

London, UK: The Chalfont Centre for Epilepsy

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HISTORICAL BACKGROUND

The National Hospital for the Paralysed and the Epileptic was founded at Queen Square, London in 1857. This Hospital has since been renamed the National Hospital for Neurology and Neurosurgery. Early physicians at the National Hospital, who established the foundations of the modern understanding of epilepsy and its treatment, included Sir William Gowers, John Hughlings Jackson, Sir David Ferrier, Sir Victor Horsley and William Aldren Turner.

The National Society for the Employment of Epileptics was founded in 1892. This was an initiative of the physicians at the National Hospital, in collaboration with philanthropic charities. There have been close links between the charity and the hospital ever since.

In 1894, the society purchased a farm in Chalfont St. Peter, Buckinghamshire, establishing the Chalfont Centre for Epilepsy. The name of the society was changed to the National Society for Epilepsy (NSE) in 1907. The NSE has provided residential care and public education from that time at its Chalfont site and, since its beginning over a century ago, has been the largest UK epilepsy charity that supports research and provides care for those with epilepsy.

In 1972, following a report by the UK Department of Health on the care of patients with epilepsy, a new National Health Service treatment unit was established at the Chalfont Centre, specially for patients with severe and complicated epilepsy. This Unit, termed the Special Assessment Unit, was run jointly by the National Hospital and the NSE and is the origin of the current National Health Service clinical inpatient and outpatient service for epilepsy at the Chalfont Centre.

In 1950, the Institute of Neurology was founded as a postgraduate Institute of the University of London.

The Institute has been closely linked with the National Hospital over the last half century.

The unique tripartite arrangement of the current era between charity (NSE), university (Institute of Neurology of University College London) and hospital (the National Hospital for Neurology and Neurosurgery—NHNN) was established in 1983, with the joint appointment of Dr Shorvon as a Senior Lecturer in Neurology at the Institute of Neurology, and Consultant Neurologist at the NHNN and at the NSE.

In 1988, the role of Medical Director of the NSE, was added to the existing posts of Senior Lecturer in Neurology at the Institute of Neurology and Consultant Neurologist at the National Hospital. This led to the restructuring and reorganisation of the clinical and research work of the NHNN, NSE and Institute of Neurology. The result was a co-ordinated and comprehensive spectrum of clinical care and research at the Chalfont and Queen Square sites and stimulated the rapid development and expansion of the range and quality of endeavours in these areas.

Since its beginning in 1894, the Chalfont Centre for Epilepsy has provided residential care for those with epilepsy and associated disorders, who were not able to live in the community.

SERVICE POPULATION

A key feature is that, whilst being an independent charity, the medical aspects of the Chalfont Centre for Epilepsy are fully integrated with the National Health Service, and the Social Care aspects are regulated by Social Services for standards and funding.

Patients attending as outpatients are in two main categories. The majority are tertiary referrals from Consultant Neurologists throughout the UK of patients

who have difficult diagnostic and therapeutic problems. In addition, the centre provides a secondary referral service for general family practitioners in the surrounding population of 200 000.

The residential population of 270 at the Chalfont Centre for Epilepsy are drawn predominantly from the Southern half of England and Wales, as there are residential Centres for Epilepsy near Manchester and Glasgow.

THE MAIN SECTORS OF THE CENTRE

Ambulatory care

At present, there are over 2000 outpatient consultations per year at the Chalfont Centre. The clinics are run as an outreach clinic of NHNN, using NHNN notes and Hospital numbers. Patients can choose whether they are seen at Chalfont or NHNN, according to which is most convenient for them. A new suite of five purpose-built consulting and examination rooms opened in February 2002.

The Assessment Centre

The Assessment Centre comprises 26 beds, and admits 280 patients per year, with an average length of stay of 25 days. An important feature is that the National Health Service (NHS) funds admissions, as to any other hospital. The contractual arrangements with Health Authorities are handled through the Contracts Department of NHNN, itself part of University College London Hospitals NHS Trust, which is one of the largest Hospital Groupings in the NHS.

