



Mersey Region  
Epilepsy Association

# European White Paper



# European White Paper on Epilepsy

**In 2001 a White Paper was presented to the European Parliament in Brussels with the following message:**

We call upon intergovernmental bodies and institutions in Europe, and individual Member States, to implement and support the following three actions:

- Improve public understanding of epilepsy via educational programmes throughout Europe to raise awareness and reduce stigmatisation of patients.
- Provide legislation to protect people with epilepsy from discrimination in the workplace to ensure equal job opportunities and thereby reduce the socio-economic burden of the condition.
- Increase investment in research in epilepsy throughout Europe.

We kindly request a response from the European Parliament, following presentation of the European White Paper on Epilepsy to its members on 22nd March 2001.

The 17th Chapter of the White Paper, concerning statutory education, was contributed by Peter Rogan, Chairman of MREA, and is reproduced below.

## **17. Epilepsy education within the statutory school system**

The perception that epilepsy always has a major effect on education is as misconceived as the assumption that children's educational performance is never affected by epilepsy. The facts are that many children with epilepsy experience no educational difficulties, whilst on the other hand, a significant number of children do encounter difficulties.

### **Educational Difficulties**

In 1970, the Isle of Wight Study (1) found that children with epilepsy who were of average or above average intelligence exhibited at least a 2-year retardation in reading skills. In a later study (2) it was found, albeit in a small sample of children with epilepsy attending mainstream schools, that 31% were maintaining an average to superior level of performance, 53% were coping at a below average level and 16% were seriously behind. The data made no suggestion that low levels of attendance were in any way significant.

**Children's self-esteem and levels of achievement are enhanced by a knowledge of their own condition.**

The results of a more recent study published in Finland (3) showed that of 143 children with epilepsy, out of a school population of 21,104, the most common neurologic impairments were mental retardation (31.4%), speech disorders (27.5%), and specific learning disorders (23.1%). In a previous study, Sillanpää(3) concluded that 27.5% of children with epilepsy did not complete their basic education or required education in schools specialising in the education of children with learning disabilities.

In broad terms it would seem that one quarter to one half of all children with epilepsy experience some degree of educational difficulty, and it is right and proper that the needs of these children are met by statutory provision.



### Understanding the problems

Since a school is made up of three main groups—teachers, parents, and children—it is essential that each component group has a knowledge of epilepsy so that the condition does not compromise the educational progress of pupils with epilepsy.

Most parents delivering their child to school for the first time are full of apprehension. It is much more difficult for those whose child has epilepsy. They quite understandably fear that their child will be at risk from a lack of understanding of the condition by fellow pupils, and teaching and non-teaching staff. Their misgivings are real in that ignorance promotes fear, which in turn promotes prejudice. Those responsible for provision of statutory education have a duty of care to ensure that children are not at an educational disadvantage because they are subject to transitory loss or impairment of consciousness due to epilepsy.

Pazzaglia and Frank-Pazzaglia (4) concluded from their study that a high proportion of teachers felt very poorly prepared for having children in their class who have epilepsy. It concluded that as well as there being a need for close cooperation within the medical management team, this cooperation should be extended to envelop the teaching profession. An obvious starting point in exercising the duty of care, therefore, is to provide epilepsy education as part of the syllabus of the teacher-training curriculum.





## Epilepsy Education for Teachers

### Recognising seizures

To the untrained eye, absence seizures in children are very easily mistaken for daydreaming. Teachers who fail to recognise this type of seizure can easily fall into this trap and the unfortunate children find themselves in unjustifiable trouble. In addition, because these seizures can occur so frequently, the amount of educational material lost to the children is considerable and the untrained teacher may not have the expertise to recognise why expected progress is not being made.

**Steps should be taken, as a matter of urgency, to provide courses on epilepsy at both initial in-service training levels.**

Convulsive seizures, though far more easily recognisable than absence seizures, can nevertheless present the untrained teacher with serious classroom management difficulties, which can severely disadvantage children with epilepsy. Teachers who openly panic at the onset of a convulsive seizure, through ignorance of the condition, transfer that panic and fear to the class of children in their care. As well as the consequences of an inability to administer correct first aid, this can unwittingly damage future inter-pupil relationships.

