

An information journal for those with a particular interest in epilepsy

If not valproate then what?

Many of our paediatric colleagues will have been involved in the recently published Epilepsy Twelve audit (Royal College of Paediatrics and Child Health 2012). This document examines the care offered to children and young people with epilepsy and as such had a broad range of quality markers based on guidelines issued by the National Institute for Clinical Excellence (NICE 2004) and the Scottish Intercollegiate Guidelines Network (SIGN 2005). The report highlights the variability of care provision, none more so than in the area of paediatric epilepsy specialist nursing with only fifty-three percent of participating centres offering the service and forty-six percent of children having access to one despite recommendations to the contrary (NICE 2012).

Nurses clearly have wide roles in supporting people with epilepsy with one of the most important being to counsel women of childbearing age. This has been recognised in the recent adult epilepsy specialist nurse competency framework (Leavy et al 2012) and can be expected to feature in the updated paediatric epilepsy nurse competencies due for publication later in 2013. Could it be that the relatively low numbers of paediatric epilepsy specialist nurses is significantly contributing to the very low levels of advice (thirty-seven percent) given to girls over the age of twelve about pregnancy and contraception (Royal College of Paediatrics and Child Health 2012)? Clearly, this is an emotive issue which can be very difficult to bring up with the young person (and their parents), yet equally knowledge in this area is vital particularly when one considers that although the rate of teenage pregnancy in the United Kingdom is falling, in 2011 (the last year for which statistics are available) there were still 5991 conceptions in girls under the age of sixteen (Office for National Statistics 2013). This has obvious implications in epilepsy with several antiepileptic drugs, chiefly carbamazepine inducing the metabolism of the oral contraceptive pill thus markedly reducing its efficacy. Add to that the teratogenic effects of antiepileptic drugs and the need for expert counselling at an early age becomes self evident. Epilepsy specialist nurses, perhaps more than any other professional group, are in an ideal position to provide that initial counselling as well as ongoing support through the formative years of adolescence.

To consider just how difficult that period of counselling can be one could hypothetically address the question posed by the title of this editorial. Let us imagine a fairly common scenario. A girl of fourteen has just been diagnosed with juvenile myoclonic epilepsy (JME). This is generally considered a lifelong condition (Panayiotopoulos 2005) and one for which treatment, whilst often successful is limited in terms of the choice of suitable medication. A thorough review of the literature by Panayiotopoulos in 2005 concluded that valproate was still the drug of choice with levetiracetam a useful newer possibility. Lamotrigine is probably reasonably effective against tonic clonic seizures and absences but not myoclonus. Similarly, topiramate is useful against tonic clonic seizures but only has a weak effect against myoclonus and

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absences. Clonazepam and possibly ethosuximide may have roles, the former as an adjunct to provide better control of myoclonus and absences in the case of the latter. As yet there has been little published on the safety and efficacy for the more recently UK licensed antiepileptic drugs, e.g. lacosamide and zonisamide. Of the older generation of drugs, phenobarbital has proven efficacy but is little used for JME in the UK.

In 2007, SANAD (Marson et al 2007) compared the efficacy of valproate with that of lamotrigine and topiramate in the genetic (idiopathic generalised) epilepsies. They concluded that, 'Valproate is better tolerated than topiramate and more efficacious than lamotrigine, and should remain the drug of first choice for many patients with generalised and unclassified epilepsies. However, because of the known potential adverse effects of valproate during pregnancy, more than the benefits for seizure control in women of childbearing years should be considered.'

This final statement has been brought into sharp contrast by the latest EURAP data on foetal malformations associated with different antiepileptic drugs (Tomson 2011), which suggests that at high doses (above 1500mg per day) the rate of major foetal malformations associated with valproate may be as high as twenty-four percent, a statistic made even more significant when one considers that the same paper suggests that foetal abnormality rates associated with lamotrigine while still dose dependent are much lower with the risks at doses below 300mg per day quoted at just two percent. A number of publications also suggest that levetiracetam is safer in pregnancy than valproate, most notably one recent publication that estimates the monotherapy major malformation rate to be under 1% (Mawhinney, 2013).

