

## Personal practice

# What should the child with epilepsy be allowed to do?

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Negative attitudes to epilepsy abound, both in the general community and among the medical profession.<sup>1</sup> These result in the main from prejudice about, and ignorance of, epilepsy. Taylor,<sup>2</sup> discussing prejudice, suggested that recurring seizures reinforce the view of witnesses that the epileptic individual cannot be relied upon to participate fully in society because he is liable, unexpectedly and at any time, to go out of control. Hence the desire in the past to set sufferers from epilepsy apart. Parents, faced with a diagnosis of epilepsy, may be similarly rejecting but are more likely to overprotect the child against life's stressful and potentially dangerous situations. Recurring epilepsy and an overprotective ambience may, however, interfere with the child's experience of normality.

The problem of how to regard the individual with epilepsy, whether child or adult, is compounded for parents and professionals by the complexity and diversity of epilepsy. The results may be a misunderstanding of the particular seizure disorder present in an individual patient, and of the risks involved to the child. Parents, friends, teachers, and doctors often impose restrictions on children with epilepsy that are out of all proportion to the severity of the epilepsy, and despite the fact that the children themselves may wish to join normally in everyday childhood activities. It is reasonable, therefore, to ask ourselves what should and should not be restricted in the daily life of children with epilepsy. What may they be allowed to do or be prevented from doing?

### The risks

Generalised seizures associated with loss of consciousness are likely to be seen as presenting the greatest risks, both inherent and external, to the child. The generalised tonic-clonic seizure (grand mal) is the archetypal convulsion associated with total loss of control. Death is an ever present fear in the minds of parents witnessing their child's first and subsequent convulsions, as studies among parents of children with febrile seizures have shown.<sup>3</sup> Death in a

febrile convulsion is now, however, a rarity, although the possibility of permanent brain damage occurring in a prolonged febrile seizure is accepted.<sup>4</sup> Sillanpää,<sup>5</sup> in a review from Finland of the medicosocial prognosis of various childhood epilepsies, found that 18 deaths occurred among 245 children studied, mainly as a result of status epilepticus and lower respiratory tract infections. The mean age of onset of epilepsy in the group was 25 months, most of the children who died were mentally subnormal, and many had neurological deficits. Molander,<sup>6</sup> in a recent survey of sudden unexpected death in later childhood and adolescence, reported 7 deaths over a 6 year period caused by known diseases. Two of these were the result of an epileptic attack, two were due to sudden cardiac failure associated with coronary artery and myocardial disease, and three were caused by sudden asthmatic attacks. This study seems to establish the relative rarity of sudden death due to epilepsy in childhood. Status epilepticus, although still a serious medical emergency at whatever age it occurs and especially so in the very young, is much more amenable now to modern treatment.<sup>7</sup>

### Drowning

**Swimming.** The risk of drowning while swimming is something that causes particular anxiety to parents of children with epilepsy. The Brisbane drowning study<sup>8,9</sup> of 149 cases of death by freshwater and saltwater drowning in children is most comprehensive, and it was concluded from it that epileptic children who swim were four times more likely to drown than were normal children but that the absolute risk of drowning was low. Furthermore, when the children with epilepsy were properly supervised while swimming, there was no evidence that they were likely to drown or suffer brain damage from anoxia after near drowning. Some 400 epileptic children were at risk from drowning each year in Brisbane during the 7 year study but no epilepsy induced pool or sea deaths occurred.

Livingston *et al.*<sup>10</sup> agree that fatalities associated with swimming are relatively rare causes of death in

epilepsy and that epileptic patients may swim with confidence if properly supervised. They allow patients whose epilepsy is controlled and those who have an occasional seizure to swim in a pool with an informed lifeguard present or with a competent swimming companion. They prohibit swimming under water and diving into deep water. Patients with rare seizures are discouraged from swimming in large bodies of water such as lakes or oceans, even with a lifeguard present. Children with frequent seizures are advised against any ordinary swimming but may be allowed to swim in a pool for brief periods with immediate and constant surveillance. This sensible advice is based on Livingston's experience over more than four decades with very large numbers of epileptic patients. He has stated that although some of the children experienced a convulsion while swimming, none drowned.

