

# LUPUS

## Information for Teachers



### **What is lupus?**

Lupus is a condition where the immune system attacks your own body. Virtually any organ of the body may be affected. It is an incurable, complex disease to live with as symptoms can be very variable and unpredictable. Children with lupus may have arthritis; skin rashes; inflammation of the kidneys, lungs and brain; headaches/migraines and depression; light sensitivity and circulation problems are also common. Severe, unremitting fatigue is a very frequent and often disabling symptom; unfortunately an effective remedy for this is currently elusive.

It is important that you as teachers and school/college staff are aware of the condition, some of the treatments involved, triggers which may worsen the condition, and what the school or college can do to help people with lupus.

### **Treatments**

The aim of treatment is to control the disease, prevent further organ damage and help the child or young person to lead as normal a life as possible. Currently there is no cure for lupus.

Patients often need to take a number of medications to reduce both the aggressive nature of the illness and the danger of major organs being affected by the disease process. These medications (which may include steroids and chemotherapy medications) are usually taken in the morning and may cause nausea, which can delay arrival at school. There are often serious side effects – for instance hair loss and weight gain could lead to sensitivity about appearance and possible bullying.

Infectious illnesses, particularly chickenpox, are a risk to many people with lupus because of the immune-suppressive medication: the school nurse should be alert to the risk of infection from other pupils as recovery from any infection often takes longer for lupus patients.

Regular hospital appointments are scheduled to monitor the patient's progress and review the effectiveness of treatment, also for particular treatments such as drug infusions or physiotherapy.

Learning to live with lupus is very difficult as it does not have a predictable pathway of treatment and cure. Patients have to learn to pace themselves in order to reduce the stresses which can increase fatigue. Fatigue is not caused just by physical activity: emotional and mental activity can also be draining. A rest during the day may reduce the possibility of collapsing physically or mentally.

## **Education**

Some children with lupus may miss significant amounts of schooling either because of in-patient treatment in hospital or not having the energy to put in a full day or even regular part time attendance at school. This does not mean that they are avoiding education - in fact many of them are extremely frustrated about missing out on school; they are eager to learn and don't want to be treated differently from their peers (many then go on to graduate, despite earlier problems). The school nurse or SENCO can often help advise staff and suggest strategies which will help.

Many lupus patients are very sensitive to cold temperatures and to sunlight; they have to take precautions like wearing warmer clothing and high factor sun protection, or may need to have an alternate form of exercise to external sports activities. A discussion between the school PE staff and the hospital team will be a good way to find an appropriate form of activity and any other particular needs that your pupil has as part of their individual care plan.

The ultimate goal of treatment is for the person to live as normal a life as possible, but it may be months before the medication shows benefit and some of their symptoms improve or subside. Any goals the school sets should be simple and implemented very gradually: pressure to make changes quickly can result in a setback and affect the pupil's confidence.

## **What schools can do to help**

- An individual work plan should be prepared in consultation with the pupil and their parents, the school nurse or SENCO, taking into account the pupil's own aims, ability and aspirations.
- Quiet space for the pupil to rest in when necessary.
- Named person (not necessarily teacher) who they can find easily and can approach if they need help or support. The school nurse should be involved in the care of the pupil.
- A locker so that they don't need to carry bags and books all day: access to a lift if necessary.
- Special arrangements for tuition if they are unable to attend on a regular basis, with a tutor aware of the difficulties the pupil has and willing to explore working at a pace which is comfortable and sustainable.

- Assistance with physical activities can help reduce pressure on the pupil's joints: this could be by a (trusted) pupil if a teaching assistant is not available. It may also help for them to have extra time during exams and other deadlines.
- If they are light sensitive they will benefit from seating close to natural light or where filters are fitted over the ultra violet light source; however ensure that they aren't sitting in direct sunlight or draughts.
- Don't forget to include the pupil in your planning: encourage them by commenting on progress, particularly achievements.

Most children with lupus are embarrassed not to be able to live a normal life: this makes it difficult for them to ask for help, as they don't want to feel different or draw attention to themselves.

### **Working collaboratively for the pupil's benefit**

Collaboration between the different agencies with responsibility for the child/adolescent is vital: this may involve social services, Connexions, Child and Adolescent Mental Health, hospital multi-disciplinary team, GP and other agencies. LUPUS UK is happy to help with further advice.

### **LUPUS UK**

LUPUS UK is the national charity for people with lupus, providing information which helps them and their families to live with lupus; funding medical research and specialist nurses, and raising awareness within the medical profession and the general public.

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