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 a manageable 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 fatigue is very common and can be very disabling, but there is currently no effective treatment for it.

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.

People with lupus 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.

Infections, especially chickenpox, can be more dangerous for people with lupus because their medicines weaken their immune system. The school nurse should watch out for possible infections from other pupils, as people with lupus usually take longer to recover when they get sick.

Regular hospital appointments are scheduled to monitor the patient’s progress and review the effectiveness of treatment. The person may also require hospital visits for drug infusion or physiotherapy.

Learning to live with lupus is very difficult because there is no predictable treatment plan or cure. People have to learn to pace themselves in order to reduce the stresses which can increase fatigue. Fatigue is not just physical but also mental and emotional. Rest during the day may reduce fatigue and in some cases may prevent a collapse.

Education

Some children with lupus may miss a lot of school because they need hospital treatment or do not have enough energy to attend full days or even go to school regularly part-time. 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 may need to take extra precautions, such as wearing warmer clothing and using high-factor sun protection, or they may need alternative forms of exercise instead of outdoor sports activities. A discussion between the school PE staff and the hospital team will bea 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 cold air.
- ·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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