**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 mayhave 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 thisis 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 medicationsto 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 itdoes 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 tolive as normal a life as possible, but it may be months before the medication shows benefit and someof 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 canfind 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 unableto 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 reducepressure 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 lupus 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 difficultfor 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  multidisciplinary 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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<http://eastmidlandslupusuk.co.uk/index.php/lupus-information-for-teachers/>