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Epilepsy and Employment — a medical symposium on current problems and best practices

**FELICITY EDWARDS, MICHAEL ESPIR
AND JOLYON OXLEY**

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Number 86

Epilepsy and Employment — a medical symposium on current problems and best practices

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Contributors

Medical Advisory Panel and Editors

Dr Felicity Edwards

Senior Employment Medical Adviser, Health and Safety Executive, Merseyside

Dr Michael Espir

Principal Medical Officer, Civil Service Medical Advisory Service, and Honorary Consultant Neurologist, Charing Cross Hospital, London

Dr Jolyon Oxley

Senior Physician, National Society for Epilepsy, Chalfont Centre for Epilepsy, Chalfont St Peter, Buckinghamshire

Chairmen

Introduction and first morning session: Sir Desmond Pond

Formerly Professor of Psychiatry, The London Hospital; and Chief Scientist, Department of Health and Social Security

Second morning session: Dr William Dixon

Head of the Medical Service, John Lewis Partnership, London

Afternoon session: Dr Ralph Aston

Chief Medical Officer, Lucas Industries PLC, Birmingham

Speakers

Mr Alec Aspinall

Chief Executive, British Epilepsy Association, Leeds.

Dr Tim Betts

Senior Lecturer in Psychiatry, University of Birmingham; Senior Research Fellow, University of Aston, Birmingham; and Chairman of Council of Management, British Epilepsy Association

Dr Ian Brown

Principal and Clinical Tutor in Family Medicine, and Occupational Physician to the National Coal Board, Tyne and Wear

Dr Tim Carter

Director of Medical Services, Health and Safety Executive, London

Dr Andrew Craig

Adviser in Health Education, National Society for Epilepsy, Chalfont Centre for Epilepsy, Chalfont St Peter, Buckinghamshire

Dr David Dick

Senior Registrar in Neurology, Regional Neurological Centre, Newcastle Upon Tyne

Dr Michael Espir

Principal Medical Officer, Civil Service Medical Advisory Service and Honorary Consultant Neurologist, Charing Cross Hospital, London

Dr Michael Floyd

Director, Rehabilitation Resource Centre, The City University, London

Professor Graham Harding

Professor of Clinical Neurophysiology, Honorary Consultant Neuropsychologist (BRHA), Department of Vision Sciences, Aston University, Birmingham

Dr Graham Lucas

Consultant Psychiatrist, Kings College Hospital and Adviser in Mental Health, Health and Safety Executive, London

Dr Jolyon Oxley

Senior Physician, National Society for Epilepsy, Chalfont Centre for Epilepsy, Chalfont St Peter, Buckinghamshire

Dr Gregory Stores

Consultant in Neuropsychiatry, National Centre for Children with Epilepsy, Park Hospital for Children, Oxford; and Clinical Lecturer, University of Oxford

Dr John Taylor

Medical Adviser, Department of Transport, Marsham Street, London

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The Editors wish to emphasize that neither they nor the sponsors are responsible for the opinions expressed at this symposium which are those of the respective authors and participants.

To know is not necessarily to understand. As an expression of this company's policy of social responsibility, Labaz-Sanofi UK Ltd is very pleased to provide a means by which those most qualified can help to create this understanding.

*J. W. King
Managing Director*

Foreword

FELICITY EDWARDS

*Senior Employment Medical Adviser,
Health & Safety Executive, Merseyside*

This symposium was the third in a series of educational symposia on epilepsy sponsored by Labaz Sanofi UK Ltd, the first of these being *Driving and Epilepsy* (held in Nottingham in 1982) and the second *Epilepsy and the Law* (held at the Royal College of Physicians, London, in 1984). The proceedings of both the previous symposia have been published by the Royal Society of Medicine in the same series as the present volume. The subject of the third meeting—*Epilepsy and Employment*—was felt to be of equal importance, and of special relevance in the present climate of recession and of widespread difficulties with employment.

The aim of the meeting was to provide a forum where the possible employment problems of people with epilepsy could be discussed, against a background of presentations covering a variety of aspects. This volume includes a review of published studies on epilepsy and employment; a review of health and safety legislation and its implications; and discussions of statutory and non-statutory barriers to employment, as well as the problems of recruitment, disclosure and employability. Other specific topics are the school leaver with a history of epilepsy; photosensitive epilepsy and employment; and driving as an occupation. Social and psychiatric aspects that may affect the employment of people with epilepsy are also discussed. Other papers look at epilepsy in the context of three separate sectors of employment—the steel industry, the coal industry and the National Health Service. Throughout the volume, there is an emphasis on the way in which some of the genuine problems encountered can be resolved. Some specific suggestions are put forward for fairer practices, particularly on recruitment.

