Epilepsy and Sleep

Introduction

There is a complex relationship between epilepsy and sleep as seizures may be exacerbated by sleep deprivation and some seizure types occur mainly during sleep or following awakenings. Primary sleep disorders (such as sleep apnoea) may also disrupt sleep and cause sleep deprivation and potentially aggravate seizure disorders. Sleep is also important for memory consolidation and poor sleep may not only affect daytime function but also quality of life. Excessive daytime tiredness and sleep difficulties are common in people with epilepsy and also in people with learning difficulties. Identification and treatment of sleep problems are important parts of patient care and may contribute to improved seizure control and quality of life.

Sleep can broadly be divided into REM (rapid eye movement) and non-REM sleep. Non-REM sleep is further categorised as light (stage I-II) and deep sleep (stage III-IV or slow wave sleep). Interictal epileptiform discharges (IED) are more frequent during non-REM than both REM sleep and wakefulness, potentially due to the more synchronised activities such as sleep spindles, delta waves, and slow cortical oscillations associated with non-REM sleep. Epileptic seizures can occur at any stage of non-REM sleep but are more frequent during lighter than deeper stages of non-REM sleep (Sinha et al., 2006). Seizures often also occur in transition between sleep stages or during instability.

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of sleep as identified on electroencephalography (EEG) with so called cyclic alternating patterns (CAP) (Terzano et al., 1985). In particular, frontal lobe seizures more commonly arise from sleep than wakefulness, however, if temporal lobe seizures occur in sleep, they are more likely to secondarily generalise (Herman et al., 2001). Studies from the 19th and early 20th century found that around 20% of patients with epilepsy had nocturnal seizures only (Gowers, 1985; Langdon-Down and Brain, 1929). Perhaps the best established relationship between epilepsy syndromes and sleep is in idiopathic generalised epilepsy syndromes, in which seizures often occur shortly after waking (Janz, 1974). This is especially evident in juvenile myoclonic epilepsy and epilepsy with generalised tonic-clonic seizures on awakening.

IED are also facilitated following sleep deprivation, even in the absence of sleep during the EEG recordings (Ellingson et al., 1984). It has been suggested that this is due to instability of sleep/wakefulness and frequent fluctuations in vigilance levels (Halasz et al., 2002). Transcranial magnetic stimulation (TMS) has been used to study cortical excitability following sleep deprivation in more details. Increased cortical excitability following sleep deprivation has been seen both in patients with generalised and focal epilepsies compared to control subjects (Badawy et al., 2006; Manganotti et al., 2006). The effect appears to be greatest in patients with generalised epilepsies where changes are seen bilaterally. Interestingly, in patients with focal epilepsy, increased cortical excitability has only been recorded from the hemisphere ipsilateral to seizure focus (Badawy et al., 2006). Changes may reflect reduced intracortical inhibition, as the most likely mechanism for an increase in excitability at the stimulation intervals used is reduced GABA activity (Badawy et al., 2006).

Certain epileptic encephalopathies also show marked diurnal variation in seizure manifestation and electrographic activity. This is a particular feature of electrical status epilepticus during sleep (ESES), which is characterised by spike and wave discharges in 85–100% of non-REM sleep. Clinical manifestations vary but often include cognitive, motor and behavioural disturbances and may relate to brain regions affected. A striking example is Landau-Kleffner syndrome characterised by acquired aphasia, epileptic seizures and paroxysmal, sleep-activated EEG discharges predominating over the temporal or parieto-occipital regions; language areas (Landau and Kleffner, 1957). Sleep is now increasingly being recognised to be important for memory and other brain functions (Walker and Stickgold, 2004). It has been shown that sleep, in particularly slow wave activity, can improve task performance after sleep (Huber et al., 2004). From this it has been postulated that the epileptic activity seen during sleep in ESES interferes with normal slow wave activity at the site of the epileptic focus and hence impairs neuronal processes and possibly local plastic changes associated with learning and other cognitive functions (Tassinari et al., 2009). This may consequently be the reason for the neurological decline in this group of patients.

