

Note of Meeting – Cross- Party Group on Epilepsy, 24 September 2015

In Attendance:

Declan Ahern, Epilepsy CNS NHS Lothian & ESNA	Yvonne Leavy, ESN NHS Lothian
Mary Antczak, People's Forum, Epilepsy Connections	Donald Macintosh, ESN NHS Highland
Jean Barclay, Observer	Lorraine Mackenzie, Observer
Jayne Baxter MSP	Alison McInnes MSP
Celia Brand, ESN NHS Lothian	Carsten Mandt, MCN Manager, SPEN
Jo Campbell, ESN NHS Grampian	Craig Miller, PA Richard Simpson MSP
Cara Cameron MSP	Alan Moir, Epilepsy Scotland
Elaine Collard, ESN NHS Highlands	Hilary Mounfield OBE, SEC Quarriers
Anthony Cornish, Observer	Dr Ann O'Hara, Consultant NHS Grampian
Pauline Donaldson, NHS Grampian	Allana Parker, Epilepsy Scotland
Janice Fyall, NHS Lothian	Derek Robertson, ESN NHS Lothian
Michael-John de la Haye, PMLR Scotland	Brian Rocks, West Dunbartonshire Support Group
John Heaney, West Dunbartonshire Support Group	Jacqui Telfer, Epilepsy Scotland
Andrena Hughes, Observer	John Thomson, NHS Lanarkshire
Jen Irvine, ESN NHS Lanarkshire	Sam Whitmore, Epilepsy Connections
Lorraine Kennedy, Observer	Margaret Wilson, ESN NHS Greater Glasgow and Clyde

Apologies:

Lorne Berkley, SEC Quarriers	Ann Maxwell OBE, Muir Maxwell Trust
Cameron Buchanan MSP	Nanette Milne MSP
Kenneth Gibson MSP	Marie Prince, NHS GG&C
Fiona Hughes, ESN NHS Forth Valley	Pauline Smith ESN NHS Tayside
Chris Jeans, SUDEP Action Scotland	Lesslie Young, Epilepsy Scotland
Claire Leonard, Epilepsy Connections	Jean Urquhart MSP
Peter Martin, Observer	

1. Deputy- convener Alison McInnes MSP welcomed attendees to today's meeting.
2. The draft note of the April 2015 meeting and AGM was approved. Recent activities included:
 - Two Members Motions mentioning epilepsy since April. Kenneth Gibson MSP drew attention to revised SIGN guidelines and the World Health Organisation's action plan for epilepsy in National Epilepsy Week in May. This month Annabel Goldie MSP congratulated Quarriers and the William Quarrier Scottish Epilepsy Centre for their contribution to families and the services provided.
 - Michael McMahon MSP submitted a Parliamentary Question (June). He wanted to know which neurological charities the Scottish Government had met with in 2014 besides the Neurological Alliance of Scotland and the National Neurological Advisory Group. Both Epilepsy Scotland and the William Quarrier Scottish Epilepsy Centre met with the Scottish Government that year.
 - Five MSPs and 14 parliamentary staff attended six free epilepsy awareness training sessions run by the Epilepsy Consortium Scotland in National Epilepsy Week, with excellent course feedback.
 - The Minister for Sport, Health Improvement and Mental Health, Jamie Hepburn MSP will address the Epilepsy Group meeting on 28 January 2016. Also discussing integrated health and social care is South Lanarkshire's Health and Social Care Partnership Chief Officer, Harry Stevenson.
 - All Scottish health boards responded to a Freedom of Information request about EEG location and provision in Scotland. Analysis is underway of current waiting times to access routine and acute EEG, local hospital data transfer capability and numbers of technician neurophysiologists.
 - This month, the Royal College of Paediatrics and Child Health launched a new epilepsy passport for children and young people. It provides essential information to assist communication between families and the health professionals involved in their care. Attendees were invited to take a look at the materials and share the details with families they know and work with.
3. The Deputy-convener introduced today's speakers: Jo Campbell is a Children's Epilepsy

Specialist Nurse (ESN) with NHS Grampian, Orkney & Shetland and she chairs the Scottish Paediatric Epilepsy Nurse Group. Declan Ahern is an Epilepsy Clinical Nurse Specialist with NHS Lothian and is also the Scottish representative for the Epilepsy Specialist Nurses Association.