A lack of knowledge of the huge variance of the manifestations of complex partial seizures means that teachers who have not benefited from epilepsy education are inadequately prepared to successfully provide for children who are subject to these seizures. It is not at all unusual for teachers to misinterpret events of a complex seizure as gross misbehaviour and act accordingly. The implications for the children are obvious.

### Knowledge of antiepileptic drugs

Even a rudimentary knowledge of antiepileptic drugs (AEDs), particularly their side effects, leaves teachers better equipped to provide the high-quality education that children deserve and indeed are entitled to.

In order for children with epilepsy to maximise educational opportunity, their teachers need a formal training to widen their knowledge of the condition. Provision must be made for them to receive this training prior to qualification or as a component of an ongoing in-service training programme.





## Epilepsy Education for Parents

### Informing the school

Parents sometimes fail to disclose to teachers that their child has epilepsy, and the first indication that the pupil has the condition is the sight of the child having a tonic-clonic seizure. This is a highly unsatisfactory situation but indicative of a train of thought that puts epilepsy in the category of an issue to be hidden rather than understood and discussed openly.

### Educating the parents

Since the primary educator of the child is the parent, it is vital that parents have a good understanding of epilepsy. Unfortunately, doctors diagnosing the condition do not usually have the time, and sometimes not the skill, to explain relevant medical information to anxious parents. The recent arrival of specialist epilepsy nurses on the scene has gone some way towards providing medical education to parents but, unfortunately, there are not enough of them. Those that are available are fully stretched and, in order to meet demand, finance has to be found to train and employ more of them.

All parents are protective of their children, and parents of children who have epilepsy are no exception. The danger of overprotection, whereby parents are resistant to their children gaining advantage from subjects in the curriculum such as physical education and workshop technology, for fear of injury, can be of great disadvantage to the child.

### Role of the voluntary sector

The voluntary sector (epilepsy associations) is the main provider of high-quality support material for parents by way of literature, video presentations, and courses to assist parents in improving their knowledge of epilepsy. Useful links already established between the voluntary sector, statutory agencies and private enterprise need to be strengthened further so as to maximise the educational potential being fostered by the charitable organisations.

# Epilepsy Education for Children

## **Educating the child about epilepsy**

It is entirely appropriate for children who have epilepsy to learn as much about the condition as possible. The acquired knowledge empowers them to reach their potential and so play a full and active part in society.

They need to know that their epilepsy is not a barrier to academic success and that they can achieve levels of attainment within normal distribution patterns. Essential to this understanding is the realisation that epilepsy is not a reason or an excuse for underachievement and that they should be subject to the same codes of conduct and discipline as their peers. They are normal children who happen to have epilepsy.

## **Educating classmates**

Children thrive on the friendship of classmates and so it is important that fellow pupils are given the opportunity to learn about their friend's condition. There is a strong case to be made for including epilepsy education in the early years curriculum so that positive images can be promoted which may be expected to remain with the children throughout their lifetimes.

## **Provision of children's literature and audiovisual material**

Unfortunately, there is not nearly as much written educational material available for children as there is for adults. What is available is good, but there remains a great need to develop more high quality, imaginatively illustrated material to meet a very real need. Further development of children's video material is highly desirable as is the need for interactive computer programmes and quality literature.

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# Epilepsy Education for Children

Steps should be taken, as a matter of urgency, to provide courses on epilepsy at both initial and in-service training levels.

Parents, as the primary educators of their children, have an overwhelming need to make provision for them to gain a sound knowledge of the condition.

Children's self-esteem and levels of achievement are enhanced by knowledge of their own condition.

Quality educational materials are urgently needed.

All involved in the formal education process have a duty to promote positive attitudes towards children with epilepsy.

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Educational difficulties for all children can have a large number of causes and the child with epilepsy is no exception. It must not be concluded, however, that a child will definitely experience educational difficulties because of epilepsy.