Epilepsy and sleep disorders are both common in children and adults with learning disabilities. Studies have shown that sleep fragmentation and scores on sleep behavioural questionnaires are worse in children with epilepsy and learning disabilities compared with those with epilepsy and normal cognitive function (Wirrell et al., 2005). Sleep fragmentation in this group of children has been confirmed using overnight polysomnography (Miano et al., 2010). Children with greater sleep disturbance also have more behavioural problems and a poorer quality of life (Wirrell et al., 2005). However, this is also seen in children without epilepsy and it unclear whether the sleep problem causes the behaviour problems or vice versa. Interestingly, children with epilepsy but no clear developmental delay may have significant sleep problems and worse neuropsychological functioning even at seizure onset (Byars et al., 2008). This further supports the importance of sleep for cognitive function.

Bed time difficulties, shorter total sleep time, reduced sleep efficiency, higher numbers of awakenings and stage shifts, increased wake after sleep onset have all been seen in people with epilepsy and learning
disabilities (Bruni et al., 1995; Miano et al., 2010; Wirrell et al., 2005). However, also in the absence of learning disability, a worse quality of life has been reported in epilepsy patients with than patients without concomitant sleep complaints (de Weerd et al., 2004). It is therefore important to ask for sleep problems in clinic as this may contribute to poor quality of life and potentially also reduce seizure threshold and contribute to cognitive problems.

Seizures and frequent IED can also disrupt sleep architecture, causing more instable sleep as measured with cyclic alternating patterns (CAPs) in both partial and generalized epilepsies (Gigli et al., 1992; Parrino et al., 2000; Terzano et al., 1992). Polysomnography following focal seizures has revealed reduced amount of REM sleep after seizures (Bazil et al., 2000). The effect was most pronounced after nocturnal seizures (from 16 to 7%) but also significant after seizures occurring the previous day (from 18 to 12%). Nocturnal seizures also reduced the amount of stage II and IV sleep and increased the amount of stage I sleep (Bazil et al., 2000). This was associated with reduced sleep efficiency and increased drowsiness the day after. It is not clear if frequent IED or nocturnal seizures interfering with overnight sleep may also contribute to for example memory problems as both REM and deep (slow wave) sleep have been found to be important for memory consolidation as outlined above.

Excessive day-time somnolence (EDS) is common in patients with epilepsy (Hoeppner et al., 1984) and is often thought to be a side-effect of antiepileptic medication or seizures. Sleepiness is also frequently reported in patients with refractory seizures undergoing investigations for epilepsy surgery and has been shown to improve after surgery (Carrion et al., 2010; Zanzmera et al., 2013). However, in other studies antiepileptic medication, seizure frequency, epilepsy syndrome or sleep-related seizures were found not to be predictors for EDS whereas the sleep apnoea score and restless leg syndrome were (Malow et al., 1997). Obstructive sleep apnoea (OSA) is reported in 10-33% of patients with epilepsy (Malow et al., 2000; Manni et al., 2003; Phillips et al., 2013). Further, antiepileptic drugs could reduce respiratory drive and upper airway tone and some drugs are also associated with weight gain that is an important risk factor for OSA. Obesity and polytherapy were more commonly seen in patients with a combination of epilepsy and OSA than in patients with epilepsy alone (Malow et al., 2000). Non-pharmacological treatment for epilepsy with vagus nerve stimulation (VNS) has also been shown to worsen OSA (Ebben et al., 2008). OSA is associated with reduced quality of life, increased cardiovascular morbidity and mortality but also worsened seizure control, presumably due to fragmented sleep and sleep deprivation. Consequently, treatment of sleep apnoea can improve seizure control which has been shown in several studies including a randomised controlled trial (Malow et al., 2008).

Other sleep disorders can also disrupt sleep in patients with epilepsy and may hence also contribute to poor seizure control. Periodic limb movements of sleep (PLMS) are repetitive, stereotyped movements often of the legs but can also involve upper limbs. These occur every 5 – 90 seconds and can cause arousals and sleep disruption that might precipitate seizures (Ehrenberg, 2000). PLMS and epileptiform discharges have been shown to appear simultaneously and there may be a reciprocal triggering effect (Nobili et al., 2006). The incidence of PLMS in patients with epilepsy is not known and although patients admitted for video telemetry often have oxygen saturation measured, it is rare for patients to have periodic limb movements recorded. In view of the potential for sleep disruption by these movements, adding leg EMG, in particular in patients with excessive daytime somnolence, could provide useful information regarding need to treat concomitant sleep disorders that may contribute to poor seizure control.

