This is a very special issue of Epilepsy Care. In many ways, it marks the end of an era. Brian Chappell has been the co-editor of the journal since its inception in 2001. He retired at the end of 2017 and this will be his final edition. Brian has overseen Epilepsy Care and ensured that it truly has been a voice for epilepsy nursing, with the majority of articles written by ESNA members. As the current chair of ESNA, I have wanted to use this editorial to pay tribute to Brian and to thank him for the fantastic help and support that he has lent to the Association for over 20 years.

Epilepsy Care will doubtless change in 2018. At the time of writing, it is not clear what form the journal will take in future. However, the same cannot be said for ESNA. The Association has over 350 members and is involved in shaping national policy, with contributions to both NICE and SIGN guidelines. ESNA has set competencies so that for the first time commissioners and employers have a sound idea of what to expect from nurses with varying levels of experience. ESNA is currently involved in setting its first national guideline, concerning the provision of epilepsy awareness and buccal midazolam training. Of course, its founding principle is to support nurses in order for them to provide excellent care to patients. This remains the Association’s focus and it organises conferences, prescribing days and, through the epilepsy Alliance (cooperative working with Epilepsy Action), study days for newly appointed epilepsy nurses.

2018 also marks the retirement of the last founding member of ESNA from her epilepsy specialist nurse post. Lorraine Reynolds has spent 30 years working exclusively in epilepsy and, for this special edition of epilepsy care, has kindly shared her memories of the Association from its inception and through its formative years. Without the commitment of Lorraine and the other founders of ESNA we would not have the fantastic organisation that we have inherited. I hope that we can all look back with pride at the achievements of our founders and carry the torch forward, both for epilepsy nursing and the wider epilepsy community.

Phil Titensor
Chairperson, EsNA
The birth of EsNA – founded 1992

I cannot take all the credit for the birth of EsNA as Dr Stephen Brown, who at the time was Clinical Director at the David Lewis Centre, suggested that I should make contact with the other nurses around the UK and perhaps meet up with them for mutual interest and support.

I had recently taken up an Epilepsy Nurse Specialist post at The David Lewis Centre and as it was a fairly new role in the world of epilepsy, I felt this to be a good idea. I invited all the nurses I was aware of to a meeting at the Centre which took place around May 1992, although I cannot remember the exact date.

The first Epilepsy Nurse was a woman named Sylvia Readman, although I never actually met her as she had retired when I started in post and had been replaced by two nurses, Velma and Beryl. Velma and Beryl were working in Doncaster alongside a GP, Dr Malcolm Taylor, who had a child with epilepsy and, as a consequence, had recognised the need for epilepsy nurses. At that first meeting there were eight of us in total from London, South Wales, Sheffield, Doncaster, Birmingham and Manchester.

The role of the nurse was given a boost when Glaxo Wellcome set up a group of 10 epilepsy nurses across the country and, although the initiative was short lived, it did raise the profile and in 1993 The National Society for Epilepsy published a paper, along with the major epilepsy charities, the British Epilepsy Association (Epilepsy Action) and The National Society for Epilepsy (The Epilepsy Society). The most eminent epileptologists were often associated with these establishments. We were invited to national epilepsy meetings and were greeted with both interest and scepticism in equal measure. I remember one person calling us the ‘paranoid nurses association!’ Clearly there were some who felt uneasy about our presence. Nevertheless EsNA went from strength to strength and many were anxious to get on the bandwagon and have their own epilepsy nurse.

At the meeting we decided that it would be beneficial to meet regularly and so we gave our small group a name and a purpose. We decided on aims and objectives which have changed very little over the years and many of our ideas are still in use today. We also thought about a logo and someone suggested the Roman Standard with the words ‘Carrying the Torch for Epilepsy’ which still remains. Brian Chappell in his then role at Epilepsy Action donated £300 to pay for the basics of headed paper and our first leaflet. Since that meeting most of the nurses have either retired or moved on and as far as I am aware only myself and Carina Mack, who is a lead nurse at the Royal Hallamshire Hospital in Sheffield, are still working in Neurology.

At that time the epilepsy world was dominated by organisations with a residential focus such as The David Lewis Centre, The Chalfont Centre, The Lingfield School and The Quarriers Centre
‘The Clinical Nurse Specialist in Epilepsy - a community initiative’ and this was followed in 1994 by an All Party Parliamentary Group promoted by The British Epilepsy Association. By 1994 there were 18 centres with an Epilepsy Nurse Specialist.

Of course there was more money around in those days and getting funding for conferences, training courses etc., was rarely a problem. Carina represented the Association at an international conference in Miami and in 1995 six epilepsy nurses attended the American Epilepsy Congress in Baltimore. Links were formed around the world, as far away as New Zealand. In 1995, The British Epilepsy Association launched its Sapphire Nurse Scheme, with funding available to support posts in the initial stages.