## The Effects of Treatment on Education

### Effect on cognitive function

Children with epilepsy invariably take prophylactic medicines that are designed to act on the brain to limit the onset of seizures. Some of these drugs have a direct adverse effect on cognitive function, and so children's progress in school is curtailed. Besag (5) surveyed studies carried out by Thompson and Trimble (1985), Trimble (1990), Andrews et al. (1986), Gallassi et al. (1988), and Richens (1989), and concluded that the consensus of opinion is that phenytoin seems to impair cognitive function. However, the more commonly used valproate and carbamazepine, prescribed in moderate doses, do not. He also concluded, from the data studied, that monotherapy has fewer detrimental effects than a multiple drug regimen.

### Other effects

As well as any direct effects AEDs may have on cognitive function, all have some sort of side effects. These can affect children in different ways and so there is always the possibility of educational progress being adversely affected. For instance, in some developing countries, Phenobarbitone is still used to control seizures in children but it can be the direct cause of them experiencing behavioural disturbances and hyperkinesia. These side effects can be the cause of grave difficulties in school. Other possible side effects of AEDs, listed in the British National Formulary (6), that could affect school performance, are:

Ethosuximide	Drowsiness, mild euphoria, dizziness.
Lamotrigine	Malaise, drowsiness.
Vigabatrin	Drowsiness, abnormal thinking, aggression.
Benzodiazepines	Irritability and mental changes, fatigue.
Gabapentin	Fatigue, dizziness, somnolence.
Tiagabine	Tiredness, concentration difficulties, speech impairment.
Topiramate	Confusion, fatigue, concentration difficulties.
Levetiracetam	Fatigue, somnolence.
Carbamazepine	Dizziness, fatigue.

### **Effect of surgery**

Surgical intervention is sometimes necessary where seizures are extremely difficult to control using drugs.

It is interesting that Goodman (7) reported that, in cases where hemispherectomy had been performed, there were not only major improvements in seizure control but also in behaviour patterns.

### **Prejudice against epilepsy**

Because of the misunderstandings and resultant prejudices, children with epilepsy can very easily find themselves being rejected by fellow pupils. This is very problematic since such an unfortunate child can start to see school as an everyday trial, rather than an experience to be enjoyed, and simply not want to attend. Feigned illness or truancy are solutions that obviously become apparent to them.

Unfortunately, teachers who are not well prepared to accept a child with epilepsy can subconsciously show signs of rejection and this transfers into the minds of the other pupils. When this happens, motivation to succeed is greatly damaged.

Since the full curriculum should be available to children with epilepsy, the overreaction and overprotection by parents and teachers should be avoided in order for the children to gain full benefit from what is on offer.

### **The Role of Specialist Schools**

It is accepted that, for the vast majority of children, the best place for them to be educated is in their local neighbourhood school, be they mainstream schools or those catering for children with some degree of learning difficulty. Equally acceptable is that there is a group of children who need to attend specialist schools, set within specialist centres, which are away from their homes. These children usually have epilepsy that is uncontrolled, and invariably the epilepsy is not a single complication. With the best will in the world, local mainstream and specialist schools cannot provide for the special educational needs of these children.

These residential schools can expertly address such issues as additional medical problems, behavioural difficulties, peer group problems, family and social problems and psychiatric problems.

## **Conclusions**

Resources should be provided to fully include as many children as possible who have epilepsy into local neighbourhood schools whilst recognising that, where epilepsy is not a single complication, adequate provision should be made in specialist schools. Issues relating to educating children with epilepsy should be an integral part of initial and in-service teacher-training provision.

Liaison between parents, teachers, and professional healthcare workers is essential to the educational provision for children with epilepsy.

Increased knowledge about epilepsy amongst children reduces the risk of isolation.







## Recommendations

Everyone involved with children with epilepsy in statutory education should receive appropriate epilepsy education.

Adequate printed and audiovisual educational materials and resources should be made available.

Teachers require better education about epilepsy, both before qualification and during in-service training.

Throughout the formal education system, there should be promotion of positive attitudes towards children with epilepsy.

## References

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