- Jo Campbell presented key findings from a regional audit into the use of epilepsy devices for monitoring children with epilepsy during sleep. This audit by the North East of Scotland Child and Adolescent Neurology Network was in response to an increasing awareness of the anxiety parents were experiencing in relation to the safety of their children during sleep. The Scottish Government had also asked for information about the types of alarms in use, their effectiveness, both how and why service users accessed these devices, the impact on family life and what information should be given to parents.
- In the UK, approximately 600,000 people have a diagnosis of epilepsy and take anti-epileptic medication. Of those, 63,400 are aged 18 and under which equates to one in 220 children and young people on medication for this condition. In the north east of Scotland there are 960 children and young people with epilepsy across Grampian (including Orkney and Shetland) Tayside and Highland health boards. The audit comprised a statistically relevant sample of about 25% of the epilepsy patient caseload. The questionnaires were not posted but given out at clinic appointments to a patient or parents to increase the yield. The Clinical Effectiveness Department used appropriate software for analysis.
- The children in the audit were predominantly of school age, from 5 to 19, because children with learning disabilities and epilepsy are often kept in children's services until that higher age. Of those audited, over two fifths (42.5%) had a learning disability as well as epilepsy.
- While the majority of families knew what type of epilepsy or seizures their child takes, it was difficult to tease out definitively some of the seizures described. However, from the 196 responses it seems 105 of these children had or still have tonic clonic or secondary generalised seizures. Nearly 70% of families reported that their child's seizures were well controlled, and this matches other study findings which suggest that 70% of children could achieve seizure control with appropriate medication. However, the responses were subjective, and better seizure control for one family meant their child's seizures reduced from 120 to 93 tonic clonic seizures a month.
- Two thirds of children were having up to 50 seizures per month or over a 100 in some cases of varying types. Over three quarters of parents were seriously worried about their child having seizures during sleep yet four in ten had not discussed this concern with an epilepsy specialist nurse or a doctor.
- The audit highlighted that two thirds of parents had or were sleeping in their child's bedroom intermittently for up to two years – in one case for 14 years. This phenomenon is recognised in research studies where, as parents first see a child having a tonic clonic seizure they think the child is dying, and this anxiety leads to them sleeping in the same room as the child.
- Nearly half of the parents interviewed had or were using some kind of monitoring device to indicate that their child was having a seizure at night. Those who stopped any monitoring fell into two main categories; either the ineffectiveness of the chosen device or reduced or controlled seizures. The majority of parents used baby alarms and less than a quarter of families had used an epilepsy alarm. Again, most of the alarms had been purchased by parents and so they were responsible for alarm maintenance.
- Almost three quarters of parents reported that the monitoring equipment being used was reliable for children who currently have tonic clonic and secondary generalised seizures. However, there was a difference in reliability ratings between baby alarms including other monitoring devices (over 75%) with the reliability ratings for epilepsy alarms (45%). Conversely, poor reliability scores were considerably higher for epilepsy alarms (55.6%) than other monitoring devices (3.4%) which would suggest other devices are thought to be more effective than actual epilepsy alarms.

Parents gave varied reasons for monitoring their child during the night: "Because I want my sleep and I have other children to look after. I wanted to get back to my own bed and husband. I wouldn't forgive myself if anything happened." Another said, "I struggled with the thought of my child being on their own during a seizure. My child's vomiting was also an issue, post seizure. The risk of Sudden and Unexpected Death in Epilepsy (SUDEP) is also very scary, and the use of monitoring allows you to feel like you are doing as much as possible to reduce this risk." One parent remarked, "I still now sleep in the same room but feel more relaxed and able to sleep with 2x alarm systems in place. Cameras allow us to be downstairs and keep a close eye on what is happening. Still wake through night and check monitor (saturation) but not up nearly as often". Another explained: "Never gone down the road of epilepsy alarm mats as I would be

going down the route of night carers and would be going off all the time. We hear the big seizures. Do I need to know about all my child's seizures? Don't want to become obsessed and don't want my child's seizures to rule our lives. A fact of life for us".