OSA but also PLMS have been associated with autonomic instability with increased blood pressure and pulse rate and it has been hypothesised that OSA
may increase the risk for SUDEP (sudden unexplained death in epilepsy) (Andersen et al., 2012; Nobili et al., 2011). The postulated mechanisms are either because of increased seizure frequency or because of induced autonomic disturbance (Andersen et al., 2012; Nobili et al., 2011). However, further research is needed to establish any relationship between primary sleep disorders and SUDEP.

**Conclusion**

There is an intricate relationship between sleep and epilepsy and sleep plays an important role both for seizure control and memory consolidation. It is therefore important to ask patients about sleep problems or excessive daytime somnolence to identify and treat sleep disorders as well as epilepsy to ensure optimal management as well as potentially improving quality of life.

**References**


When planning the content of the review the core inspiration has always been the range of issues presented in my epilepsy clinic and themes emerging in the literature. These are then matched to excellent professionals who we know can produce concise educational articles. In this issue we cover some key issues from the clinic.

Two articles approach areas of great importance in care delivery. These are areas that when they go well complement our treatment, but when not working as planned offer barriers to care. Walter Louden discusses the development and content of a learning disability and epilepsy clinic, many such clinics occur with differing models. The model described here, a joint clinic by an epilepsy specialist nurse and a learning disability nurse is interesting and further information on its impact on care will be valuable. We are lucky to have a distinguished GP, Dr Greg Rogers, discuss the role of primary care in the management of people with epilepsy. Primary care has made real advances in organising and improving care for people with epilepsy; Dr Rogers describes these and highlights future directions for primary care.

Our other two articles approach two common clinic issues. Dr Ann Johnston has chosen as her key clinical paper a classic paper from Queens square showing how clinically significant arrhythmias can be seen in patients with chronic epilepsy. One of the most complex issues to address in our clinics is that of sleep disturbance. Dr Sofia Eriksson provides us with a thorough review of sleep disturbance and its association with epilepsy.

As always I hope this edition does supply you with information that can be applied in clinics and help in improving the morbidity associated with epilepsy in our patients.
Introduction

Primary care like many other areas of the NHS has had its moments of bad media coverage and I am conscious that some of these images have stuck. However, I hope to show that while primary care is not perfect, it does have a good deal it can contribute to support people with both learning disability and epilepsy.

General practice represents a sizable workforce, with around 60,000 doctors registered as being GPs on the GMC register for the UK. This community placed resource is ideally located to play a supportive role for people who have both learning disability and epilepsy.

In this article I hope to look firstly at the past, review the current and finally to look to potential future roles of primary care for this group.

The Past:

In 2002 the National Sentinel Clinical Audit of Epilepsy-Related explored three key areas one of which was the care received prior to death, in both general practice and secondary care. Amongst their findings were many reports of inadequate access to appropriate epilepsy care and they frequently discovered a lack of education of healthcare professionals about the principles of epilepsy management. The deficiencies in care were sited to be present on both primary and secondary care and had also been reported by other authors at the time.

Around this time there was also concern over quality of care for people with learning disability. Even though people with learning disability tended to visit their GPs more frequently they did not do so about their epilepsy. The authors’ suggestion that the likely reason was that it may reflect the limited involvement of GPs in the care of epilepsy in general.

This does not place a very firm foundation to build on but steadily, since then improved awareness in primary care for people with learning disability and epilepsy were made.

Present – looking at the current programmes of care:

Since 2006 the Quality and Outcomes Framework [QOF] has included an indicator for learning disabilities which at first glance appears very simple but which represents a step forward. The indicator LD1 requires the practice to produce a register of patients aged 18 years and over with learning disabilities. This then forms the basis for further pro active care, being followed in 2011 with LD2 which requires the practice to identify patients over 18 on the learning disability register with Down's syndrome, who have a record of...
blood TSH in the preceding 15 months. As everybody in the UK has a GP, proactive structured care becomes possible and helps to overcome the cultural and regional differences in care provision. These factors are known to have an impact on social exclusion for people with learning disabilities.