Patients may be admitted for a variety of reasons and for lengths of stay that range from 2 days to 6 months. The principal reasons for admission are:

- Presurgical evaluation (advanced MRI at NSE MRI Centre, medical, psychological and social work assessment, EEG): typical admission 3 days.
- Diagnostic evaluation (advanced MRI at NSE MRI Centre, medical, psychological, psychiatric and social work assessments, video taping of seizures, 24 hours 16-channel ambulatory EEG): typical admission 5–10 days.
- Complex diagnostic evaluation (advanced MRI at NSE MRI Centre, medical, psychological, psychiatric and social work assessments, 5–10 days of ambulatory EEG, video taping of seizures): typical admission 3 weeks.
- Optimisation of antiepileptic drug treatment, assessment and treatment of psychiatric, psycholog-

ical and social concomitants of epilepsy: typical admission 3–8 weeks.

- Assessment and treatment of non-epileptic attacks. In 15% of admissions of patients with a previous diagnosis of chronic epilepsy the diagnosis is found to be other than epilepsy: typical admission 2–4 weeks.
- Assessment of abilities and potential for independent living, employability, assessment of future care needs, liaison with local medical and social services for planning and implementation of short-, medium- and long-term care and therapy plans: typical admission 2 weeks.
- Assessment for suitability for NSE Rehabilitation Unit: typical admission 2 weeks.

A new, purpose-built Assessment and Treatment Centre opened in February 2002. This centre has 26 beds, 18 of which are in single rooms. There are rooms for digital video-EEG telemetry, designated areas for counselling, patient recreation, active rehabilitation and direct access to the epilepsy MRI Unit. The centre is named the Sir William Gowers Centre, after the neurologist who contributed greatly to our current understanding about epilepsy and who had a lead role in establishing the society.



Passmore Edwards House

Rehabilitation department

The LINKS Rehabilitation Unit currently has nine spaces and is run by Clinical Psychologists and rehabilitationists. There are six admissions per year, and these are typically for 12–18 months. The emphasis is to increase independence and maximise the potential of the service users. The funding of the Rehabilitation Unit is not by the Health Service, but by the Social Service (i.e. welfare) departments in the locality from which the user originates. With constraints on social care budgets, it can be difficult to get an admission for rehabilitation funded, even when the user, their family and professional advisers regard this as being appropriate.

The rehabilitation department also manages four houses for younger people with epilepsy and two independent living projects. The younger houses provide accommodation and rehabilitation for up to 68 residents. In addition, a supported living project houses 32 more independent residents and the supported housing project run in conjunction with a housing association provides 24 self-contained units of accommodation.

In the future it is planned to increase the number of spaces for rehabilitation, and to also provide this service away from the main campus.

Residential social care and nursing departments

Long stay residential accommodation is provided for 114 residents in six separate houses on site. A further 56 places are provided in three houses that provide nursing care as well as long-term residential care. The majority of these residents have lived at the NSE for many years and constitute a stable residential population. Each year there is a small number of new admissions, amounting to 15 or 20 people. All prospective new residents spend up to 4 weeks on the house to which they are being considered for admission for detailed assessment and the preparation of an individual care plan.

The nursing services also include a 22-bed medical centre to which residents may be admitted if they require medical or nursing care, either for acute seizure management, or for the management of trauma and other non-neurological problems. It is home for eight patients with long-term medical needs, and severe multiple disabilities and also provides respite care for people living with epilepsy in the wider community, primarily to give the person's usual carer a break.

A Consultant Epileptologist undertakes the care of the epilepsy of the residential population, and there is a part time consultant psychiatrist. A resident junior doctor deals with acute problems, and there is a resident medical officer at all times. All the other medical care of residents is managed by two general practitioners, who consult at the centre as well as in the neighbouring town.