The British Epilepsy Association,<sup>11</sup> in a leaflet entitled *Swimming and epilepsy* designed for use by schools, advocates the 'pairing' system—known as the 'buddy' system in the USA—whereby all children are advised and expected to swim in pairs. This provides additional safety for weaker swimmers generally, and for children with epilepsy particularly. Children with mental or physical handicap, or both, who may also have partially controlled epilepsy are at greater risk and should be carefully supervised in the water.

**Bathing.** Drowning in the domestic bathtub is a much greater hazard for the epileptic patient than is misadventure during swimming. Rose and Tizard<sup>12</sup> wrote to the *Lancet* in 1968 describing such a tragedy and emphasising that conversations with general practitioners, paediatricians, and neurologists had indicated an unawareness of this particular risk. In each of the fatal cases of bathtub drowning associated with epilepsy described by Livingston *et al.*<sup>10</sup> the patient had bathed alone in a bath which was completely or almost completely filled with water. They advised that older patients with epilepsy, if bathing alone, should do so in a water depth of not more than 5–7.5 cm. They also warned against the possible risks of showering alone, especially in glass or plastic enclosed stalls, citing accidents following seizures where unconscious patients fell through glass or plastic or against hot water taps. They recommended showering while seated as being less hazardous.

There is general agreement that young children, whether epileptic or not, should not be permitted to bathe without surveillance by a responsible person, and that older children should be encouraged to shower rather than bathe—preferably with the plughole open and the bathroom door unlocked.

**Fishing.** There is yet another risk of drowning during a seizure which is associated with that most popular of water pastimes, fishing. Worster-Drought<sup>13</sup> described a youth on regular treatment for epilepsy who was found drowned in a shallow river. He had been fishing from a river bank and fell forwards into the water during an attack.

**Precipitating mechanisms.** The possible role of precipitating mechanisms in epilepsy induced drownings should be remembered. Seizures triggered by a specific sensory stimulus are described as reflex epilepsy,<sup>14</sup> the most familiar example being television induced photosensitive epilepsy. Photosensitivity may occasionally be responsible for seizures occurring at the seaside or swimming pool and induced by the shimmer of bright light on rippling water. The part played by reflex epilepsy in epilepsy induced drowning is uncertain. The term 'startle epilepsy' is sometimes applied to brief clonic or tonic-clonic seizures provoked by sudden and unexpected auditory or touch stimuli and might be triggered during the horseplay so often engaged in by children in swimming pools or by diving into cold water or from a height. True water immersion epilepsy (bath epilepsy) is rare at any age although Keipert<sup>15</sup> has described a case induced by water immersion in an infant aged 5 months. In adults, it can be shown that, in order to provoke an attack, the bathwater must be at 37°C and that the legs and perineum must be immersed.<sup>16</sup>

### School activities

There is general agreement that the child with epilepsy should have as normal a school life as possible but there is no readymade answer to the question of what limitations, if any, should be imposed on his or her activities there. The advice given should be based on common sense and not determined simply by the presence or absence of seizures. Factors such as the severity and frequency of attacks, their timing in relation to waking and sleeping, and the child's judgement and perception of the risks should be taken into account. Most children with epilepsy attend normal schools, and it is important that teachers should be correctly informed about epilepsy and encouraged to have an enlightened and optimistic attitude towards the condition. They should be instructed about the emergency treatment of a child having a major seizure in the classroom.

### Sports

The question of participation by the child in gymnastics and athletic activities at school needs

consideration. There is general agreement that children with epilepsy should not perform activities where a fall would ensue if a seizure were experienced without warning. These include rope climbing, climbing on bars, rock climbing, the use of parallel bars, and trampolining. These restraints might be waived, however, for a child who had been seizure free for a prolonged period. Factors which may operate during athletic exercise are pertinent, and hyperventilation is one such. Voluntary hyperventilation produces an alkalosis and thereby increases the susceptibility to absence seizures in true petit mal whereas, during active physical exercise, the lactate/pyruvate acidosis produced is anti-epileptogenic. This may be just one of the protective factors operating during physical exercise. Berney *et al.*<sup>17</sup> have shown that while inhibitory effects predominate in most epileptics during exercise, a minority have their epileptic discharges activated during exercise and during the post-exercise recovery phase.