This development lays a good foundation for more specific annual health checks for people with learning disability in primary care amongst who are people with epilepsy. The structured health check allows for the assessment to be more effective to identify physical, psychological and social problems. Some of these needs may be met by the primary care team but for areas outside of the GP’s scope people can be signposted to other health care professionals or the voluntary sector. These checks should be commissioned as being in addition to the quality and outcomes framework and should focus more clearly on learning disability specific health issues.

The Directly Enhanced Service (DES) in England for Learning Disability was introduced in 2008 and was based on the Cardiff Protocol now called the Welsh Health Check for Adults with a Learning Disability and on the Social Services Register. The uptake for the health check has steadily increased with 23% of the eligible population receiving the check in 2008 increasing to 43% by 2011. Educational events to support the primary care team understand more the needs of the learning disabled may increase this uptake by practices further. In the second version of the health check there was a recommendation for epilepsy specialist review every three years however this unfortunately has been removed in the latest version.

This does not prevent however the patient’s GP arranging such a referral when epilepsy related problems are identified that are beyond the practice’s clinical expertise.

An additional benefit of the DES for learning disability is the production of the Health Action Plan which is a useful tool for people with learning disabilities to offer to their GP when they are being seen about any other health matter.

### The Future...looking at ways to improve primary care involvement

**General Practice.** Every three years the Royal College of GPs selects four clinical priority areas and this year epilepsy has been chosen as one of these. The hope is that it will become a catalyst for GPs to become more familiar with epilepsy care aiming to reduce the 20% treatment gap for epilepsy, and looking to support the impact the diagnosis of epilepsy can have on people’s lives particularly the vulnerable groups.

**General Practitioners with a Special Interest in Epilepsy.** Throughout the UK there are GPs accredited with additional skills in epilepsy [GPwSIs] and these numbers are steadily increasing. The RCGP clinical priority program offers an opportunity to refresh and hopefully increase their numbers. They work as GPs with extended roles who can receive direct referrals for areas needing more specialist care such as someone with learning disability with an epilepsy related problem. The criteria for referral to the East Kent primary care epilepsy service include: on-going seizures, side effects of medication, review of diagnosis or pre natal or antenatal care. The clinics are held usually in GP surgeries and tend to be less formal than hospital epilepsy clinics. When a higher level of expertise such as the requirement for video telemetry or for someone suffering with complex symptoms is required, onward referral to neurology clinics can be offered. The GPwSI clinics can also be used to facilitate an early discharge from these specialist clinics and later can continue care in the community.

Everyday in general family practice surgeries, GPs daily clinics involve the making and reviewing of diagnosis, organising appropriate investigations, interpreting results, suggest treatment changes and arranging forward referral when required. As a GPwSI the process is similar apart from making the initial diagnosis of epilepsy which is left to the hands of a neurologist.

This model differs slightly to a specialist nurse in learning disability and epilepsy who can be either community or hospital based. They provide a key role by ensuring a larger emphasis and expertise in
Coordinating care and offering specialised patient support\textsuperscript{17}. Their work also enhances the shared care protocol between hospital services and primary care\textsuperscript{18}. The regional epileptologist I would regard as the clinical lead of the epilepsy service and has oversight of the whole epilepsy team.

**Conclusions ....serving patients and respecting their rights**

I hope that primary care continues the process of further developing services for people with learning disability and epilepsy; embracing the human rights of adults with learning disabilities using proactive programs of care. It will be good to see an increasing trend to providing a positive approach in the surgery for people with learning disability ensuring that this group are well catered for and intervening if they discover epilepsy related problems\textsuperscript{19}. In such a situation one option could be a referral to GP with an extended role in epilepsy.

The shape of local health services now is placed in the hands of the newly formed CCGs and they should be supported in their commissioning of appropriate services. Services for people with epilepsy need to be part of their planning and those also with learning disability given special consideration\textsuperscript{20}.

Finally, it would be good to see the trend continue towards closer working between all of the agencies involved in supporting people with learning disability and epilepsy as we face the many challenges ahead.

