Central Manchester and Manchester NHS
Children's University Hospitals
NHS Trust

Dear Parent or Teacher,

We have been asked to provide some information for parents of children who have been diagnosed as having a fetal anticonvulsant syndrome or whose children were exposed in the womb to antiepileptic medications and who are now having difficulties.

Fetal Anticonvulsant Syndrome is the name given to a distinctive pattern of physical features, birth defects, learning and neuropsychological problems detected in a child whose mother needed to take certain medications during pregnancy.

There are currently only 3 confirmed Fetal Anticonvulsant Syndromes and these are named after the medications that the syndrome is associated with:

1) Fetal Valproate Syndrome
2) Fetal Carbamazepine Syndrome
3) Fetal Hydantoin Syndrome

Children who have a diagnosis of one of these syndromes will have been reviewed and diagnosed by a Clinical Geneticist or a Specialist Paediatrician. To make a diagnosis the Doctor will review the child for a constellation of physical and development features consistent with the syndrome. This diagnosis cannot be confirmed on a blood test and is based on the pattern of problems with which the child presents. In many cases, however, the doctor may have tested to rule out other common causes of learning problems. Research and experience suggests that Fetal Valproate Syndrome is the most common of the Fetal Anticonvulsant Syndromes.

Learning and Development

Whilst our knowledge about the development of children exposed in the womb to antiepileptic drugs is improving we still do not have a comprehensive understanding of the development of cognitive abilities over the later childhood and adolescent years. What is provided here is a summary based on research completed to date and on clinical experience.

Published research demonstrates that children who have been exposed to sodium valproate (trade name Epilim in the UK) in utero are at an increased risk of having difficulties in one or more areas of cognitive functioning. The most common difficulties are:

- Language difficulties (expressive and comprehension)
- Attention difficulties
- Working memory difficulties
- Memory for verbal information (things told)

Our advice is limited to this recommendation letter and we have not given our opinion to other areas of the parent or education pack.

- Poorer levels of intellectual ability (likely due to other cognitive difficulties)
- Difficulty writing for long periods due to joint laxity
- Social difficulties

Children with Fetal Anticonvulsant Syndrome may also have a number of physical problems which might affect them at school. These include:

- Lax joints leading to clumsiness, difficulty in walking long distances and difficulty in writing
- More difficulty with toilet training and bladder control
- Tendency for ear infections in childhood which can lead to time off school and hearing problems
- Long or short sight. Vision should be checked if there are any concerns.

As with all children, each child with fetal valproate syndrome (FVS) is unique and may not display weaknesses in all of the above areas, however most children will show a degree of deficit within their language processing abilities. Difficulties in these cognitive areas may in turn impact on other areas of cognitive ability such as intellectual functioning, memory ability and social functioning.

Recent research has also shown that children exposed to sodium valproate in the womb are at an increased risk of being diagnosed with an autistic spectrum disorder. Whilst this risk is larger than in the general population, it is still relatively small at 4-8% of children exposed to sodium valproate. It is thought that children are more likely to receive this diagnosis because of the language and social difficulties they experience.

On the whole, fewer children appear to be affected by exposure in the womb to phenytoin (Trade name Epanutin in the UK) or carbamazepine (trade name Tegretol in the UK). However a number of children do experience difficulties in their cognitive abilities following exposure in the womb to these medications and a small number will be diagnosed as having a fetal anticonvulsant syndrome or fetal carbamazepine syndrome. Less is known about the abilities and impairments of children with a history of phenytoin or carbamazepine exposure but from the limited information we have it appears that they are more likely to struggle with language development and verbal tasks and are possibly more likely to have poorer concentration skills.

Cognitive difficulties such as these present a huge challenge to the child, to their parents and to their educators. Children with a fetal anticonvulsant syndrome or those with cognitive difficulties following exposure to an antiepileptic medication do not always meet the criteria for special school or learning disability support. This can understandably lead to frustration for parents who want to see their child supported in the best way possible.

Our advice is limited to this recommendation letter and we have not given our opinion to other areas of the parent or education pack.

Advice on how to help your child

A good working relationship between school and home is key.

It is important that everyone has a full understanding of your child’s cognitive abilities and that their personal strengths and weaker areas are documented. Information on cognitive strengths and weaker areas is key to assisting education and providing learning support at home.

A comprehensive neuropsychological assessment should be carried out by an Educational or Clinical Psychologist to give a full understanding of how your child’s brain is functioning. Sadly this is easier said than done due to Educational Psychologist budgets being incredibly tight and the services offered by Clinical Psychologists varying from area to area. As a first step speak to your child’s teacher and the special educational needs officer (SENCO) at the school. Enquire as to whether the school is in a position to fund Educational Psychologist time for a formal neuropsychological assessment. If the school is unable to assist with this it will be worth contacting your local Child Development Centre or Child and Adolescent Mental Health Service (CAMHS) for advice on a referral to them for a formal neuropsychological assessment. It is worth bearing in mind that you will need to be referred in to NHS services by your GP or Paediatrician and that waiting lists can be long due to high demand for services.

It is important that the neuropsychological assessment includes an assessment of language (expressive and receptive), attentional capacity, rate of learning and of general memory functioning as well as intellectual functioning. Some children with a fetal anticonvulsant syndrome may have an intellectual ability within the low average range but may have language and attentional deficits which are much more severe. The abilities of children change over time and an assessment completed three years or more ago may not be a reliable reflection of your child’s abilities now.

Where possible an Educational Psychologist or SENCO could be consulted in the planning of lessons for your child. Each child is an individual but generally, due to the severe impairment in attentional and working memory abilities, children with a fetal anticonvulsant syndrome are likely to struggle in the classroom to follow instructions and to retain information, especially if the information is presented verbally.

It is really important to have a good working relationship with your child’s school. Strategies to maximise your child’s learning within the class room will also be useful to employ at home. As parents you are in a unique position to support your child and complement the work completed at school. Daily tasks to revisit information covered at school during that day may prove to be useful. Small rewards can be useful to keep a child motivated and should be used to praise effort and not necessarily achievement.

The language difficulties experienced by children with FVS may also lead to social difficulties within their peer group. Talking through difficult social situations with your child (e.g. an argument with a close friend) explaining the reasons and the consequences involved will enhance their understanding of social interactions and the intentions of others. Formal social skills training or social inclusion packages designed for children with other difficulties (such as Autistic Spectrum Disorder) are likely to be useful but their availability depends very much on the facilities of the individual school or local NHS child services.

Our advice is limited to this recommendation letter and we have not given our opinion to other areas of the parent or education pack.

Our knowledge of children with FVS is increasing all the time and we will update this advice letter as it becomes available.

Yours sincerely,

Jill Clayton-Smith

Dr Rebecca Bromley
Clinical Psychologist
Royal Manchester Children's Hospital

Prof Jill Clayton Smith
Consultant Clinical Geneticist
St Mary's Hospital, Manchester

Our advice is limited to this recommendation letter and we have not given our opinion to other areas of the parent or education pack.