What then are we to tell our fourteen-year-old patient and her family? The bottom line is that she has a lifelong type of epilepsy with her best chance of good seizure control coming from a drug that carries significant risks if she ever wants to start a family. The facts on their own seem to be at odds with the 'can do' message that we try to convey both to our patients and colleagues through educational programmes such as PET (BPNA 2013). This is where the advantage of an experienced highly skilled yet at the same time readily accessible paediatric epilepsy specialist nurse can make a crucial difference. The real debate isn't so much whether to use valproate or not but rather to ensure that the decision making process, expertly led by the specialist nurse, enables the young person (and her family) to make a decision that is right for her. This must include a thorough, honest appraisal of the risks and benefits of the various treatment options available coupled with the most recent available evidence for strategies to minimise risk.

This very short review has focused on a small part of the Epilepsy Twelve audit (Royal College of Paediatric and Child Health 2012). Nevertheless, it illustrates a need for timely, specialist and accessible support and information to be made available for all children and young people with epilepsy. Epilepsy specialist nurses are ideally positioned to offer this support and in collaboration with their adult counterparts could, through the use of transition clinics, develop a seamless pathway for the patient through childhood, adolescence and into adulthood. Of course, there are many services in the UK that adopt this model but as the Epilepsy Twelve audit has shown this is far from being universal with significant variations in care and low involvement of epilepsy specialist nurses being two of the audit's key conclusions. This may well be reflected in the patient satisfaction results. Overall satisfaction levels of parents and carers and young people with their epilepsy care are fairly high (seventy-eight percent and eighty-two percent respectively). However, satisfaction with the level of epilepsy information given to children and young people and the liaison between health services and schools are much lower with the latter hovering around the fifty percent mark. These are precisely the areas where epilepsy specialist nurses can make a huge difference.

The Health and Social Care Act (Department of Health 2012) which came into force in April 2013 provides an opportunity for clinicians to shape local health services. This is a time where commissioners can be influenced and the Epilepsy Twelve audit provides a vehicle for clinicians at a local level to make a strong case for additional resources to address the shortfalls found in the audit report. It will be interesting to examine the impact of the report and changes that are made as a result of it when the re-audit takes place in 2013/2014. With proactive action from clinicians, and particularly paediatric epilepsy specialist nurses, significant improvements could be achieved.

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Delivering epilepsy care: Clinical Commissioning Groups and new ways of working

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Introduction

The government published the White Paper, Equity and Excellence: Liberating the NHS in 2010. This paper announced that GPs would take over the commissioning role as part of the government's aim to create a clinically driven commissioning system, which was more sensitive to patient needs (DoH, 2010). To deliver healthcare in this way 211 Clinical Commissioning Groups (CCGs) replace the 151 Primary Care Trusts (PCTs). All of the 8000 GP practices in England are now part of one of these CCGs, each of which commission care for an average of 226,000 patients (Kings Fund, 2013).

From April 2013 the Clinical Commissioning Groups (CCGs) become responsible for designing local health services in England by commissioning or buying health and care services (PHORCAST, 2013). This includes responsibility for arranging urgent and emergency care, and most community health services, working in partnership with patients, healthcare professionals and local communities and authorities.

The King's Fund has outlined priorities for commissioners (Naylor et al, 2013); CCGs should spend resources so that outcomes are maximised and achieve value for money. CCGs are required to employ a more systematic approach to chronic disease management, to further patient empowerment, to improve self care, to improve primary and secondary prevention, and to reduce admissions for people with ambulatory care sensitive conditions (ACSCs).

CCGs are using their new responsibilities to commission services in new ways, with local circumstances and conditions influencing activity. This represents both opportunities and threats to nurses providing specialist services, so it is prudent for epilepsy nurse specialists and health providers to be aware of the priorities and proposals of their local CCGs and to engage in two-way dialogue with them.

The introduction of CCGs will change the way in which services are commissioned. They are not obliged to fund existing providers or indeed existing services. Almost 66% of CCGs do not have, nor do they plan, a written needs assessment of the health and social care needs for people with epilepsy. Almost 74% (75/102) of responding authorities do not include a section mentioning care of people with epilepsy in their Joint Strategic Needs Assessments (Epilepsy Action, 2013a). With approximately 350 epilepsy nurse specialists in the UK currently there will be many CCG catchment areas where epilepsy nurse specialists are not employed. This may suggest to other CCGs that they also do not need to employ epilepsy nurse specialists and can accordingly make cost savings. Even where CCGs do commission epilepsy nurse specialists, they may elect to commission alternative providers, perhaps on a freelance basis or on short term contracts. This may have implications for levels of nurse specialist autonomy with adverse effects on grading.