**Acknowledgements**

\textit{I am very grateful to Matt Hoghton, Medical Director of the Royal College of GPs Clinical Innovation and Research Centre who was the previous clinical champion for Learning Disabilities who contributed many helpful comments on earlier versions of this article.}


9. **Kerr M.** Assessment in Primary Care. PSYCHIATRY 5:10 351 2006


The diagnostic work-up in suspected cases of epilepsy is commonly illustrated, with due emphasis on the clinical story, on an eye-witness account followed by an appropriate avenue of investigation. The NICE 2012 guidance illustrates the need for timely assessment and intervention, and accounts for cardiac arrhythmias as a differential diagnosis of epilepsy. Timely assessment of suspected first seizures and episodes of transient loss of consciousness has heralded the emergence of first seizure clinics and necessitated close working relations with cardiology. Seminal papers like this, by Dr Fergus Rugg-Gunn however also illustrate that even when the diagnosis of epilepsy is secure, cross-specialty working is essential, particularly in complex cases and serves to highlight that epileptologists must also keep an eye on matters of the heart.

In a recent publication Dr Nashef’s work on the incidence of SUDEP gathered from post-mortem reports, death certification and coroner’s cases, prompted the modern era’s scientific quest to elucidate potential mechanisms. Even prior to the knowledge that SUDEP was commoner than we originally thought, theories dating back many decades have focused on cardiac arrhythmias, pulmonary oedema and central apnoea. More recently at risk groups are considered to include refractory patients with frequent generalised seizures, those with a long duration of epilepsy, treatment with two or more anti-epileptic drugs, low serum drug concentrations and some lifestyle factors such as sleeping alone and/or prone.

One of the biggest challenges in the study of and ultimate prevention of SUDEP is the identification of at-risk patients; surgical cohorts however, provide such an opportunity. This paper by Dr Fergus Rugg-Gunn reveals the under-reported serious consequences of on-going epileptic seizures, and illustrates that even a detailed yet routine surgical work-up may miss such a chance opportunity to identify and treat potentially fatal cardiac arrhythmias.

This small study utilised implantable cardiac loop recorders to study cardiac rhythm in 20 patients with refractory epilepsy (without known cardiac disease) in association with and without seizures. The device was programmed to detect bradycardia (< 40 beats
per minute) or tachycardia (> 140 beats per minute) and also when required had the facility to be externally activated by patients, and/or relatives in the event of a seizure. Data was captured over a 24 month period, in which 220 000 patient hours were monitored, recording 3377 seizures, of which cardiac rhythm was captured in 377 seizures.

Overall ictal tachycardia was seen in 16 patients in which, the median heart rate during habitual seizures exceeded 100 beats per minute. Ictal bradycardias were a rare occurrence, seen in only 2.1% of recorded events, however taking into account the very small numbers in this study, it is potentially concerning that ictal bradycardias actually affected 7 (37%) patients. Four patients (21%) had bradycardia or periods of asystole requiring permanent pacemaker insertion, three of which (16% of total) had potentially fatal asystole.

This is a small study, so caution is advised in the interpretation of these findings in the wider context of epilepsy, however in this refractory cohort the headline summary statistic of a third of patients suffering an ictal bradycardia, with over half being serious events warranting the insertion of a permanent pacemaker is certainly striking. The authors, certainly do not state the causality of tachy/brady arrhythmias, although certainly plausible, demonstrate that neurogenic cardiac arrhythmias may accompany refractory epilepsy and therefore SUDEP

Clinical observations make starting points for further research; the co-localisation of brady arrhythmias with the left insular region and sympathetic activation as a right hemisphere function, seen in this study (in very small numbers), certainly poses avenues for future study. Maybe this observation also strikes a personal note, as we reflect on patients from our own clinical practice who initially presented to cardiology and had pace-makers inserted, who subsequently then, (maybe years later) have been diagnosed with epilepsy. As the body of evidence grows maybe also it is not just coincidental that the individuals in this study with the most severe arrhythmias were young men with refractory seizures on multiple AEDs?

There are some practical ramifications from this study, particularly as epilepsy surgery gathers momentum; none more pertinent than in the training of medical and nursing staff involved in the monitoring and management of in-patient telemetry beds especially when drug-reduction protocols take hold in pre-surgical evaluations.