The investigatory facilities: MRI, EEG, Psychology, Drug level monitoring are freely available.

Residents needing more intensive neurological care, for example as a result of status epilepticus or head injury, are admitted to NHNN, where the same Consultants can care for them, as at the Chalfont Centre for Epilepsy. Residents with non-neurological problems who require hospital care are admitted to a local District General Hospital that is 15 km distant.

The dependency and complexity of the needs of the residents is increasing. This requires an increase in trained staff to manage and anticipate problems, particularly in the domains of learning disability and conduct disorder. In the next year, an epilepsy Specialist Nurse will start, to assist with the epilepsy management in the residential houses, and there will be an increase in the numbers of carers who are trained in learning disability.

An extensive programme of modernisation of the residential and nursing facilities on site is planned over the next 5 years, in response to the introduction of new national standards by Central Government. This will present a major challenge to the Chalfont Centre and may result in a reduction in the residential population on site with a consequent increase in the number of people supported by the society in more independent accommodation off-site.

Day time activities

There is a very active daytime activities department. This includes a sheltered workshop for about 70 individuals, a printing and bookbinding workshop that is run commercially, social and art centres, music therapy, a sensory room, specialist IT equipment designed for people with disabilities and recreation facilities. Sports facilities are provided in the local community. In addition, many residents attend local colleges for further education.

The Daytime Activities Department also has responsibility for organising holidays and recreation for residents and we endeavour to offer every resident at least 1 week's holiday in a suitable off-site venue of their choice every year.

Fund-raising

Approximately 80% of the society's income of £13.4 million (20.5 million ECU) comes from fees charged to Central and Local Government for the Services it provides under contract to them. The balance comes from fund-raising. A small fund-raising team organises a programme of fund-raising activities each year and co-ordinates applications to grant giving organisations and Central Government Departments to secure the additional funds needed each year by the society. In 2000/2001, more than £1.6 million was raised by the Fund-raising Department.

PERSONNEL AND ORGANISATION

The Chalfont Centre for Epilepsy is owned by the charity, the National Society for Epilepsy, and is run

by a Board of Governors, who undertake their work in a voluntary capacity. Overall responsibility for the Governance of the Chalfont Centre and the NSE as a whole rests with the Board of Governors. There are 16 Governors drawn from a variety of walks of life, including medicine, law, social work, business, banking, and nursing. Responsibility for the day-to-day operation of the centre rests with a full-time salaried Chief Executive, who is responsible to the Board.

The society operates through five Directorates:

- Medical;
- Services;
- Finance;
- Personnel and training;
- Fund-raising.

Each Directorate is headed by a Director who reports to the Chief Executive and the five Directors and the Chief Executive form the Society's Senior Management Team. Other specialist functions, e.g. Information and Education, Communications and PR, Buildings, and Service Development report direct to the Chief Executive. Overall, the society employs over 430 people.

Recruitment to the caring professions has been difficult in the UK for some time now. This is a national problem due in part to low levels of pay and also to the public perception and status of the jobs. This is exacerbated in Chalfont by the high cost of housing locally and poor public transport links. Recruitment and retention initiatives have been introduced in recent years, including on-site housing, subsidised transport and enhanced remuneration packages.

Recruitment of medical and paramedical staff has not been such a problem. The key reason for this is the integration of these services with the NHNN and with the Institute of Neurology of UCL, which bring high prestige and avoid isolation. All senior staff have joint appointments with the NSE, the NHNN and with the Institute of Neurology, and would spend days at each site through the week. This is crucial to ensure ongoing collaboration and efficient complementarity of provision.

Junior medical staff work in a rotation, with 3 months spent at the Chalfont Centre for Epilepsy, followed by 6 months at NHNN. Neurological trainees on the London Neurology training Programme spend 4 months of their 5 years training attached to the Epilepsy Unit of NHNN and the Chalfont Centre for Epilepsy, and spend 1 day per week at Chalfont through this time. The consequence is that an increasing number of UK Consultant Neurologists have had direct experience of the NSE and the Chalfont Centre for Epilepsy and appreciate the role of the

charity in the management of complex epilepsy and its ramifications.