- It is important to understand from a parents' perspective all their reasons to monitor a child. One parent commented: "My child isn't safe if not monitored. I have to be able to see my child as well as hear because of silent seizures. I can often intervene and stop a seizure from happening by altering a feed, position, general comfort. For practical reasons, my child needs observation." In this example, a parent was hoping to pre-empt a seizure through hearing and seeing her child. In this case no alarm would have gone off because a seizure had not happened. The parent was trying to be pro-active. Nurses and doctors may need to consider the impact of their words when asking if a child has any seizures at night as this may lead parents to worry. The child may not necessarily have the type of epilepsy that lends itself to having seizures through the night.
 - Overall, parents monitored their child so they could be present if the child was having a seizure. Their main worries were if the child was choking, having breathing difficulties, injuring themselves or "the long term effects" of missed seizures. Surprisingly, very few parents (6) mentioned the fear of their child dying and that included the four parents who used the term SUDEP.
 - In looking at the literature on epilepsy monitors, none are 100% effective. They may have a place for children with refractory epilepsy who have on-going tonic clonic or secondary generalised seizures. As this audit showed, many parents preferred to use baby monitors and deemed them more reliable than currently available epilepsy alarms. There has been an explosion in new technology but the quality of literature on monitoring alarms is not gradable by SIGN standards. Sometimes it is unclear if the device aims to alert someone to seizures with the intention of intervention, or whether the monitor is merely to detect seizures. The seizures in the studies are variable making comparisons hard to ascertain. The measurements used to assess efficacy in the studies are also variable; some measure sensitivity and specificity while others talk about the potential predictive value and levels of effectiveness. There is a need for more robust research around these alarms.
 - Optimum control of seizures is a priority. Parents need to be offered the opportunity to discuss monitoring in the context of the type of seizure the child has and the epilepsy syndrome because not all epilepsy syndromes involve seizures occurring at night. Parents need to be encouraged to measure the level of control for their child's seizures and to optimise this. ESNs need to talk to them about adherence to medication, discuss the side effects of medication that might be stopping the achievement of optimum control, and to discuss the perceived versus real risks.
 - Some people think of risks in terms of SUDEP but this is a very, very, low risk for the majority of children and people with epilepsy. Epilepsy alarms and monitoring devices do not prevent SUDEP. The risks parents in the audit mentioned were the risks of choking and aspiration. Risks include the strains on family life and from interrupted sleep as reported in a Family Fund study. If it is the parents' choice to monitor their child during sleep then this choice should be respected and supported appropriately. The audit concludes that the blanket issuing of epilepsy monitoring devices is not appropriate. From the vast array of family experiences of the children served by ESNs, one monitor size doesn't fit all, as the children and their parents have varying needs. The rate of change in new technology might mean more effective solutions are available in the future.
4. The Convener thanked Jo Campbell for her presentation and invited questions:
- Yvonne Leavy thanked Jo Campbell for a really good piece of work, even though there was not much headway in terms of the alarms themselves. She agreed specialist nurses have to bear in mind parental concern with having well-adjusted and not overly anxious young people who take seizures. It was about balancing perceived risk with actual risk and also looking at the normal social development of the child. This needed some care because sometimes children are not given the freedom they can and should be able to have, as they are not a high risk.
- Jo Campbell agreed and cited comments by parents who have stopped using alarms. These mentioned wanting to give their child some independence and privacy.
5. The next guest speaker, Declan Ahern, presented details of epilepsy specialist nurse (ESN) provision in Scotland. As happened with his ESNA predecessor Sheena Bevan, he was asked to collate these figures which turned out to be no easy task. Nurse numbers on the handout had been broken down per health board region. There was one correction for NHS Lothian where the paediatric epilepsy service has two and not three whole time equivalent ESNs, as one national neurosurgical epilepsy nurse specialist is based in NHS Lothian.

