The Chalfont Centre, Bucks, United Kingdom

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1. HISTORICAL BACKGROUND

The National Hospital for the Paralysed and the Epileptic - now called the National Hospital for Neurology and Neurosurgery (NHNN) - was founded at Queen Square, London in 1857. Early neurologists at the NHNN, who established the foundations of the modern understanding of epilepsy included William Gowers, Hughlings Jackson, David Ferrier, Victor Horseley and William Turner.

The National Society for the Employment of Epileptics was founded in 1892 (renamed as the National Society for Epilepsy in the 1920s and as the Epilepsy Society in 2011). This was an initiative of the neurologists at the NHNN, in collaboration with philanthropic charities. There have been close links between the charity and NHNN ever since. In 1894, the society purchased a farm in Chalfont St. Peter, Buckinghamshire, establishing the Chalfont Centre for Epilepsy (CCE), which has provided medical and residential care and public education ever since. Epilepsy Society (ES) is now the largest UK epilepsy charity supporting research and providing care for those with epilepsy.

In 2013, ES opened the new Research Centre in Chalfont St Peter to enable advanced epilepsy research and translate it into clinical practice. The centre integrates research with the medical facilities, an epilepsy-dedicated MRI unit and therapeutic drug monitoring unit. It includes a spacious laboratory, consulting rooms, offices, seminar room and video conferencing facilities. On site research focuses on two distinct areas: brain imaging and genetics. ES is using exome and whole genome sequencing to unravel the complex genetic architecture of the epilepsies and to take new discoveries directly to care. Research at Chalfont is carried out in close collaboration with NHNN and is closely affiliated to Institute of Neurology of University College London (UCL).

2. SERVICE POPULATION

Despite being an independent charity, the medical aspects of CCE are fully integrated with the National Health Service (NHS). The Social Care aspects are regulated by the Care Quality Commission for quality standards, and are funded through local authorities and the NHS.

People with epilepsy attending as outpatients fall into two main categories. The majority are tertiary referrals from Consultant Neurologists throughout the UK. These referrals are for those who have difficult diagnostic and therapeutic problems. The centre also provides a secondary referral service for general practitioners in the surrounding population of 320,000. The residential population of 100 people with severe epilepsy and complex needs is drawn predominantly from the Southern half of England and Wales.

3. THE MAIN SECTORS OF THE CENTRE

Ambulatory care

At present, there are over 2,200 outpatient consultations per year. The clinics are run as an outreach clinic of NHNN. People can choose whether they are seen at Chalfont or NHNN, according to which is the more convenient for them.

The Assessment Centre

The purpose-built Sir William Gowers Assessment and Treatment Centre has 26 beds, 6 telemetry recording suites, designated areas for counselling, patient recreation, active rehabilitation and direct access to the MRI Unit. Investigatory facilities include: advanced structural MRI and functional MRI (motor, language, memory and vision); neurophysiology and neuropsychology; and drug level monitoring. There is also a suite of cutting-edge research tools: optical coherence tomography for measuring peripheral vision and the thickness of the retinal fibres; 3D imaging to establish links between face shape and genetic variations, and transcranial magnetic stimulation for measuring cortical excitability. In addition, an in-house developed smart surgery Epilepsy Navigator helps to identify critical areas of the brain structure and function, to improve accuracy and precision of surgery. If people require further investigations such as EMG, DAT, PET or SPECT, they are referred to the NHNN.

The Assessment Centre admits over 1,200 people a year reimbursed by the NHS. The contractual arrangements with Commissioners are handled through the Contracts Department of NHNN, itself part of University College London Hospitals NHS Trust (UCLH), which is one of the largest UK Hospital Groupings.

People may be admitted for a variety of reasons and for lengths of stay that range from 2 days to 4 months. The main reasons for admission are:

- Presurgical evaluation (MRI, medical, psychological and social work assessment, EEG): typical admission 3 days.