CCGs may of course terminate existing services and may be more likely to do so if they do not understand the need for the service or if they do not feel that it is cost-effective. Mynors, Perman and Morse (2012) advise multiple sclerosis (MS) nurse specialists to ensure that their services are visible, valued and accessible. Nurse specialists need, to be aware of their activity levels and cost, and to demonstrate that they can deliver savings (ibid) as well as effective care.

Personal situation

On retirement after 34 years of continuous service as a nurse within the NHS I became self-employed in order to complete some work with the local CCG. Twenty seven years of my career had been spent working as a learning disabilities nurse, the last ten of which were spent in developing epilepsy services for adults with learning disabilities. During this time I completed the Epilepsy Diploma through Leeds Metropolitan University. This was followed by seven years as an epilepsy nurse specialist during which time I completed the MSc in Epilepsy Practice,

again through Leeds Metropolitan University. During one of the modules in the MSc I completed some work on non-elective admissions made by adults with epilepsy, which was later published (Mantri, 2008). On retirement, I was asked by Epilepsy Action to comment on the draft Annual Epilepsy Review template devised by NHS North Yorkshire and Humber. My experience and qualifications partly fulfilled the requirements of three local CCGs who had prioritised developing their primary care epilepsy service.

My work with CCGs

CCGs can commission any service or individual to carry out activities which they deem will achieve their goals. I am currently working with three CCGs, one in a self-employed capacity for specific projects or aspects of larger pieces of work. This is in a mainly rural area with areas of social deprivation. The epilepsy care here is carried out largely by GPs within 15 general practices. They access secondary care neurology and epilepsy nurse specialist services from the regional epilepsy service and also from a visiting neurologist at the local hospital who has a local community-based epilepsy nurse specialist attached. The work with the other two CCGs is in a different area which is urban and in close proximity to the large regional hospital-based epilepsy service. These two CCGs both include areas of social deprivation and affluent areas, each having 18 general practices. Whilst these two CCGs are funding the post, the nurse is based within the hospital-based epilepsy service, sharing an office with the epilepsy nurse specialists. Employment here is through the hospital nurse bank.

CCG 1

The self-employed work is within a CCG where they have prioritised a project, "Improving services for people with epilepsy". This project commenced in 2011. It was GP-led and the nurse specialist was delegated specific parts of the project; education, and reviewing and reporting on non-elective hospital admissions made by adults with epilepsy. Initially the nurse arranged a meeting between the GP lead and a member of Epilepsy Action to discuss the Annual Review template and the Primary Care toolkit.

i) Education

The CCG held half day Protected Learning Time events (PLTs) and one was designated for epilepsy education. The nurse was involved in the organisation and content of the epilepsy education event for practice nurses and GPs, and identified and contacted speakers. The nurse gave a presentation to the practice nurses about Annual Epilepsy Reviews based on the aforementioned template as the CCG had adopted this throughout their GP practices.

ii) Non elective hospital admissions

The CCG identified patients by NHS number and practices were forwarded these numbers along with a questionnaire devised by the GP lead and the nurse. The practices each held a practice review which the nurse and/or GP attended. The nurse wrote the first draft of a report based on these findings and this was reviewed by the GP and the nurse, resulting in a completed report with recommendations. The GP compiled an action plan from these recommendations after consultation with the CCG and the nurse has been involved in taking forward some of these actions. This has included liaising with the local learning disability service and organising a meeting with all of the (six) epilepsy nurse specialists in the region, looking at working practices and referrals.

iii) Comment

The former PCT had advised the nurses that it was "not core business" to review non-elective admissions. The CCG, however, felt this was important activity and was in a position to commission this work directly without having to rely on the existing provider. This meant that the existing nurse specialist and provider organisation had no input into the report and its emerging action plan, although the PCT nurse was involved in the education event. Existing services thus need to be aware of CCG aims and priorities, and to ensure that they are involved in epilepsy service planning and dialogue with CCGs or there is a danger that they may be excluded.