- There is no central database for recording ESN numbers and staff moves. There are a few anomalies in what to count as specialist nurses because jobs are shared between epilepsy nursing and the community, while others are split between adult and learning disability with no detailed proportion of allocated hours. Such posts were not included in this data.
 - Epilepsy specialist nurses are unlikely to keep a central database of the number of patients under their care due to clinical commitments and time constraints to gather this information. Instead, patient numbers have been estimated to reflect health board populations and do not include actual referrals to any individual nurse's caseload from outside their area.
 - ESN data has been split into learning disabilities, adult services and paediatrics services. An estimated one per cent of the population has epilepsy. Depending on the definition, approximately 2 – 2.5 per cent of the population has a learning disability, and a quarter of those have epilepsy ranging from mild to severe. An estimated half a per cent of children are likely to be diagnosed with epilepsy, affecting 1 in 200 children. Young people will transition at different ages depending on their readiness, that of their family and the clinical assessment. Cross-overs between all these epilepsy services are common but the figures don't reflect higher paediatric numbers or adult ESN services which see patients with a learning disability.
 - Current national provision for ESNs in adult services is 14.1 (whole-time equivalent) doing a total of 532 hours. Using health board populations, there are an estimated 53,277 people with epilepsy which gives an average case load of 3,779 patients. Similarly, there are 13.3 (whole-time equivalent) ESNs working 489 hours in paediatric services to serve 29,968 children and young people. This gives an average case load of 2,002 patients each. For the 6.8 (whole-time equivalent) nurse specialists who work 255 hours assisting 29,968 people who have epilepsy and learning disabilities, this equates to an average 4,407 patient case load.
 - Within those numbers are shared post anomalies that could marginally reduce patient case load numbers. For example, NHS Grampian nurses share 53 hours between both the adult and learning disability services while one NHS Lanarkshire whole time equivalent post is shared between the epilepsy nurse specialist service and the community. Another ESN adult and learning disability whole time post is charity funded (Quarriers) and is not part of the data.
 - It may be useful to compare ESN numbers with staffing figures and prevalence levels for other chronic neurological conditions. Around two in 100,000 people may develop motor neurone disease (MND) and currently 460 patients have MND in Scotland. Using NHS Lothian as one example, there are two MND nurses (1.6 whole-time equivalent) in post. About two in 10,000 people develop multiple sclerosis (MS) and NHS Lothian has two MS nurses (whole-time equivalents) with another due to be recruited. Similarly for Parkinson's disease, which has the same prevalence rate (0.2%) as MND, there are three (whole-time equivalent) nurses for 1,428 patients. Their patient case load is 476 compared with 3,779 in for two ESNs.
 - There is also an erosion of the role of the ESN. More of these nurse specialists are being asked to do clinical shifts on the wards. Some are being asked to take hospital bleeps for bed management and hospital staff management. It takes time away from patient care when there is already enough pressure and problems. The consequence is not being able to meet current SIGN guidelines and recommended clinical standards. Even the Joint Epilepsy Council (JEC) recommended figure suggests one epilepsy clinical nurse specialist per 100,000 head of population. This means 53 ESNs in Scotland with an approximate 1,000 patient case load.
 - While some appointments have been made to ESN posts and vacancies, it usually takes three to four years for a new nurse recruit to reach the clinical competence levels set out by the RCN for both paediatric and adult epilepsy nurse specialists. In addition, it will take a number of years to reach the JEC target given existing specialist nurses may leave their posts or retire.
6. Alison McInnes MSP thanked Declan Ahern for his presentation and asked the first question regarding any Health Boards currently without any ESNs.

Declan mentioned some health boards provide epilepsy services for others. For example, NHS Grampian also covers NHS Orkney and NHS Shetland as neither has its own dedicated epilepsy clinical nurse specialist, nor does NHS Western Isles and NHS Dumfries and Galloway. There are also a number of areas without a learning disability ESN (eg NHS Ayrshire and Arran, Borders, Forth Valley and Tayside). NHS Borders does not have an ESN for adults yet and NHS Forth Valley has no paediatric ESN.