Membership of EsNA was expanding, especially amongst Learning Disability and Paediatric nurses, and national meetings became too large to manage and so in 1999 the structure of the Association changed, with the advent of locality groups, which could feed back into the national Committee. It was at this point that the word ‘specialist’ was omitted from the title in order to reflect the diverse and developing nature of EsNA. Leeds Metropolitan University launched their Professional Diploma in Epilepsy Care, which many EsNA members went on to complete. In 2001, a new journal, Epilepsy Care, was launched, edited by Brian Chappell from NeuroEducation, and this was, and still is, free to EsNA members.

The photograph above was taken in 2001 at a National EsNA meeting which took place at the Natural History Museum. We had a gala dinner at a long table underneath the dinosaur which was, until recently, suspended in the entrance hall of the museum – those were the days!

I have continued to be involved with EsNA over the years, albeit in a lesser capacity, as locality organiser of EsNA Northwest, which I have now handed over to a colleague. I have watched EsNA grow into the major force for epilepsy nursing that it is today and I do admit to a little burst of pride when the logo pops up on my facebook page or when I receive my weekly email. I can only pass on my thanks and admiration to those who have continued to give their commitment to EsNA in an increasing challenging work environment.

Lorraine Reynolds
One of the originals
Teratogenic effects of antiepileptic drugs - A Case Report

Erica B Chisanga, Consultant Nurse - Epilepsies, Cambridge University Hospitals NHS Foundation Trust

Summary
Antiepileptic drugs (AEDs) are teratogenic and care must be taken in the management of women of child-bearing age with epilepsy. Different drugs used in the treatment of epilepsy carry varying associated risks of teratogenicity. The best antiepileptic drug regimen to use in pregnancy is that which is most effective at preventing seizures, whilst taking into account co-morbidities and lifestyle factors, in a given patient. Sodium valproate is known to pose the highest risk of minor and major birth defects and can cause lower intelligence quotient (IQ) in affected children. If possible, it should be avoided in women with the potential to become pregnant. This has been underscored by the recent guidance published by the Medicines and Healthcare products Regulatory Agency (MHRA) in April 2017.1

In the case presented here a woman with a diagnosis of epilepsy and receiving antiepileptic drugs (AEDs), came seeking advice regarding pregnancy. She previously gave birth to a child with congenital malformations and development delay due to her AEDs, an event which could have been prevented.

Background
Epilepsy and AEDs may impact upon the outcome of pregnancy. The majority of adverse health outcomes in pregnancy are not due to epilepsy itself, but rather the teratogenicity of AEDs. Fertile women with epilepsy should meet with a specialist to discuss the possible consequences for their own health, and that of their child’s, if they were to become pregnant.2 However, it is apparent this is not happening for a significant proportion of women with epilepsy; many cannot make informed decisions about their families as they do not receive adequate information about the risks of epilepsy and pregnancy. While there is an awareness of some key issues, many women have insufficient knowledge about the teratogenic effects of AEDs and require more information prior to choosing medication or planning a pregnancy. It has been found women wish to be more informed and work is ongoing to determine the barriers preventing this.3

Case presentation
A 28-year-old woman attended clinic with her partner to discuss planning a pregnancy. She has focal epilepsy and at the time was receiving lamotrigine 150mg per day. She was also taking folic acid 5mg per day and had been doing so for six months. She was not using any form of contraception. She experienced infrequent seizures, occurring at times of stress or when medication was omitted, and her last seizure occurred seven months previously. The majority of seizures occurred nocturnally. She had been pregnant twice previously, both children living with their respective fathers. She is currently unemployed and lives with her partner and his four children.

She has a history of right hemiplegia and epilepsy secondary to post-operative brain damage. Aged 2, the patient underwent open heart surgery for the closure of three ventricular septal defects and a patent foramen ovale. She sustained severe brain injury as a result of an intra-operative air embolus and suffered extensive cerebral infarction and oedema in the left parieto-occipital and right frontal regions. She was diagnosed with epilepsy aged 17 after three nocturnal seizures were witnessed by her mother. She was prescribed phenytoin 300mg daily. This reduced her seizure frequency without producing seizure freedom. She had two awake seizures during the following year, where she experienced déjà vu and head version pre-ictally and would find herself on the floor, had urinated and was confused following the seizure. Since these episodes aged 17 and 18-years old she has not had a further awake seizure.

At 22-years-old she had her first child. She found out she was pregnant at 13 weeks gestation and at this stage folic acid 5mg daily was prescribed. Her phenytoin levels were monitored and the dose of the drug elevated to 350mg daily following a generalised tonic-clonic seizure several weeks before her due date. She had a spontaneous vaginal delivery and her baby was healthy. The following year she experienced three generalised tonic-clonic seizures in nine months and she noticed that phenytoin was causing gum hypertrophy, which she was unhappy about. She was gradually changed from phenytoin to sodium valproate over the course of four weeks, at the end of which she was managed on 800mg per day sodium valproate with no phenytoin. Following this she continued to have seizures and her sodium valproate dosage was increased to 1000mg per day. It was discovered that she was no longer taking folic acid supplements and was advised to do so due to the teratogenic effects of sodium valproate, despite the patient expressing she planned on having no further children.