- Diagnostic evaluation (MRI, medical, psychological, psychiatric and social work assessments, ictal video recording, 24 hours ambulatory EEG): typical admission is up to 5 days.

- Complex diagnostic evaluation (MRI, medical, psychological, psychiatric and social work assessments, 5–10 days of ambulatory EEG, videotaping of seizures): typical admission 3 weeks.

- Optimisation of drug treatment, assessment and treatment of psychiatric, psychological and social concomitants of epilepsy: typical admission 3–8 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.

Residential social care and nursing departments

Long-stay residential accommodation is provided for circa 100 residents in 6 separate houses on site. About half of these residents have lived at ES for many years and constitute a stable residential population. Each year there is a small number of new admissions, amounting to 4 or 5 people. All prospective new residents spend up to 4 weeks in the house to which they are being considered for admission for detailed assessment and the preparation of an individual care plan.

A Consultant Epileptologist undertakes the care of the epilepsy of the residents and a junior doctor deals with acute neurological problems. Other aspects of the medical care of residents are managed by 2 general practitioners, who consult at the centre as well as in the neighbouring town.

Residents needing more intensive neurological care, for example for status epilepticus or head injury, are admitted to NHNN, where the same Consultant as at CCE will care for them. Residents with non-neurological problems who require hospital care are admitted to a local District General Hospital which is 15 km away.

Activities

There is a very active daytime activities department including a social and an art centre, music therapy, a sensory room, specialist IT equipment designed for people with disabilities, and recreation facilities. Sports facilities are provided in the local community. Many residents also attend local colleges for further education. Activities 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.

Fundraising

Approximately 90% of ES's income of £16.7 million comes from fees charged to Central and Local Government and NHS for services provided. The balance comes from fundraising. In 2015/2016, around £2 million was raised or provided as a legacy. A small fundraising team organises a programme of fundraising activities each year and co-ordinates applications to grant-giving organisations and Central Government Departments to secure additional funds.

4. PERSONNEL AND ORGANISATION

CCE is wholly owned by Epilepsy Society and is run by a Board of Trustees, who undertake their work in a voluntary capacity. Overall responsibility for the governance rests with the Board of Trustees. There are 12 Trustees drawn from a variety of backgrounds, 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 4 Directorates:

- Medical & Research;

- Care Services;

- Finance & Corporate Services; and

- External Affairs & Fundraising.

Each Directorate is headed by a Director who reports to the Chief Executive, and the 4 Directors and the Chief Executive form the Society's Senior Management Team. Other specialist functions, e.g. Information, Communications and Marketing, Buildings, and Stakeholder Relations report direct to the Chief Executive or the Chief Operating Officer. Overall, the society employs 355 permanent, and 163 bank staff.

Recruitment to the caring professions in the UK is difficult – partly due 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 local housing, and poor public transport links. Recruitment and retention initiatives have been introduced in recent years, including on-site housing, a referral bonus, encouraging a move from bank to permanent, and recruitment software to make applications easier. Nurses are the hardest group to recruit.

Recruitment of senior medical staff has not been so problematic. The key reason for this is the integration of these services with the NHNN and with UCL Institute of Neurology, which brings high prestige and avoids isolation. All senior medical staff have joint appointments with ES, the NHNN and with UCL and spend days at each site through the week. This is crucial to ensure ongoing collaboration and efficient complementarity of provision.

Junior medical staff and neurological trainees work in a rotation at CCE and NHNN. The consequence is that an increasing number of UK Consultant Neurologists have had direct experience of ES, 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. It remains to be seen how the effect of Brexit will impact recruitment, though it is anticipated to have a notable effect across the organisation – from research fellows to care staff.

5. 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 NHNN and ES. The same clinical records are used at both sites. There is a free flow of patients between CCE and NHNN. Patients from NHNN are referred to the 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 Clinical Commissioning Group (CCG). The CCG holds the budget for all drugs prescribed in primary care, including antiepileptic drugs (AEDs). Increasingly Central Government looks to coalitions of charities in consultations about the provision of medical and social services.