Brian Rocks commented on seizure alarms mentioned by Jo Campbell. Last year he tested a "buddy system" device for adults with epilepsy introduced by West Dunbartonshire. It can tell

what type of seizure the person is having and sends information to a central office to alert the wearer's emergency contact. It is suitable for those aged 12 and over. Jo Campbell cited published information about a new smart watch device where its sensitivity or accuracy was described as 16 per cent. It could not be recommended by professional nurses as evidence-based advice to parents. Lorraine Mackenzie asked Brian Rocks about the buddy alarm as she lives in a nearby area. It is provided by the council's telecare community alarms.

Alan Moir announced that following a joint pilot project to develop epilepsy services with Epilepsy Scotland, NHS Dumfries and Galloway are about to appoint an ESN trainee. Epilepsy Scotland's own ESN will remain in post in NHS Dumfries and Galloway for 18 months with a mentoring role in developing the trainee. The band for the post is yet unknown. While Declan Ahern had earlier expressed concerns on the management outcomes of a project post which was pharma funded and not an NHS post, he appreciated and valued the benefit for patients with epilepsy. Alan Moir explained that with the project concluded, there is an ESN post partially funded by the NHS which Declan Ahern agreed is a long term outcome.

Based on her 16 years' training experience, Yvonne Leavy advocated standardised training for epilepsy nurses, where if someone comes into a post, they are mentored by senior nurses who practice with a clinical case load. The post holder's competencies are assessed and the patients get the benefit. This would be in line with the Royal College on nursing competencies which she authored. Alison McInnes MSP said this reflected Declan Ahern's point where new nurses can take four years to reach clinical competency with appropriate support and assessment throughout.

Margaret Wilson concurred with all Declan Ahern said and made the point that epilepsy is not one condition. She is an epilepsy nurse in Glasgow with the highest number of patients while her colleagues in diabetes have 10 specialist nurses and two support posts for smaller numbers. Dealing with a single condition is easier, there's a much stronger parental pressure group and the number of diabetes nurses is greater, probably across all health boards. Declan Ahern said he imagined this being the case for nurses treating asthma and other similar conditions.

Jo Campbell mentioned co-morbidities and epilepsy had a knock on effect for child development and education. In the context of an integrated health and social care system, ESNs also had to be mindful to support children within education and social settings. Paediatric ESNs are dealing with behaviour and education at every consultation unlike more straightforward conditions. Ann O'Hara highlighted that the audit, though a lot of work, provides information that shows different families have different needs at different stages in their child's condition. The findings dealt with some of the apprehensions of professionals that families would think that if the child had a monitor everything would be fine, or it would prevent the risk of their child dying unexpectedly with epilepsy. What came across was parents want to know how to keep their child safe. The findings and further research ideas have been presented to SPEN (Scottish Paediatric Epilepsy Network).

Lorraine Mackenzie noted huge changes in the professions providing services to children like her now older son who was born with a lifelong condition. She was quite alarmed to hear that nurses were being taken away from a specialist role to provide care in other areas. She wondered if this issue could be taken forward with the Scottish Government along with a plea for more funding for future specialist nurses in epilepsy? It was mooted as being useful to learn why health boards feel this change should take place. Alison McInnes MSP agreed to pick this up through Parliamentary Questions. She also wants to explore on a future agenda the support networks in place for families. She again thanked Jo Campbell and Declan Ahern for their interesting presentations.

7. Alison McInnes MSP asked for any brief points of information people wanted to share?

Sam Whitmore mentioned a forthcoming partnership conference on 3 October in the Scottish Epilepsy Centre Glasgow between Epilepsy Connections and Epilepsy Action. The programme focus was on paediatric epilepsy and the ketogenic diet. Places were still available.

Celia Brand said she had nearly concluded mapping the availability of seizure alarms for children with epilepsy in Scotland. Of 32 local councils, 25 do not have any issues about providing seizure alarms and will do an assessment of any other alarms that might be useful for children and families. Two councils refuse to provide seizure alarms and this is being addressed in writing. The remainder have still to be contacted. Once the information is collated, the list will go on the SPEN website, with contact details and how to make a referral. Celia will send a link to the Secretariat.

8. The Deputy-convenor thanked everyone for attending and the date of the next meeting will be Thursday 28 January in Committee Room 2. Two eminent speakers will share their views on integrated health and social care for epilepsy.