Epilepsy:

The Social Conse-quences

by Evelyn Muirden,

Epilepsy Foundation of Social Welfare, Victoria.

David was a fully qualified electrical technician. He had been a top apprentice and held a good job with a well-known firm. At the age of 24 he became "ill" and found difficulty carrying out his duties. His employers persevered for six months in the hope that time and treatment might produce improvement but were eventually forced to relinquish David's services as the persistence of his symptoms made the job too dangerous . . .

Mrs Brown felt hurt and confused by her neighbour's change in attitude. The Brown children used to play with the children next door and the parents had a baby sitting roster. However, when five year old Johnny Brown's "turns" were diagnosed, the neighbour said she could no longer take responsibility for minding him and did not want her children to play with him any more . . .

Betty was an 18 year old girl of attractive appearance and good education. She had a clerical job she hated but could not give up in case she could not find another position with a tolerant employer. Betty refused most invitations, preferring to spend her leisure in the safety and privacy of her home rather than risk and embarrassing incident while in public. Betty's mother was distressed by her frustration and isolation . . .

The common factor in all these cases is the client's medical status. David, Johnny and Betty have epilepsy and this has disrupted their lives and caused anxiety for their families.

Epilepsy is one of the oldest and most mysterious conditions known to man. Although as long ago as 460 BC, Hypocrates claimed that seizures were due to afflictions of the brain, the myth has persisted until modern times that epilepsy is a manifestation of devil possession or a punishment of sin by God. The sudden onset of attacks and equally sudden disappearance only confirmed the long held view that supernatural powers were at work.

INCREASED KNOWLEDGE

It is only in the last century that increased knowledge of the functioning of the brain has led to a greater understanding of epilepsy. The word "epilepsy" comes from a greek word meaning "seizure" or "to be seized". However, according to current medical thinking this term is believed to be a misnomer. Wright[1] has suggested that it might be better to speak of the "epilepsies" because of the wide variation in the types and severity of seizures, age of patient at onset, seizure frequency and causes of the condition.

The age of onset of epilepsy is highest in early life, especially in the first two decades. For this reason, workers in the child welfare field are likely to encounter cases where epilepsy is a single or complicating factor, and might benefit from some understanding of the nature and implication of this complex condition.

WHAT IS EPILEPSY:

According to Lagos[2] epilepsy is a "chronic disorder of brain function characterized by seizures which are

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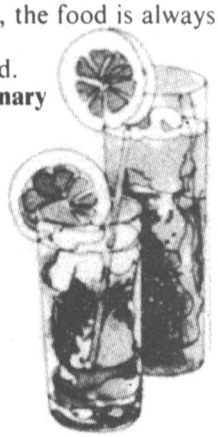

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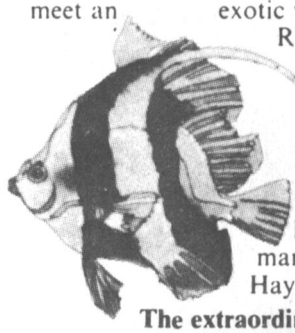

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due to abnormal, sudden, transient electrical discharges". However, he and other writers point out that any single definition is 'unsatisfactory because epilepsy is not a specific disease. Rather, it is a symptom or manifestation of abnormal cerebral function which may be due to a large number of different causes.

A complete classification of epileptic seizures may be found in medical text books but for the purpose of this paper fits may be divided into two main types — Grand mal manifested by loss of consciousness possibly accompanied by unconscious, involuntary movements, and Petit Mal which is a momentary blankness sometimes mistaken for day-dreaming.

INCIDENCE OF EPILEPSY:

As epilepsy is not a notifiable disease estimates of incidence are difficult to obtain. There have been numerous studies in the United States and Europe but the results are unreliable for two reasons —

(a) because of prevailing prejudice in the community, many epileptics and their relatives conceal the existence of the disorder.

(b) lack of agreement among medical personnel as to differentiation and classification of seizures creates significant variation in the data produced.

It is generally agreed that one person in 200 suffers from epilepsy but this would be an underestimate.

CAUSES OF EPILEPSY:

(a) congenital defects and diseases

(b) birth injuries

(c) head injuries

(d) infectious diseases — meningitis, encephalitis, measles

(e) brain tumours

(f) diseases of blood vessels of the brain

(g) toxic agents — alcohol, lead, ergot, etc

(h) metabolic disorders causing chemical imbalance.

These factors account for only 20 per cent to 30 per cent of epilepsy. The majority of cases where symptoms have no ascertainable cause are known as Idiopathic Epilepsy — seizures of unknown origin.