CCGs 2 and 3

This temporary post was advertised and commenced in May 2012. This post had much broader parameters and the nurse was asked to look at non-elective hospital admissions, and practice and educational needs. The nurse devised a plan to address these requirements;

ELEMENTS OF THE POST

1. Liaison with practices
2. Review of non-elective hospital admissions
3. Education and development
4. Clinical
5. Liaison/other
6. Strengths and limitations of the post

i) Liaison with practices

PURPOSE

Unfamiliar with the geographical area and local services, the nurse set out to visit each general practice and to hold a discussion based on a proforma devised by the nurse (see Table 1).

These meetings were designed to initiate discussion with the practices about their concerns/issues/problems in epilepsy management within primary care, liaison with secondary care and to identify any educational needs. Prevalence, registers and Annual Epilepsy Reviews were also discussed.

Table 1: Meeting proforma

GP Practice meetings	Practice name, present, date
Identify	<ol style="list-style-type: none"> Adults (≥ 18 at time of admission) who have had emergency epilepsy-related admissions 01 April 2010 – 31 March 2012 (CCG is supplying this data) People who are not seizure free (QOF) Any specific problems – patients, annual reviews...or support needed Any educational needs for practice (with view to $\frac{1}{2}$ day educational event or in-practice education if required)
Consider	<ol style="list-style-type: none"> Validating register – national prevalence 0.75% – 0.97% Epilepsy audit
Discussion	<ol style="list-style-type: none"> Annual epilepsy reviews – by clinician (toolkit/templates) Primary/secondary care liaison/ systems/problems Other

PROGRESS

Participation within practices has varied from two nurses or one GP to the majority of practice members including GPs, nurses and practice managers.

Some practices incorporated the meeting into existing practice meetings so that the whole practice was involved, which tended to generate the most effective discussion. The nurse also gave practices hard copies of the Primary Care Resource Pack and Annual Epilepsy Review Templates which were discussed during the meetings. These are also available electronically. The nurse gave Practices a range of patient information booklets about a variety of aspects of epilepsy management (including, diagnosis, treatment, safety, driving and employment) and informed them how to obtain these and a range of factsheets electronically. Updates in epilepsy management were also discussed including management of bone health, awareness of raised risk of anxiety and depression, and preconception counselling.

The nurse visited 28 (of 36) practices who responded to requests for visits. The nurse has tabulated responses from these discussions and is using them to formulate an action plan. This will be discussed during a meeting when the CCG reviews the completed activity after one year in post and with the secondary care epilepsy service.

ii) Review of non-elective hospital admissions made by adults with epilepsy

PURPOSE

The literature and a recent local review carried out in CCG 1 suggests that people with epilepsy have disproportionately high use of health resources including non-elective hospital admissions. The local review suggested that approximately 33% of admissions were potentially avoidable or inappropriate. In times of economic austerity and the need to make more efficient use of resources including the reduction of admissions CCGs need to be aware of their local situation.

PROGRESS

The nurse is currently undertaking a review of non-elective hospital admissions made by adults with epilepsy. The CCGs provided raw data for all admissions made by people with epilepsy between 01 April 2010 and 31 March 2012. The nurse has made this data more accessible, identifying individual patients by NHS number and grouping them by practice. By this process it can be easily seen how many admissions each patient made and which GP practice they were listed under at the time of their admission.

The nurse has provided each practice within each of the two CCGs with details of patient admissions including costs. The nurse has reviewed the discharge letter from each admission and is in the process of liaising with individual practices to discuss how to identify and manage inappropriate or avoidable admissions.

iii) Education and development

PURPOSE

Developments in epilepsy practice and management have been relatively rapid over the past ten years. In this time there have been many new AEDs, NICE guidelines for epilepsy management were published in 2004 and updated in 2012, seizure classification has been reviewed (ILAE, 2012) and with technological advances and research more is known about epilepsy and its management. DVLA regulations have also been changed in this time (very recently).

Primary care practices have relatively few people with epilepsy on their caseloads, thus affording little opportunity to build up clinical expertise (CCGs 2 and 3 averaging a practice prevalence of 0.7%).

Many primary care practitioners advise that any complex epilepsy management is carried out in secondary care, that they have had no recent epilepsy education and feel deskilled, therefore lacking confidence in epilepsy management. The combination of these three factors makes it very difficult to manage epilepsy confidently within primary care.

