

28. SYSTEMIC LUPUS ERYTHEMATOSUS

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28.2 Introduction

28.2.1 Systemic lupus erythematosus (also known as lupus, L.E. or S.L.E.) is one of the so-called connective tissue or auto-immune diseases. It is a condition in which the immune system, instead of attacking intruders, such as bacteria, attacks the body. Virtually any organ in the body may be affected.

28.3 General

28.3.1 The commonest problem in S.L.E. is arthritis, affecting 95 per cent of all those with S.L.E. The arthritis is usually painful, but is rarely deforming, and the symptoms can usually be controlled by analgesics (pain-relieving drugs). Skin lesions are also common, but rarely give serious trouble. However, some people with S.L.E. are particularly sensitive to sun exposure, which may make the skin problem worse, as well as activating more serious internal disease.

28.3.2 Nearly every system in the body can be affected in S.L.E. However, the two most serious complications are renal (kidney) and neurological involvement, with or without psychiatric symptoms. Both of these complications carry a poor outlook.

(i) Kidney disease is often rapidly progressive and difficult to control, leading to total kidney failure. Dialysis is often required, and kidney transplants may well fail because the new kidney could be rejected or become affected by the disease.

(ii) Neurological involvement can take almost any form, from damage to a single nerve in the arm or leg, to major psychiatric disorder. Fits, strokes (hemiplegia) and unsteadiness and loss of co-ordination (ataxia) are all seen. Frequently disablement occurs rapidly, resulting in major care and mobility needs. Psychiatric disorder can cause major disruption to a person's way of life and put a considerable strain on carers. The prognosis for neurological involvement is generally poor as medical treatment is often ineffective.

28.4 Care Needs

- 28.4.1** Care needs can vary considerably. Many people with mild disease lead entirely normal lives, including following normal occupations. Others have more aggressive disease, but with rigorous medical treatment can also be little inconvenienced by their condition. The fact that a person is taking a number of apparently powerful drugs, including steroids, is not itself evidence of a requirement for help with care or mobility.
- 28.4.2** For the majority of those with more severe, less well-controlled disease it is relatively unusual for help to be required with normal daily activities. However, pain can be severe, and turn what would usually be simple tasks into difficult ones.
- 28.4.3** Kidney failure treated with dialysis gives rise to the same care needs as normally required for this form of treatment [see Chapter 24]. By the time people require dialysis, their general condition is likely to be such that they will be unable to manage CAPD [see 24.6] or CCPD [see 24.7] without help.
- 28.4.4** If neurological or psychiatric symptoms are present, care needs may be considerable. Paralysis, frequent epileptic fits and poor co-ordination will give rise to day and possibly night needs. If a person is exhibiting psychotic behaviour or is suicidal, considerable supervision needs will arise. [See Chapter 19].

28.5 Mobility Considerations

- 28.5.1** As with care needs, many people will not have significant mobility needs. However, if there is significant arthritis then mobility will be restricted. Pain may be a serious problem.
- 28.5.2** Mobility is likely to be restricted in the presence of neurological disease. People who have had strokes or are experiencing unsteadiness and loss of co-ordination may well be unable to walk.
- 28.5.3** People with major psychiatric involvement may well need supervision when in unfamiliar surroundings.

28.6 Duration of Needs

- 28.6.1** S.L.E. is potentially a treatable disease. Care must therefore be taken to make no hasty decisions about outcome, especially in the early stages. However, if the disease is of longstanding and still disabling, despite vigorous treatment, then it is reasonable to assume that improvement will not occur. If serious renal or neurological disease occurs, it is unlikely that the condition will improve.

28.7 Further Evidence

28.7.1 Because S.L.E. is relatively uncommon, it is usually advisable to obtain a hospital factual report. This is particularly true if major care or mobility needs are reported. Additional advice may be obtained from an occupational therapist or physiotherapist, while a community psychiatric nurse may give valuable information if neuro-psychiatric illness is present.

28.8 Other Multi-System Disorders

28.8.1 There are a number of other multi-system disorders, including systemic sclerosis (scleroderma), polyarteritis nodosa and sarcoidosis. All of these are uncommon and their effects can be widespread and variable in severity.

It is usually necessary to seek medical advice whenever a case involving any of these conditions is seen.