In the past it was thought that all types of epilepsy were inherited. According to the current view, a **predisposition** to develop epilepsy may be inherited, rather than the epilepsy itself.

DIAGNOSIS OF EPILEPSY:

Epilepsy is not an easy condition to disagree because it is intermittent, transitory and in most cases leaves no permanent mark. A diagnosis is generally made on the basis of observed behaviour and clinical tests.

1. Observed Behaviour: The most important data leading to a diagnosis of epilepsy is the information supplied by relatives, and experiences reported by the patient himself. However, there are many other conditions[3] whose symptoms resemble an epileptic seizure. These include breath-holding spells of childhood which may follow an unpleasant experience or stimulus, unconsciousness due to head injury, syncope, certain heart conditions, and hysterical attacks. Since it is difficult to differentiate between a genuine epileptic seizure and some of these other conditions, neurologists believe there is a significant degree of mis-diagnosis. To minimize this possibility physicians should take a complete and accurate history of attacks.

2. Clinical Tests: The electroencephalogram (EEG) is the most useful clinical tool for diagnosing epilepsy. It records the electrical activity of the brain. People with epilepsy may have different brain wave activity to non-sufferers. However, it is not uncommon for epileptics to have normal EEG tracings and those with no clinical manifestations of the disorder to have abnormal readings. Therefore the EEG is not a reliable technique for establishing a diagnosis, but merely a useful adjunct to a good case history. Skull X-rays and Brain Scan are often used to determine whether seizures are due to operable abnormalities such as tumours or other cerebral lesions. However these tests do not contribute to the physician's knowledge of epilepsy, but eliminate the possibility of other causes of fits.

TREATMENT OF SEIZURES:

In general the only treatment for epileptic seizures is the regular and continuous intake of anti-convulsant medication. The exact action of these drugs is not known, but they have been found to increase the brain's resistance to seizures. Drug manufacturers claim that up to 80 per cent of all patients will achieve seizure control with the regular use of anti-convulsant drugs. This figure is somewhat exaggerated, but medication certainly reduces the frequency and severity of fits even if they are not entirely controlled.

Although successful surgical treatment of epilepsy has been reported this is not in common practice today. Surgery can only be considered if the location of the abnormality can be found and is accessible without affecting other vital areas of the brain. Generally the risk of brain damage in such cases far outweighs the benefits derived from eliminating seizures. There are some forms of epilepsy for which surgery would be totally inappropriate.

It is generally agreed that epileptic children should be encouraged to

lead a life as close to normal as possible. However where seizures are frequent and without any warning it may be necessary to impose realistic restrictions. Experts disagree, however about the safety of cycling, horse-riding and tree climbing for seizure-prone children. A child's activities may have to be determined on an individual basis, depending on the attitudes of the particular patient, his physician and parents and the nature of his fits.

Problems Arising from Epilepsy

Epilepsy affects people from every socio-economic strata irrespective of intellectual or cultural background, and seizures can vary enormously in type and severity from one individual to another. For these reasons it is not possible to categorize the problems confronting epileptics in terms of a rigid set of variables. Some epileptics are so well controlled that they experience very few difficulties as a result of the condition. However there are problems arising from epilepsy which fall into two main categories. Firstly, there are those of a practical nature which are not unique to epilepsy. Secondly those which are specifically related to epilepsy and have social as well as practical implications.

1. PRACTICAL ISSUES:

(a) **Education** — Many epileptic children make poor progress at school. This may be due to frequent absenteeism, brain damage, or the side-effects of medication — or a combination of all three. Educational programmes and medical treatment should be adjusted to accommodate these factors. It is important for epileptics to reach a reasonable educational standard if they are to function adequately in later life.

Unfortunately our present school system is not geared to deal adequately with a child who is handicapped or in fact, deviates to any extent from the normal in his educational requirements. Many epileptics are not even recognized — their momentary absences (Petit mal) are mistaken for day-dreaming and incur unwarranted censure.

PETIT MAL

Even if Petit mal episodes are understood by the teacher, the constant interruption to mental functioning has a disastrous effect on learning.
Some children with epilepsy have specific learning difficulties even if they are of normal intelligence. Unfortunately the facilities for handling such problems are limited both in the state school system and the private sector.

(b) **Accommodation** — Many epileptics cannot live at home because their parents are unable to cope with the frequency of seizures and associated behaviour disorders. Others need to live closer to their work, or move to an area where suitable employment is available. Because of society's negative attitude to epilepsy, and the complete lack of supervised hostels, accommodation represents an enormous problem.