However, maybe the real take-home-message from this study is that our current diagnostic epilepsy work-up and even our detailed pre-surgical evaluation will fail to identify these potentially treatable cardiac arrhythmias, and so maybe unknowingly we are missing an opportunity to minimise risk of harm from seizures, and SUDEP? This calls for an even closer interaction between epilepsy and cardiology; not simply in the diagnostic process, but also as we consider the investigation and management of patients with on-going seizures, even prior to surgery.

Overall this research represents an important stepping-stone in the on-going SUDEP journey and as the story continues to evolve, even as the headlines change, or come and go, it reminds us that hearts and minds are inexplicably linked, and, for the epileptologist papers like this must not be kept on the qt.
Notes on an Epilepsy/Learning Disability Outpatients Service in a Large London Hospital

Background

Epidemiological studies indicate that 0.5 to 1 percent of the population are affected by epilepsy. Looking further at this figure it’s thought that approximately one quarter of people with epilepsy are people who also have learning disabilities. (Lhatoo and Sander 2001). In 2010 Iddon et al explored the implications of misdiagnosis and suggested that studies indicate high levels of misdiagnosis in people with and without a learning disability. In addition to this people may experience a combination of epileptic and non epileptic events making the diagnosis not only difficult but sometimes impossible.

Potential reasons for misdiagnosis are many and varied but what does seem clear is the need to ensure that epilepsy is not being under or over diagnosed (Iddon et al 2010).

The National Society for Epilepsy highlight that diagnosing and treating epilepsy can be more difficult in people with learning disabilities as unusual behaviour, appearing confused or having difficulties in communicating may also be present for other reasons. The NICE guidance (2012) recognises the difficulty in diagnosis of epilepsy for people with learning disability and recommend longer appointments that care and attention be paid re investigations and identifying any underlying cause.

The Royal London

In 1999 links were developed between the Epilepsy service within the Royal London Hospital and Tower Hamlets Community Learning Disabilities Team (CLDT). The aim of this was to improve Epilepsy care and management for local people with a learning disability & Epilepsy.

This was initially managed through joint home visits, educational programmes for day centres, development of protocols, care plans and improved epilepsy management. However, a particular gap was identified in the service, and, after consultation it was agreed that a specialist epilepsy/learning disability clinic should be established.

What’s in place now?

The Epilepsy/Learning Disability Clinic is held every four weeks, and is jointly run with an Epilepsy Clinical Nurse Specialist and a Community Learning Disability Nurse.
Initially it was planned that there would be longer (thirty minute) appointment slots to allow clients and carers enough time for education and support. However this now seems to be impossible to achieve due to waiting times. Most people due to the nature of their epilepsy will return to clinic on a 3, 6 or 12 month basis.

It was also planned that a thorough assessment of birth and developmental history be obtained and a detailed seizure history, seizure description including a comprehensive medication history be obtained. In practice much of the background history is obtained from their initial appointment with the neurologist and added to in the Epilepsy/LD clinic.

The clinic should ensure a holistic approach, including thorough assessment of the client’s social care and general support needs (considering the impact upon wider health and Epilepsy).

Within this model the learning disability nurse role should include:

• Support attendance to clinic via prompts to client / social support network
• Support mobile clinics with home visits to house bound clients (jointly with Epilepsy nurse specialist and/or Neurologist)
• To enable decisions made at clinic to be followed thorough in the community ensuring all carers, and care agencies are part of the changes made
• To provide a community perspective to the clinic
• To screen and facilitate appropriate referrals made for the client group to both CLDS and other agencies
• To provide support to client and their support network to facilitate complex medication regimes to take place which can help reduce hospital admissions
• To act as a link nurse between the acute service and the community
• To provide training to community based services on epilepsy and emergency medication

• To support the production of emergency medication protocols supporting seizures to be maintained within the community and reducing hospital admissions
• To support the effective recording of seizures by providing seizure recording charts and promotion of how to record
• To review the clinic annually to ensure effectiveness and development of the clinic to meet future needs

The Expected Benefits & Measurable Outcomes Were:

