Firstly, it is important to realise that brain involvement in lupus is extremely common. Secondly, in the vast majority of patients there is complete resolution of the problem with time and most patients get better. If the brain symptoms start dramatically, for example with fits or severe neuropsychiatric disease, the treatment, as with most active forms of lupus, is with steroids and immunosuppressive drugs. The doses of steroids used are less than in the old days – for example 40mg daily in the majority of the worst cases - rarely is a higher dose than this required. An alternative way of giving steroids is by “pulse” injection on an intermittent basis. This is becoming more popular as it is a simple and more rapidly effective way of giving steroids, especially in an emergency. A separate form of brain involvement in lupus is associated with antiphospholipid syndrome (Hughes syndrome). In this form of the disease the cause is totally different - blood clots or “sticky blood”. In patients where this is suspected, brain scans are usually required. These may show localised areas where brain blood supply has not been adequate. The treatment in these patients is different and requires thinning of the blood, either with aspirin or, in more severe cases, with anticoagulants such as warfarin (coumadin). For less dramatic brain involvement the choice of treatment in many ways is more difficult. Many, many patients are not treated who perhaps should be treated. In some patients the depression is a major problem and requires conventional anti-depressant treatment. The more modern pills for depression are very superior to older medications and cause far less side-effects. The opinion of a psychiatrist or psychologist may need to be sought as to whether medical treatment is appropriate, especially where there might be dangers of drugs interacting. In summary, in the experience of lupus specialists, the vast majority of patients who have brain involvement can be treated successfully with a full return to normal daily activities.
LUPUS and the Brain

This factsheet endeavours to answer some of the many questions asked regarding lupus and the brain. Doctors throughout the world are now recognising the importance of subtle forms of brain involvement in lupus as well as the more obvious brain problems. Never underestimate brain involvement. It may vary from mild depression, to memory loss or ‘brain fog’, to much more severe problems such as seizures. In general there are two main causes of brain disease in lupus. The first is lupus disease itself which can cause alterations in the brain activity. The second is the clotting disorder associated with some lupus patients, antiphospholipid or Hughes syndrome. It is very, very important for the doctor to try to distinguish between these two major causes of neurologic involvement as the treatments are clearly very different.

Depression

Depression is an important manifestation of lupus – in some it is the presenting sign of the disease. Depression is an integral part of lupus in some patients – indeed management of the lupus often itself lifts the depression. Although depression can arise in response to having a chronic painful illness, it is important for patients and doctors to recognise that lupus itself can cause depression, which can be quite severe. The management of depression in lupus rests on a combination of treating the underlying lupus as well as possibly adding in antidepressant therapy. In severe depression, especially if there are other symptoms like anxiety or hallucinations, the help of a specialist psychiatrist is essential. One of the medical advances in the last decade has been the introduction of newer milder antidepressants with less of the severe side-effects which so hampered older treatments.
Headaches are common in lupus. In some patients a history of headache going back to their early teens is a feature of the disease. They may be a part of the lupus itself or may be associated with a clotting (antiphospholipid) syndrome. They may or may not have a migrainous element with flashing lights and visual disturbances. In any patient with lupus who suffers from headaches a systematic search for known causes should be carried out including blood pressure checking and, very important, an examination of the blood for antiphospholipid antibodies (‘sticky blood’) and ultimately, if indicated, a brain scan.

Problems with memory, often referred to by patients as ‘brain fog’, are very common in lupus. Doctors refer to this as cognitive dysfunction and this can be quite debilitating and alarming for patients. There are many causes of memory loss in lupus, including depression, active lupus causing confusion and sticky blood antibodies, which can cause slow blood flow in the brain. Treating active lupus can result in improvements in memory and patients with antiphospholipid antibodies may improve with low dose aspirin.