The question of competitive and body contact sports is also debated. Pearn<sup>9</sup> believes that competitive swimming should be prohibited since somatic stress to the point of exhaustion may trigger an attack. To some extent, however, this factor should be influenced by the physical training and conditioning of the patient. An unresolved problem is the potential exacerbation of pre-existing organic pathology by subsequent head trauma during contact sports. It has been proposed<sup>18</sup> that repeated head trauma may lead to further neuronal damage and loss, and thus compound the problem of epilepsy already present. This seems an unlikely event except in boxing.

As far as contact sports in general are concerned, the writer agrees with Baird<sup>19</sup> when he asks 'Are they worth it?' He suggests avoiding the issue and channelling the athletic youngster with epilepsy into tennis, golf, or athletics. Tennis provides adequate exercise, satisfies competitive instincts, and can be continued as a lifelong pursuit. The recommendation of the Committee on Children with Handicaps of the American Academy of Pediatrics<sup>20</sup> that 'one must strike a balance between the needs of the child to participate with his peers in their daily activities and the limitations to living a full life which any restriction may impose', is also relevant here.

Many children with epilepsy have far fewer seizures when active and engaged in normal childhood activities than when they are idle, or at rest, or bored. Some may even excel in athletics and, provided their epilepsy is under satisfactory control, there seems little point in making distinctions between epileptic and non-epileptic children as far as their participation in athletics is concerned.

## Cycling

All children are subject to risks in their daily lives, especially in urban situations. Bicycling in traffic is a hazard for the normal child, as it is also for children with epilepsy, but parents of the latter may have reasonable anxieties about the added danger of absence attacks occurring while the child is cycling on a busy road. Each case has to be judged on its merits but it is comforting to remember that it has been known for a long time that the frequency of seizures is lessened by tasks requiring some degree of concentration or arousal.<sup>21</sup> Ounsted and Hutt<sup>22</sup> showed that seizure discharges occurred less frequently in circumstances which were neither boring nor excessively stressful. If the degree of attention required became too stressful, however, the seizure discharges increased and performance declined. Clinical and subclinical spike wave paroxysms may disrupt the registration and storage of information by the brain, and focal epileptic discharges may interfere with normal functioning of the area involved. The complexity of modern traffic is such as to prohibit exposing the child with epilepsy to unnecessary risks unless his seizure control is excellent.

## Discothèques

The current popularity of discothèques has heightened parents' anxiety about the effects of loud music and flashing lights on the child with epilepsy. Berney *et al.*<sup>17</sup> carried out a valuable study of this problem and showed that most epileptic children were not particularly vulnerable in discothèques. They suggested that photosensitive children, aware of their vulnerability and discomfort when exposed to flicker, may deliberately avoid the risk or even develop a learned aversion to discothèques. The energetic exercise of disco dancing may have a protective or normalising effect and the study supported this. The investigation also identified a small minority of children with epilepsy, however, whose epilepsy seemed to be activated by exercise and who were also susceptible to a wide range of other stimuli including voluntary eye closure, music, hyperventilation, and intermittent photic stimulation. These children were at risk from stroboscopic illumination even at the relatively low frequency employed in discothèques.

## Conclusion

Overprotection must be avoided if possible in dealing with the school age child who has epilepsy. As with all chronic long term disorders, epilepsy

requires adjustment on the part of the child and the family. Some aspects of the disorder cannot be altered, no matter how well they are understood or accepted. Learning from mistakes and experience and making decisions about physical and other restrictions must gradually become the responsibility of the child and not that of the parents or school personnel. The doctor who is consulted for advice should have a wide knowledge of this common disorder so that he can counsel caution when necessary or recommend when new responsibilities may safely be given to the child. A recent Japanese study<sup>23</sup> among paediatricians, seeking information about allowing school children with epilepsy to join in sporting activities, showed that young, specialist and hospital doctors were more liberal in their attitudes than were older and less specialised doctors. This suggests to the writer that the great increase in interest and knowledge of childhood epilepsies in the last decade and the availability of more effective anticonvulsants are changing the long established and over cautious medical opinions about this common problem of childhood.

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