6. SCIENTIFIC CONTRIBUTIONS, EDUCATION, INFORMATION AND PUBLIC RELATIONS

Scientific Contributions

CCE is at the forefront of basic and clinical research, working individually, partnering with UCL and NHNN and reaching out globally to undertake collaborative studies, both to decipher the challenges facing people living with epilepsy, and to improve clinical practice. It has made major contributions to epilepsy imaging, epidemiology, pharmacology and genetics – including discovery and causes of rare epilepsies, epilepsy traits such as photosensitivity, outcomes such as SUDEP (Sudden & Unexplained Death in Epilepsy), epilepsy pharmacogenetics; identifying previously unidentified genetic cause of antiepileptic drug-related rash, providing a better understanding of the effects of the genetic changes detected, and improvements in epilepsy surgery.

Research can only be advanced by implementing essential infrastructure and research excellence; which is dependent on support from external organisations. ES, in association with UCL, bids for peer-reviewed competitive research grants from sources such as Wellcome Trust, the Medical Research Council, EUH2020 and other granting agencies.

Education & Information

ES operates an information and education service, which aims to inform, educate and support people with epilepsy, along with their families, friends and carers, health and social care professionals, and allied stakeholders. Fundamental to the aims of the service is to reduce the negative impact of a diagnosis and of living with epilepsy, by providing information which is clear, easy to understand, accurate and current. In addition, continuous contact with people affected by epilepsy is maintained through a phone helpline, which receives over 6000 calls a year.

Public Relations

ES has a marketing department tasked with raising awareness of epilepsy in the media, increasing the profile of research and informing people how best to manage the condition through Information Services. In 2015/16 over 110,000 information resources were distributed, and there were over 1.8m visits to the information pages on epilepsysociety.org.uk. ES has a vibrant social media community with almost 50,000 on Facebook and there is an Epilepsy Toolkit App (available on Android and iTunes). Members receive a journal, Epilepsy Review, three times a year and UK-based professional members are entitled to order information for distribution in their clinics.

ES also has a department focussing on policy, which seeks to expand the reach and influence of the organisation through advocacy, lobbying, and thought leadership. The policy team engages with a wide variety of stakeholders in the health policy and medical research arena, from Government bodies, Members of Parliament and commissioners, to the NHS, other neurological charities, industry and beyond. This has proved an effective way to help shape the external environment to better reflect the aims and objectives of the charity.

7. FINANCIAL PERSPECTIVES AND STRATEGIC DELIBERATIONS

The annual running costs of ES are approximately £17.7 million. The major funding challenging facing ES is to secure adequate fee income from local authorities to meet the full cost of the care services provided under contract to them. Currently these services are subsidised from voluntary income and fundraising. Negotiations are proceeding to increase fees to eliminate the subsidy. Fundraised income is also used to fund research and to develop new and improved services.

8. HOW TO OVERCOME BARRIERS

Charities in the UK have been significantly impacted by the ongoing economic crisis, which has affected both fundraising income across the board, and fees from local authorities for specialised care services. This double hit has forced a more proactive approach to income generation, and ES has welcomed opportunities to diversify and embrace change. This involves greater collaboration within and across sectors, and a prioritisation of our medical and research work. In the wake of an impending Brexit, with all its uncertainties, this will prove more important than ever.

At our research centre, we are at the cusp of undertaking a ground-breaking project on genomics. This demands multi-stakeholder collaboration to deliver the project, and to realise the benefits for those affected by epilepsy: it will focus on accelerating ‘bench-to-bedside’, and offering translation of that research through an on-site genomics clinic. We strive to harness innovative opportunities in research and care, and it is our view that by remaining flexible, involving patients early in the process, and thinking creatively, we can achieve transformative change for people with epilepsy over the next decade.