consequence of damage caused through physical trauma (such as a difficult childbirth, hysterectomy or other surgery). Incontinence is one of those features that people find embarrassing to talk about which can result in the problem increasing anxiety and nervousness, limiting

social interaction activities and ultimately impacting on quality of life. It is important to understand that there is a lot that can be done to help alleviate symptoms. This can involve referral to another specialist physicians and allied health professionals such as physiotherapists. Through these specialists care causes and treatments can be found. In many cases, treatment will involve strengthening muscles through exercise and retraining personal toileting habits and responses, and overtime incontinence issues can be reduced and managed.

A sixth and final topic for discussion amongst the symptoms that aren't often spoken about is sexual dysfunction. The dryness of Sjögren's causes pain during intercourse and this can lead to a secondary cycle of reduced desire and arousal as well as avoidance, creating some extra distance in relationships. For males, erectile dysfunction can develop as part of an autoimmune condition and all of the sexual problems can be aggravated by underlying mood disturbance.

The problems that aren't often spoken about are potentially amenable to specific therapies and the step taken in faith towards opening up and revealing these symptoms is often rewarded by the provision of assistance and advice which can offer real improvements in quality of life.

Best wishes.

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