Example — Richard is a 29 year old child of elderly parents. He sustained serious brain damage following a motor car accident and now suffers from poorly controlled epilepsy. Richard is an only child and is cared for at home, but his parents feel that they must make plans for his future care when they can no longer manage. Despite the family's adequate financial resources there are no existing facilities for Richard's care and he is likely to end up in a state psychiatric institution. Although this is totally inappropriate.

Robert is a 12 year old mildy retarded boy suffering from frequent seizures. He has associated behaviour problems and is in continual conflict with his parents and three siblings. Robert's mother has requested temporary care for him to relieve the constant tension his behaviour creates. She fears that this will led to a breakdown of her marriage and disruption of normal family functioning. The only accommodation available is provided by an institution for grossly retarded children. This is not acceptable to the mother and could be detrimental to Robert.

(c) **Employment** — Epileptics of all ages have difficulty finding and holding suitable jobs. The present depressed economic climate has aggravated the situation, and many epileptics are being retrenched. However, it is the school leaver with poorly controlled fits and inadequate education who presents the greatest problems.

Example — Helen is a 22 year old girl whose only ambition was to become a nurse. She had an excellent work record since leaving school but refused to give up her vocational choice. Since Helen had only passed Form V and realized that epilep-

sy might be a bar to a nursing career, she decided to undertake nursing aide training just to see if she could stand the pressure. She had not had a seizure for five years. Helen was rejected by most hospitals and the Nursing Aide School because of her diagnosis despite her more than adequate educational qualifications, a good employment history and a medical certificate from her private physician.

REJECTED BECAUSE OF EPILEPSY

Eventually she applied to a hospital without revealing her diagnosis. She passed all qualifying tests before revealing her epilepsy. Intake procedures continued despite her disclosure. She was measured for uniforms and accommodation arrangements were finalized. At the last moment she was told she could not undertake the training because of epilepsy.

PARENTS DISTRESSED

Helen's parents were so distressed that they approached their MP who made strenuous efforts to reverse this decision or find another placement. It was concluded that the nursing aide administration was completely rigid and unreasonable in its attitude to epileptics barring them regardless of their individual capacities or medical histories. On the other hand several epileptic girls have completed nursing training although it requires more study and incurs greater responsibility.

(d) **Medical Care** — Medical care is frequently a problem experienced by epileptics. Because epilepsy is a chronic condition, and rarely presents an emergency situation, doctors become complacent about treatment after the initial assessment and diagnosis is made. Frequently patients remain on the same medication for long periods without review.

PATIENTS WISH TO KNOW MORE

Epileptic patients and their relatives wish to know more about their condition and its treatment than they are generally told. However experience suggests that patients with a good understanding of epilepsy will accept the diagnosis more readily and make a better social adjustment. Many people are so depressed by their lack of seizure control that they will look outside the traditional areas of medical care for treatment. Patients who are not well controlled by anti-convulsant medication turn to chiropractors, herbalists and acupuncturists but there is no medical evidence to justify these actions and there are serious dangers in following unorthodox procedures.

(e) **Behaviour Disorders** — Many children with epilepsy also present behaviour disturbances. It is difficult to determine whether these difficulties are a manifestation of the epilepsy or a condition consequent to the disorder and the frustration it creates.

At present children with personality problems are referred to the Counselling, Guidance and Clinical Service section of the Education Department or regional clinics of the Mental Health Authority. Others are treated by private psychiatrists. One of the limitations of current treatment is the lack of consultation available in existing treatment between doctors, social workers and educationists.

2. SOCIAL FACTORS

(i) **Prejudice** — people with epilepsy who are rejected by society may become aggressive, insecure and isolated. The presence of such emotional disorders will undermine even the best medical treatment. Epileptics have enough to contend with learning to live with fits without the added burden of coping with the stigma of epilepsy. Throughout life epileptics may be exposed to prejudice, ranging from resentment of parents and ignorance of teachers through to rejection by employers. The resulting feelings of inferiority and inadequacy will produce anti-social behaviour.

(ii) **Intermittent Nature of Epilepsy** — Because of the periodic and unpredictable nature of epilepsy, many patients live in fear and uncertainty. Frequency of fits can curtail the individual's activities, and can also disrupt the lives of his family. Furthermore, many clients believe that it is harder to adjust to epilepsy than to other physical handicaps because it is not always visible. Consequently it is more difficult to explain inconsistent behaviour and performances to teachers, employers and other social contacts.