Sometimes lupus first starts in the most dramatic way with a seizure or a series of epileptic fits. This is usually when the patient is untreated and the disease fairly active. It is also an important feature of antiphospholipid syndrome (Hughes syndrome). It is sometimes associated with high fever. Fits or seizures are one of the non-specific ways the brain reacts to severe illness. Once the lupus is treated further fits are the exception rather than the rule.
**Movement Disorders**

The same applies to movement disorders. Occasionally, patients develop chorea with jerky hand movements or head movements. This is simply a manifestation of abnormal brain function and, once again, is often associated with antiphospholipid syndrome (Hughes syndrome).

**Spinal Cord**

Rare, but extremely acute and very dangerous, is spinal cord involvement, which may lead to permanent paralysis. It is now recognised that immediate treatment with both steroids and possibly anticoagulants may reverse this. Fortunately, it is a very rare manifestation of neurologic lupus.

**Psychiatric Disturbance**

During severe lupus flares patients can experience a variety of psychiatric disorders varying from mild personality disorders to severe psychotic behaviour with hallucinations and paranoid behaviour. Some lupus patients are wrongly diagnosed as having schizophrenia at the onset of their illness. Interestingly, treatment of the lupus in these patients results in total improvement in the psychiatric features. This is one of the most important observations to come out of lupus research as it provides possible insights into other mental disease. Milder forms of psychiatric disturbances are relatively common, including anxiety attacks. Lupus doctors are now beginning to realise how common and important this aspect of the disease is. Clearly, any patient who feels that this is a major feature of the disease requires full neurologic examination, possibly including MRI, as well as testing for the antiphospholipid syndrome.
Firstly, it is important to realise that brain involvement in lupus is extremely common. Secondly, in the vast majority of patients there is complete resolution of the problem with time and most patients get better. If the brain symptoms start dramatically, for example with fits or severe neuropsychiatric disease, the treatment, as with most active forms of lupus, is with steroids and immunosuppressive drugs. The doses of steroids used are less than in the old days – for example 40mg daily in the majority of the worst cases - rarely is a higher dose than this required. An alternative way of giving steroids is by “pulse” injections on an intermittent basis. This is becoming more popular as it is a simple and more rapidly effective way of giving steroids, especially in an emergency. A separate form of brain involvement in lupus is associated with antiphospholipid syndrome (Hughes syndrome). In this form of the disease the cause is totally different - blood clots or “sticky blood”. In patients where this is suspected, brain scans are usually required. These may show localised areas where brain blood supply has not been adequate. The treatment in these patients is different and requires thinning of the blood, either with aspirin or, in more severe cases, with anticoagulants such as warfarin (coumadin). For less dramatic brain involvement the choice of treatment in many ways is more difficult. Many, many patients are not treated who perhaps should be treated. In some patients the depression is a major problem and requires conventional anti-depressive treatment. The more modern pills for depression are very superior to older medications and cause far less side-effects. The opinion of a psychiatrist or psychologist may need to be sought as to whether medical treatment is appropriate, especially where there might be dangers of drugs interacting. In summary, in the experience of lupus specialists, the vast majority of patients who have brain involvement can be treated successfully with a full return to normal daily activities.
A range of fact sheets are available as follows:

1. LUPUS Incidence within the Community
2. LUPUS A Guide for Patients
3. LUPUS The Symptoms and Diagnosis
4. LUPUS The Joints and Muscles
5. LUPUS The Skin and Hair
6. LUPUS Fatigue and your Lifestyle
7. LUPUS and Pregnancy
8. LUPUS and Blood Disorders
9. LUPUS and Medication
10. LUPUS and the Kidneys
11. LUPUS and Associated Conditions
12. LUPUS and the Brain
13. LUPUS The Heart and Lungs
14. LUPUS The Mouth, Nose and Eyes
15. LUPUS and Light Sensitivity
16. LUPUS and the Feet
17. LUPUS and Men
18. LUPUS and Mixed Connective Tissue Disease

LUPUS UK is the registered national charity caring for people with presently incurable lupus and has over 6,000 members who are supported by the Regional Groups.

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Please contact National Office should you require further information on the sources used in the production of this fact sheet or for further information about lupus. LUPUS UK will be pleased to provide a booklist and details of membership.

LUPUS UK is certified under the requirements of the Information Standard.