In editing the proceedings, the medical editors have been very conscious of the fact that the inclusion of so many topics in a one-day meeting meant that speakers had only a short time in which to make their presentations. This publication includes the full texts on which speakers based their presentations and, in some cases, authors were able to extend both their papers and their bibliographies to include references to papers published since the meeting was held. A point of special interest was raised by correspondence after the meeting and has been included after the relevant paper. In addition, and partly because time did not allow a paper on the services available to help people with epilepsy to find suitable employment, two appendices have been added on the medical advisory and employment services available from the Health and Safety Executive and the Manpower Services Commission respectively.

Advice on a patient's medical condition and how it may—or may not—affect his choice of job, his application and recruitment into work, or his continued

employability, can be sought from those practising in a number of medical specialties: physicians, neurologists, paediatric neurologists, psychiatrists, family practitioners and occupational physicians. As well as doctors, however, members of other professions—occupational health nurses, social workers, Disablement Resettlement Officers and members of voluntary organizations—are frequently involved in advising people with epilepsy. Members of all these professions and specialties were present at the symposium and it is hoped that this volume will be of practical use to them as a reference publication and will provide the basis for greater consistency of advice than is sometimes given.

It is sad—but true—that many people (and sometimes, regrettably, members of the medical and other health care professions) tend to look at the person with epilepsy as if he, or she, were the same as any other person with epilepsy. There is a tendency to apply the label ‘epileptic’ to anyone who either has, or had, a variety of epilepsy. And yet, as anyone who has experience of this condition knows, epilepsy is *not* a single entity. It is a term that can apply to people with dissimilar histories, dissimilar types and severity of seizures, with a wide range of therapeutic control, different prognoses, and to those who may have other significant handicaps, or none. One of the most important lessons to be learned from this volume is that there is no such person as an ‘epileptic’: there are people with epilepsy and they are all different.

The other message—particularly from those papers covering recruitment, employability, health and safety legislation and different occupations—is that, equally, there is a very wide range of jobs. Many jobs are perfectly safe for many people with epilepsy and both the hazards of the job as well as the way in which epilepsy affects the individual concerned, must be taken into account when giving advice on employment. The Department of Transport’s regulations have different medical standards for applicants for ordinary driving licences and for applicants for vocational drivers’ licences, the restrictions being much more stringent for the latter. Occupational requirements may be looked at in the same way and it would be justifiable for employers to use similar criteria to those required for a heavy goods vehicle licence for people who are to undertake jobs with special hazards.

With regard to most other jobs, however, the feeling is beginning to spread (and this opinion was expressed by many who attended the meeting) that for the person with epilepsy fitness for employment in jobs which are *less* hazardous should be determined by the same criteria that form the basis of the regulations for the issue of ordinary driving licences. These are that, if epilepsy is controlled, the licence may be granted if the person satisfies the following conditions:

1. He shall have been free from any epileptic attack during the period of 2 years immediately preceding the date when the licence is to have effect; *or*
2. In the case of an applicant who has had such attacks whilst asleep during that period, he should have had such attacks only whilst asleep during a period of at least 3 years immediately preceding the date when the licence is to have effect; *and*
3. The driving of a vehicle by him in pursuance of the licence is not likely to be a source of danger to the public.

If these regulations are used as a yardstick when considering fitness for employment of people with epilepsy, as is suggested in some of the papers in this volume, it is important that all three conditions are considered. This is discussed further in *Driving and Epilepsy* (1) and in the chapter on epilepsy in the latest edition of *Medical Aspects of Fitness to Drive* (2). The importance of this third condition is that, although the individual’s attacks may fulfil the first two conditions, fitness for driving or employment may also be dependent in some cases on continuing treatment and freedom from unwanted drug effects. There may also be other factors requiring

consideration, such as intellectual or psychological handicaps or other cerebral deficits.

