

Although it is hoped that medical research will bring improvement in control of symptoms, core help now and for the foreseeable future will depend on the provision of educational support and understanding, as for all children with learning difficulties in whom there is no “magic bullet”. Schooling is an important part of the child’s life: affected children can learn if provided with the right support. Fine motor skills programmes help. There is a spectrum of educational difficulty in this group of children and the educational support package should be geared to the individual child’s needs rather than to the rare diagnosis. It is vital however that help is provided early – these children may well develop cumulative difficulties and there is no place for a ‘wait-and-see’ approach.

Whilst there is no evidence that other conditions such as attention deficit-hyperkinetic disorder occur more frequently in children with DES than in those without, they may be complications which require management in their own right.

Further information can be found on the web sites of DESST at: www.dancingeyes.org.uk, and of the Neuroblastoma Society at: www.nsoc.co.uk



Dancing Eye Syndrome
Support Trust (DESST)



INFORMATION SHEET FOR TEACHERS AND SUPPORT STAFF.

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This brochure has been prepared at the request of parents of children who have educational problems after having developed a very rare neurological disease known in the UK as the dancing eye syndrome (DES), also sometimes called opsoclonus-myoclonus syndrome or Kinsbourne syndrome (after the doctor who described it in the 1960s). The condition starts, as its name suggests, with chaotic eye movements, usually in children under 3 years. This is accompanied by jerky movements of limbs and trunk, with poor balance and severe incoordination. The onset, can be rapid over a few days, or gradual over several weeks. Children in the untreated phase of the illness are usually inconsolably distressed, with very disturbed sleep.

Some affected children are shown to have a neuroblastoma, a tumour found almost exclusively in young children, usually in chest or abdomen. Circumstantial evidence strongly suggests that in both those children with neuroblastoma and those without, there is a reactive immune response which attacks tumour cells specifically but also, indiscriminately, attacks normal nerve cells in areas of the brain which are important for

control of eye movements, coordination and learning.

Although some affected children recover spontaneously and completely, most require treatment with steroid or a steroid-producing drug (ACTH) for several months; sometimes children will need treatment with steroids and other immune modifying treatments for years. Steroids usually suppress abnormal movements and reduce distress but unfortunately, in the majority of affected children, there are enduring problems of learning, behaviour and coordination and it is these which prompted the DESST to prepare this brochure for you.

In those children having steroids or ACTH you may notice that they are overweight, often with a ruddy complexion, side effects which, with raised blood pressure and increased appetite are frequent. But it is the psychological aspects and learning problems which worry parents most. In a recent study, 71 % of children had persisting neurological problems- clumsiness and incoordination. In 62 % the full-scale IQ was below the normal range. In all, there was at least some deficit in the

neuropsychological functions assessed: language, visuo-motor integration, memory, attention span and motor activity. In another study, it was shown that expressive language was more impaired than receptive language. Speech was impaired in intelligibility and output. Oppositional behaviour and sleep disorders were also frequent. Some children are distressed by loud noise especially a fire alarm.

Fluctuation in the severity of the condition is common. Parents of one girl have described the condition varying from day to day, their daughter recognising words one day, forgetting them the next, usually in parallel with well-being and tiredness.

Relapses, often triggered by coincidental infections, are heralded by increasing irritability with increasing clumsiness and usually require reintroduction of medication or adjustment of dose. Unsurprisingly relapses are more frequent in winter.