The patient had her second child aged 25. The patient did not seek advice prior to the pregnancy. Her dosage of sodium valproate was increased to 1200mg following a seizure at week 28/40. The baby was born with foetal valproate syndrome and had dysmorphic features (smooth and elongated philtrum, thin
upper lip and prominent epicanthic folds) and developmental delay. Following this she was taken off sodium valproate, which was replaced with lamotrigine 150 mg daily.

Outcome and follow up

Following discussion with the patient she stated lamotrigine was controlling her epilepsy to an acceptable standard. The risk of teratogenicity is lower with lamotrigine compared to sodium valproate. Therefore no changes were made to her medication or dosage. She began taking folic acid several months before trying to conceive and planned to continue taking it until after the 12th week of gestation. She was informed about the scans she would receive during her pregnancy and also informed that she would be seen again in clinic once she was pregnant.

Discussion

Around one in 250 pregnancies are exposed to AEDs; the safety of these drugs in pregnancy has been well studied. While most pregnancies in women with epilepsy are uneventful, it has been shown that, even the safer AEDs used in monotherapy, can double the risk of major foetal abnormalities, while polytherapy triples the risk of both minor and major birth defects, compared to pregnancies where the foetus has not been exposed to AEDs. The majority of women with epilepsy must continue their medication for the duration of pregnancy. Stopping or altering antiepileptics during this time can be dangerous. It is therefore crucial that treatment is optimised before conception, aiming to use the lowest dose of a single drug which is most efficacious for seizure type/s or the syndrome.

All AEDs are known to be teratogenic. Sodium valproate, phenytoin, primidone and phenobarbital are considered to carry the greatest risk of teratogenicity. Carbamazepine, although possibly only at doses below 400 mg per day, lamotrigine and levetiracetam are safer options. Sodium valproate has been found to be particularly problematic.

Sodium valproate was first used as an antiepileptic more than 50 years ago and is believed to prevent seizures through modulation of enzymes involved in gamma amino butyric acid (GABA) and sodium channel regulation. It has since been discovered to have multiple teratogenic effects, together termed as ‘foetal valproate syndrome’. The exact mechanism of these teratogenic effects is still largely unknown. Features of foetal valproate syndrome include; numerous congenital malformations, dysmorphic features, spina bifida, abnormal facies (epicanthal folds, upturned nose with flat nasal bridge, prominent upper lip), underdeveloped nails, arachnodactyly, diastasis recti, hypospadias, CHD, tracheomalacia, talipes, equinovarus, hip dislocation, developmental delay (especially language) and behavioural problems. Increased risk of autism, autistic spectrum disorders and Asperger’s syndrome have also been noted with sodium valproate, this risk has not been reported in any other AEDs.

The first 12 weeks of pregnancy carry the highest risk of malformations, because this is the most important phase of structural development during pregnancy. A dose of over 1000mg/day is associated with increased risk of all teratogenic consequences of sodium valproate. It is important to note that epilepsy is not the sole indication for the majority of AEDs and women with other conditions requiring treatment with these drugs also carry increased teratogenic risk. AEDs can lower serum and red blood cell folic acid. Folate supplementation is advised in women with epilepsy, because they have an increased risk of conceiving a child with neural tube defects than pregnant women without epilepsy. They are recommended to begin taking folic acid, 5mg daily, at least three months before conception and to continue taking it throughout pregnancy.

In this case the patient was prescribed sodium valproate while she was of child-bearing age. It is recommended valproate is not prescribed in such cases unless other alternatives have been tried and failed and following detailed discussion of the risks. While phenytoin was prescribed prior to sodium valproate, no other AEDs were trialled and unfortunately in this instance this decision resulted in her second child being born with birth defects. The patient had previously received counselling on the possible harm sodium valproate may cause in pregnancy, but it is unclear as to whether she fully understood the risks associated with the drug.

It is important to ensure all women with epilepsy have adequate knowledge about how epilepsy may affect them during pregnancy, in order to allow them to make informed decisions prior to conception. There are several charitable organisations, such as Epilepsy Action and Epilepsy Society who aim to inform patients with epilepsy on all aspects of the condition. Co-ordination is required between, the patient, healthcare professionals and the charities to ensure patients can access this information easily.

Points of note

• Many women with epilepsy are not receiving adequate pregnancy counselling
• Knowledge of the teratogenic effects of AEDs amongst women with epilepsy remains poor
• Evidence shows women want to receive more information, especially in relation to the teratogenicity of AEDs
• Proactive supplementation with folic acid 5mg/day for women with epilepsy of childbearing age may be advisable as
most pregnancies are not planned
• Proactive preconception advice should be offered to young adults as they transition from paediatric to adult services
• Consideration should be given to use of AEDs with low teratogenic profile in women of child bearing age

References

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.neuroeducation.org.uk. From the home page click on “Epilepsy Care” (bottom right). The access code is esna2009. This 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).

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