Recruitment of nursing staff in the whole of the UK, particularly in the London area, is very difficult, as wages are not competitive with salaries offered by business. In consequence, in the last year, there has been extensive recruitment of nurses from outside of the UK, which has enriched the centre, but has also required readjustment and increased the need for on-site training. The society is keen to develop further links throughout Europe and to attract nurses from Europe to work at the Chalfont Centre, either on short-term secondments or on a more permanent basis.

CO-OPERATION AND NETWORKING

There is an integration of neurology and psychiatry services with NHNN. This is ensured by the joint appointment of medical and paramedical staff at Hospital, charity and University. The same patient note files and patient administration computing system are used at both sites. There is a free flow of patients between the Assessment Centre at Chalfont and NHNN. For presurgical evaluation the basic medical assessment, MRI, psychology is carried out at Chalfont. Patients from NHNN are referred to The Epilepsy MRI Unit at Chalfont for optimal brain imaging.

The residential population of the Chalfont Centre is regarded as being in primary care and the budget for this provision is held by the local Primary Care Trust (PCT) (The Chiltern and South Bucks PCT). The PCT holds the budget for all drugs prescribed in primary care, including antiepileptic drugs (AEDs). The current annual budget for AEDs for the residential population is £290 000 and this is under great pressure with the advent of the new AEDs. There are also ongoing discussions between the charity and the PCT as to the responsibility for funding the costs of medical care of the residents, which amounts to £450 000 per year. At present, the PCT makes a contribution of £59 000 per year, in recognition of the medical services provided by the charity on the campus and which spare the use of local community and secondary care facilities.

Increasingly Central Government looks to coalitions of charities in consulting about the provision of medical and social services. The NSE is an active member of the Joint Epilepsy Council (JEC), a coalition of 20 organisations involved with all aspects of epilepsy, and the JEC works with Central Government to promote the interests of people with epilepsy and those organisations seeking to work with and for them.

EDUCATION, INFORMATION, AND PUBLIC RELATIONS

The society operates an information and education service, providing literature to its 2500 or so associate members as well as to professional audiences and the general public. In addition to printed material the society operates a web site, including a professional section, and a helpline which receives over 6000 calls a year.



MRI Unit

Recent developments have included the establishment of an advice service in hospitals and clinics around the country, staffed by trained and supported volunteers. These helpdesks are designed to give non-medical information to people with epilepsy and their carers following appointments with consultants, in particular information about how epilepsy might effect their lifestyle.

The society also operates a small training department to train its own staff and increasingly to offer training to staff and volunteers in other organisations

as well as members of the public. The society collaborates with a local university to offer specialist training in epilepsy for nurses and we are actively developing specialist degree and post-graduate programmes in epilepsy alongside specialist vocational training.

The society also has a Public Relations/Communications Department that produces a quarterly journal, *Epilepsy Review*, and seeks to promote good relationships with press and television.

FINANCIAL PERSPECTIVES AND STRATEGIC DELIBERATIONS

The annual running costs of the society are approximately £13.4 million or 20.5 ECU. The major funding challenging facing the society is to secure adequate fee income from Social Services and Health Authorities to meet the full cost of the care services provided under contract to them. In recent years the society has run these services at a substantial loss and negotiations are on going to secure the correct level of funding.

Currently these services are subsidised from voluntary income and fund-raising. Negotiations are proceeding to increase fees to eliminate the subsidy. In addition, fundraised income is used to fund research and to develop new and improved services.

The future strategy envisages a reduction in the number of people with epilepsy living on the Chalfont site, and the development of more independent forms of supported housing in the wider community. The society will work with others, local authorities and housing organisations, to realise these plans. Detailed planning for the implementation of the future planning will take place in 2002.