• Clients receiving regular reviews and treatment (with relevance to the context of other existing support)
• More holistic clinic appointments providing a more person centred approach
• Time efficiency enabling first hand direct contact with clinic and outcomes achieving better communication as opposed to telephone conversations, paper referrals and follow up which can be a lengthy process
• Nurses attending the clinic tend to have a level of knowledge about the client (such as services involved in care) which helps produce a more effective clinic appointment with better outcomes
• Appointments attended and not attended can be monitored and DNA’s explored with clients & families via CLDT staff who have ongoing interventions
• Client/Carer satisfaction through feedback
• Better quality of life
• Concordance with medication
• Decreased hospital admissions and use of emergency medication
• Decreased risks
• Greater Client/Carer knowledge
• Buccal midazolam protocols in place

Plans for further development

Audit

There seems to be an obvious need to clearly identify measurable outcome so that the effectiveness of the service becomes more than a feel good factor.

Under consideration is

• A patient questionnaire which in reality will be divided between patients, carers and family
• This clinic provides some possibility at looking at reasons for missed appointments or DNA (Did Not Attend)
• Seizure frequency
• Improved access to community facilities
• Reduced attendance at Accident and Emergency departments

More Clinics

Traditionally this clinic was for people within the Tower Hamlets area covered by the Royal London Hospital. However Barts Health NHS Trust now covers a much wider area and people from further afield now attend the clinic. The Community Learning Disability Nurse only covers Tower Hamlets and spends some time contacting colleagues from other areas.

Plans are therefore being made to start Epilepsy/Learning Disability clinics in other areas to ensure a Learning Disability Nurse from that area can be involved in the clinic.

Improve Current Clinics

Following a clinic a letter is dictated with copies to GP and other relevant professionals as well as the patient.

We are currently considering a letter template that could be completed during the clinic and would form that individuals care plan for their epilepsy. Any protocols re emergency medication e.g. buccal midazolam, rectal diazepam would be completed in clinic as well. This could be printed off to be taken away by the patient.

Barriers

The obvious barrier to this is time. It would need clinic appointments of at least 30 minutes and would mean fewer appointments with perhaps longer waits for an appointment.

This raises the question as to whether we aim for quality of service or quantity of patients seen. However it could be argued that if the quality is good then the patient should not have to return to clinic on as frequent a basis as in the past allowing for more new patients to be seen.

References

## Future Meetings

Below are details of future educational conferences and events relevant to epilepsy and learning disability. This is an ongoing feature so please advise us about any meetings that you may be holding on epilepsy and LD which might appeal to a national / regional audience. We will then attempt to include them at the editor’s discretion.

### Forthcoming Meetings

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| **5th – 7th September** ILAE UK Chapter Annual Scientific Meeting 2013 Glasgow  
http://www.ilae-ukconf.org.uk/ | **11th February** Learning Disability Masterclass Warwick Bespoke Professional Excellence  
For further details contact:- Natasha@BESPE.com |
| **26th November** Learning Disability Masterclass Warwick Bespoke Professional Excellence  
For further details contact:- Natasha@BESPE.com | **27th – 28th February** British Neuropsychiatric Association  
27th Annual Meeting UCL Institute of Child Health London  
http://www.bnpa.org.uk/ |
| **6th – 10th December** American Epilepsy Society (AES) Annual Meeting Washington DC  
http://www.epilepsystockholm2014.org/ |
Application is now open for the 2013-2014 Virtual Epilepsy Academy (VIREPA) Distance Education Program. VIREPA courses will start between September and November of 2013 and last until between February and May of 2014.

All distance education courses are Internet-based, e-moderated courses with downloadable learning material. Tasks will be completed within an active online communication process among all participants, guided by the experts. The tasks will strengthen the theoretically gained knowledge and enable the participant to transfer this knowledge to his/her clinical practice.

For details about the courses below, visit http://www.ilae.org/Visitors/Centre/VIREPA.cfm. For questions, please contact ILAE VIREPA staff at courses@ilae.org.

- EEG & Sleep – New course!
- EEG in the diagnosis & management of epilepsy – Basic, Part 1
- EEG in the diagnosis & management of epilepsy – Pediatric
- EEG Score
- Genetics, Part 2 – Clinical
- Medical Treatment of Epilepsy - Advanced Course (formerly known as Clinical Pharmacology & Pharmacotherapy)
- Neuroimaging (Part 1 & 2)
- Psychiatric Aspects (Part 1 & 2)