A well known saying has it that 'you can't see the wood for the trees'. Where epilepsy is concerned, however, it is all too often the other way round and many people, when advising on epilepsy and employment fail to see the 'trees' (the individual and the job) for the 'wood' (the label of epilepsy). For each person with epilepsy is different, jobs have different hazards, and many of the apparent problems put forward as barriers to the employment of people with epilepsy are, in fact, non-problems. We will have advanced a long way toward both greater consistency of advice and fairer recruitment and employment practices, if those advising on employment and epilepsy bear this in mind and can base their advice on some of the principles and practices so ably outlined in this volume.

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- (2) Raffle PAB, ed. *Medical aspects of fitness to drive* 4th edn. London: Medical Commission on Accident Prevention, 1985.

It was with deep regret that we learned of Sir Desmond Pond's death on 29 June 1986. Sir Desmond had an active and long standing interest in the study of epilepsy, on which he was an acknowledged authority. The sponsors and editors of this volume wish to record their appreciation of Sir Desmond's outstanding contribution to the subject of epilepsy and particularly of his personal contribution and support for this symposium.

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Chairman's introduction

SIR DESMOND POND

*Formerly Professor of Psychiatry, The London Hospital,
and Chief Scientist, Department of Health and Social Security*

When I did my survey of epilepsy in general practice more than 25 years ago, I became very aware of the difficulties that many adults with epilepsy experienced in keeping appropriate levels of employment. However, my study was necessarily superficial and this volume contains further thought and some more exact studies of the present position.

In some ways employment has changed dramatically, quite apart from the problems of being handicapped and in employment. When my previous study was published, full employment seemed a permanent law of society; now it seems very different; it is almost as if long-term unemployment has become a permanent aspect of society. There are also, of course, dramatic changes in the nature of work with, on the whole, much less hard manual labour and a great deal more machinery of all sorts—both changes having some implications for people with epilepsy. The employment regulations have also been tightened up and organized in a much clearer way.

There have, however, been fewer changes in personal relationships. As usual human nature does not change as fast as machines do, and the psychological and social problems are possibly more dictated by ignorance and prejudice than by understanding. All these factors can lead to problems for the person already handicapped by epilepsy, who is seeking employment, and often to all sorts of subterfuges if people develop epilepsy while they are actually in employment.

The point of paid employment is usually regarded in the first place as providing the wherewithal to live. Perhaps that is not quite so important now, with welfare provisions helping those who are not able to work, or work fully, to maintain some standard of living. Paid employment has usually been equated with work. 'Work' is quite difficult to define. Everybody knows when they are doing it, but it is not necessarily just a boring chore. It has many more implications for life and for personal development than simply providing the wherewithal to live. Freud said, and I think it is a very good phrase, 'work provides man's strongest hold on reality'. This is a typical sentence of his, implying that unless one has the discipline and the motivation of work then retreat into a fantasy world is only too easy. There are various aspects of work in this sense which have been particularly elucidated by some classical studies of the unemployed, both in the 1930s and the present, such as those carried out by Marie Yahoda. These studies show that work, and I use the term rather than

employment at the moment, provides many things—companionship, colleagues, and status. Such things, perhaps too much in our society, depend on what work you do. After all, almost the first thing one tends to ask about a stranger is ‘what does he do?’. This information provides immediately some sense of the person’s level of education, ability and class.

Another very important aspect of work is that it organizes time. One of the things that many people discover on retirement is that they still tend to wake up early in order to catch the 8.20 train or the first shift, or whatever, when there is no longer any need to do so. They find that time seems suddenly to become both lengthy and boring and there is a certain amount of emptiness in it. There are also many other networks of social structures and organizations into which the entrée is provided by the work situation. All these things are especially important for a person with a handicap, such as epilepsy.

The connection between being in full time paid employment and having these companionships, status and organization within one’s life is coming under considerable strain at the present time. Perhaps it calls for a fundamental change in social attitudes. I am rather worried that we have not yet really started to think about a category which I prefer to call ‘non-employment’, because when people say they are unemployed it has the implication that they are not working for one reason or another but that they should be. One has to recognize increasingly that there may well be a time coming soon, when there will not be much work, especially for certain types of worker. Some people may welcome this but, if the organization of time, companionship and so on formerly provided by work are not compensated for in other ways, then life may become very empty and difficult.

So, although this volume is directed towards the idea that we want people with epilepsy to obtain the best possible level of employment compatible with their abilities, I hope we shall spare time to think about the fact that the point of this is not necessarily, or only, to provide a decent living standard but also all the other social advantages of being employed.