(iii) **Restrictions of Individual Action** — Although patients who achieve good seizure control can lead normal lives, epilepsy still restricts their life style to some degree. Example of the restrictions are:

(a) lack of mobility through not being able to drive a car
(b) limited vocational choice
(c) the need for regular and persistent medication despite its possible undesirable side-effects, and despite society's negative and suspicious attitude to "pill-poppers".

SERVICES TO AID EPILEPTICS

In Australia specific services for epileptics are only starting to develop. The Epilepsy Social Welfare Foundation was established in Victoria in 1964 by a group of concerned parents. At present its limited resources are directed towards counselling epileptics and their families, and developing an educational programme aimed at reducing the general ignorance and prejudices against epilepsy which still exist in our community.

ONLY AGENCY

The Foundation is the only agency in Victoria solely concerned with epilepsy and is aware that its present services do not adequately meet the presenting needs of its clients. The Australian Government has allocated funds for an Epilepsy Centre to be built in Camberwell where existing services will be expanded and a program of rehabilitation and diversional activities will also be developed.

The Epilepsy Social Welfare Foundation is fortunate to have the services on a sessional basis of an employment counsellor from the Department of Labour and Industry. (Handicapped Persons Section). Epileptics requiring retraining, assessment, sheltered employment and psychiatric care are forced to use the general facilities available in the community. Unfortunately existing rehabilitation programmes and sheltered workshops are not always appropriate to the needs of epileptics and do not reflect specialized knowledge of their unique problems.

INADEQUACIES IN EXISTING SERVICES

1. In many cases medical treatment is inadequate. Doctors appear to be solely concerned with obtaining seizure control and underplay the social problems arising from epilepsy. Very few referrals are received by the Foundation from doctors which clearly demonstrates this point.
2. Many epileptics and their families express a need for opportunities to discuss their condition, both with experts and fellow sufferers. There are no support or educational groups exclusively for epileptics functioning on a regular basis and easily accessible to those in need of them.
3. The presently available rehabilitation and retraining programmes are too general and have long waiting lists. These schemes are not always appropriate to the needs of epileptics and do not reflect specialized knowledge of their unique problems.
4. In many cases epileptics with associated behavioural disorders have difficulty relating to normal groups and become increasingly isolated. There is a need for a therapeutic programme to provide epileptics with diversional activities and experience in socialization.

However the Foundation's efforts to provide such a programme were unsuccessful in the past and many people believe that separation of single disability groups is not consistent with current rehabilitation policy.

It is hoped that the foregoing may give readers some understanding of epilepsy and insights into some of the problems its sufferers may experience. The Epilepsy Foundation is anxious to assist all people with epilepsy and support any professional or other groups involved in their welfare. A number of pamphlets and books may be obtained from the office at 196 Flinders Street, Melbourne 3000. Several good quality overseas films are also available by arrangement, and identification jewellery may be purchased.

1 WRIGHT, G. N. (1975) *"Epilepsy Rehabilitation"* — Rehabilitation and the Problem of Epilepsy page 1 — Little Brown & Co.
*2 LARGOS, J. C. (1974) *"Help for the Epileptic Child"* page 3 — Macdonald and Jane's, London.
3 FAIRFIELD, LETITIA (1954) *"Epilepsy"* — Gerald Duckworth & Co. Ltd.
*4 SCOTT, DONALD (1969) *"About Epilepsy"* — Gerald Duckworth & Co. Ltd.

The books marked * maybe purchased from the Foundation.

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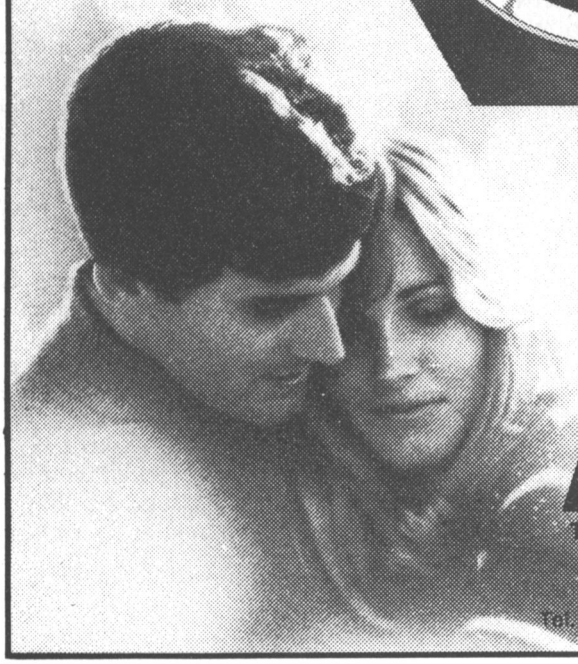

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