PROGRESS

Each CCG has protected learning time events and the nurse requested sessions at each. CCG 2 offered two sessions, one to introduce the post by having a stand and an opportunity to meet healthcare professionals. Primary Care Toolkits and information leaflets were made available and some practice visits were arranged. At the second event the nurse held a joint epilepsy workshop with the two neurologists who specialise in epilepsy, looking at women and epilepsy, FAQs and annual epilepsy reviews. This was well-attended with over 60 GPs present and several practice nurses.

The nurse also held a joint presentation with the hospital-based epilepsy nurse specialist at one of CCG 2's nurse meetings, highlighting primary and secondary care epilepsy nurse roles and incorporating epilepsy care and annual epilepsy reviews.

The nurse also met with Practice managers from CCG 2 to outline the new role and the function of practice visits.

Following practice visits the nurse is liaising with practices who have requested in-practice education sessions.

Practices in CCG 3 have not responded to any offers of epilepsy education.

iv) Clinical

PURPOSE

Practices have expressed difficulties in managing patients with complex epilepsy and repeated non-elective hospital admissions. The nurse offered joint mini-clinics at practices with practice staff to review patients with more complex epilepsy and to identify when patients should be (re-) referred to neurology or have AED therapy increased or changed, also to identify problems and to give advice or information.

PROGRESS

The nurse has held three mini-clinics and seen two patients at home in CCG 3. The nurse made a range of interventions including increasing antiepileptic drugs (AEDs), changing AEDs and recommending that one patient is referred to neurology to clarify seizure classification.

One practice in CCG 3 requested a notes review with recommendations for patients with learning disability and women of child-bearing age.

CCG 2 has not requested any clinical input.

The nurse has also made e-mail and telephone advice available to practices which both CCGs have taken up.

v) Liaison/other

PURPOSE

In recognition of the complexity of issues faced by some patients with epilepsy it is necessary to liaise with existing local agencies to ensure the best care is provided. In recognition of intensive services required by a small number of patients locally and in the surrounding area (specifically nonepileptic events); it may be useful to network with interested professionals in other areas to explore economies of scale.

PROGRESS

The nurse shadowed clinics of each member of the secondary care epilepsy service (two neurologists and an epilepsy nurse specialist).

The nurse has held three liaison meetings with local learning disability services, followed by their request to hold quarterly liaison meetings. These meetings sometimes involve the neurologists and psychiatrists.

The nurse introduced the GP lead from CCG 1 to the secondary care epilepsy service and to lead GPs in CCGs 2 and 3.

The nurse has met with Emergency Department and Emergency Admissions Unit staff to discuss issues with non-elective admissions made by adults with epilepsy.

The nurse has discussed issues of alcohol/epilepsy with alcohol services and will be meeting with social work representatives and staff from walk-in centres.

vi) Strengths and limitations of the post

STRENGTHS

From discussions with primary and secondary care there is a need for a liaison post such as this, providing enhanced liaison between primary and secondary care, and with other services.

It can be beneficial to see patients in primary care where they do not need to come to secondary care services but would benefit from minor alterations to AED regimens, other discussions, advice or information-giving and such patients often prefer to be seen in their local practice. There is scope to offer a more personalised service, particularly for those who find it difficult to access hospital services (due to mental or physical health).

There is a need to provide epilepsy education and updates, particularly during times of rapid development and changes in epilepsy management, which are difficult for primary care services to keep abreast of.

Such a post affords CCGs some ownership of the post, which should help to ensure that practice needs are met.

LIMITATIONS

The current post-holder is only able to work two days a week and this post needs to be carried out on a full-time basis to be effective and to afford timely feedback to practices.

There are currently no pathways for referral to or from the nurse, as this has been a temporary post.

Conclusions

From limited experience of working directly with three CCGs it is apparent that they each work in different ways, reflecting local geographical issues, existing systems, local health, social and voluntary services, priorities and personnel.

There seems to be a desire for more community-based care where appropriate and this may have implications for both hospital-based and community-based epilepsy services.

There is an interest amongst CCGs in developing epilepsy services and it is in epilepsy nurse specialists and providers' interests to ensure that they are involved in the dialogue with CCGs to ensure that high quality epilepsy care is provided for patients with epilepsy. It is also an opportunity for epilepsy nurse specialists to work on a freelance basis.

There is a potential for epilepsy nurse specialists to secure long term funding but CCGs are more likely to commission epilepsy nurse specialists if they can demonstrate their value. Mynors, Perman and Morse (2012) suggest logging activity levels and publicising examples of cost-effectiveness. They suggest identifying and liaising with a lead GP for neurological conditions and make many constructive suggestions which epilepsy nurse specialists may be able to adapt to their own specialism. However, Epilepsy Action (2013a) advise that only 17% of CCGs/CCG confederations have appointed a clinical lead for epilepsy.

From personal experience, CCGs are interested in reducing avoidable non-elective hospital admissions. It is important to be aware of the CCGs aims and priorities and to support general practices. The epilepsy nurse specialist has expertise in epilepsy management as well as awareness of the range of psychosocial support people with epilepsy may need. Epilepsy nurse specialists can help to ensure that their patients continue to have access to this expertise.

The Neurological Commissioning Support (NCS) have identified the need for an epilepsy nurse specialist in a national role to support commissioning for epilepsy with joint funding by the Epilepsy Society and Epilepsy Action. The aim is for this nurse to give guidance to CCGs on how to improve epilepsy nursing services within hospitals and local neurology services to support CCGs to design better services that include epilepsy specialist nurses (ESNs) and support people with epilepsy (DoH, 2013). It is not yet clear how this post will operate or what effect it may have. Epilepsy Action (2013b) says;

"Epilepsy Specialist Nurses are regularly being asked to evidence the outcomes of their post and to focus on how they can reduce costs associated with poor epilepsy care. Whilst there is a wealth of qualitative evidence around the very real difference they make to their patients; service managers and commissioners are often focusing on quantitative data in order to examine what savings can be attributed to an ESN. These savings can be brought about by:

- Management and adjustment of medication, leading to increased seizure control
- Avoided admissions
- Education of people with epilepsy, leading to increased self management
- Educating carers and family on the use of rescue medication
- Regular review, often through telephone clinics
- Education of general medical staff, including ambulance and A&E staff

Whilst nurses can often collect data to show how their time is being spent, they are often unable to look in detail at what the costs of the service are compared to the savings being made. There is a clear need for a simple, easy to use audit tool, which will collect key information and produce an overall analysis of what savings can be achieved. Epilepsy Action is keen that the contribution of ESNs is fully recognised so that the role can continue to gain support and development. We believe that through our work in beginning the development of an audit tool, evidence can be collected to show the worth of the ESN and to justify their role.”

Recommendations

1. To advise CCGs 2 and 3 to tender for a full time community-based epilepsy nurse specialist, based with the secondary care epilepsy service but working with CCG and practices. This should include clinical and educational activity.
2. To establish formalised referral pathways, considering “Choose & Book” as an appropriate mechanism for referral to the community nurse.
3. To liaise with neighbouring CCGs regarding development of shared services and practice where identified as appropriate, e.g. provision of care for management of nonepileptic events.
4. To continue with a review of non-elective hospital admissions, including individual practice reviews to identify and discuss strategies to address avoidable and inappropriate admissions.
5. To investigate tools such as the cost-calculator under development by Epilepsy Action and to inform CCGs of the contribution epilepsy nurse specialists make from a cost perspective as well as in terms of quality of care.

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Recently Published Papers

As per normal this section highlights recently published papers. Hopefully this will be very useful to all, helping to keep everyone up to date with the latest developments. It will certainly save you research and reading time.

There are many (often over 600) epilepsy papers published every six months, so what follows has been edited. All animal papers have been excluded and as many review papers as possible have been included. We hope you find the papers of interest in your pursuit to keep abreast of the very latest knowledge. You can instantly access all the previous abstracts for all the previous papers by using the on-line pdfs for "Epilepsy Care". These are available at <http://www.vnccprofessional.org/index.asp>. The access code is esna2009. From the home page click on "E-library", then "Free journals" and finally scroll down to "Epilepsy Care". The final link takes you to the present issue and all the back copies (the ones for the papers here are in the other email attachment you received).

Neurology. 2012 Nov 21. [Epub ahead of print]
Depression in epilepsy: A systematic review and meta-analysis.
Fiest KM, Dykeman J, Patten SB, Wiebe S, Kaplan GG, Maxwell CJ, Bulloch AG, Jette N.

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The border-land of epilepsy--Revisited.
Barkley GL.

Seizure. 2012 Nov 23. pii: S1059-1311(12)00290-7. doi: 10.1016/j.seizure.2012.11.001. [Epub ahead of print]
Women living with epilepsy, experiences of pregnancy and reproductive health: A review of the literature.
Weckesser A, Denny E.

Dev Med Child Neurol. 2012 Dec 4. doi: 10.1111/dmnc.12044. [Epub ahead of print]
Understanding relationships between autism, intelligence, and epilepsy: a cross-disorder approach.
van Eeghen AM, Pulsifer MB, Merker VL, Neumeyer AM, van Eeghen EE, Thibert RL, Cole AJ, Leigh FA, Plotkin SR, Thiele EA.

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ESNA News

Epilepsy Care

Welcome to the first electronic only version of the Epilepsy Care journal. The format has changed slightly but we hope that ESNA members will continue to find it informative and topical. The aim is still to provide a vehicle for nurses to write about their own interests and research in the field of epilepsy. The co-editors would like to hear from any members interested in submitting articles and would also welcome any comments about the new format. We very much want to provide a journal which meets the needs of its readership and to that end feedback is vital.

ESNA conference 2014

Although we are only halfway through 2013, the ESNA executive has already been considering options for next year's conference. The overriding concern has been to make it accessible to as many members as possible. As well as its geographical location consideration has also been given to the day (weekday or weekend) that the conference should be held and cost for delegates.

The ESNA executive feels that there are two reasonable options for conference. The first would be a two-day programme similar to the previous events in 2010 and 2012 held at a location in the Midlands close to an airport and with good road and rail links. Alternatively, two separate days with similar content could be organised one in the North and one in the South of the country. Again, we would consider proximity to an airport and good rail and road links to be essential. The cities of Newcastle upon Tyne and Bristol have been considered as venues that would meet those requirements. A questionnaire will be sent out by email shortly to elicit the views of the membership about these options.

There has been considerable discussion about the cost of conference. With challenging economic times, it is unlikely that we will be able to attract the level of sponsorship that our conference has enjoyed in previous years. Utilising postgraduate medical centres for single day events without an overnight stay would undoubtedly reduce the costs significantly. The ESNA executive are actively looking for ways of reducing costs compared to those incurred for conference 2012 to provide members with real value for money.

The ESNA AGM for 2014 will take place during the conference if a single two-day event is chosen. If two, one day events become the preferred option then the AGM will take place at one of them. Notice will be provided about the AGM in accordance with the ESNA constitution.

The ESNA executive has shortlisted a dozen possible topics for presentation at the conference based on feedback from conference 2012. Members are welcome to contact any member of the executive with further suggestions before the programme is finalised later this year.

ESNA AGM 2013

A summary of the AGM, particularly the revised constitution will be made available for members via the ESNA website.

Epilepsy Alliance

Unfortunately, Glaxo Smith Kline has decided not to continue their involvement with the Epilepsy Alliance. ESNA would like to thank them for the support that they have given through the Alliance over the last couple of years. In that time there have been some significant achievements; most notably the adult and learning disability epilepsy nurse competencies have been published, which should have a positive impact both on commissioning of services as well as the evaluation of an individual's performance and development.

There have been a series of Epilepsy Alliance study days which have been well received by nurses. The next of these scheduled for the ninth and tenth of October at Warwick University will still be going ahead. It is planned that the long-awaited portfolio designed to accompany the nurse competencies will be launched at this meeting. Further information will be circulated in the usual manner.

Finally, the Alliance has been involved in funding the relocation of the diploma in epilepsy care from Leeds to Edinburgh Napier University (in partnership with Brian Chappell from NeuroEducation, Epilepsy Action and ESNA). A Masters level epilepsy course is also being considered.

There is considerable will from Epilepsy Action and ESNA to maintain the Epilepsy Alliance and both organisations plan to continue working together on specific projects under this banner.

Paediatric competencies

These are in the process of being updated in a similar format to the adult and learning disability competencies. At the time of writing a first draft from the authors was thought to be imminent. When this arrives it will be circulated for comment in the same way as the earlier documents.

ESNA News (continued)

Paediatric epilepsy training (PET)

This training programme is now almost ready for release. It is hoped that it will standardise high-quality epilepsy training and also that its content could easily be adapted for both adult and learning disability specialisms. It is hoped that the British Paediatric Neurology Association (BPNA) who have been working on the project will have the opportunity to present their work at the ESNA conference in 2014. The final training packages will be available from the ESNA website following the launch.

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