

Draft: Note of Meeting – Cross Party Group on Epilepsy, 29 January 2015

In Attendance:

Jean Barclay, Epilepsy Scotland	Ann Maxwell, Muir Maxwell
Andrew Boyle, ESN Dunfermline	Shirley Maxwell, Epilepsy Connections
Beatrice Cant, SIGN	Nanette Milne MSP
Gerard Gahagan, Scottish Epilepsy Centre	Hilary Mounfield, Scottish Epilepsy Centre
Kenneth Gibson MSP	Allana Parker, ECS Secretariat
John Heaney West Dunbartonshire Epilepsy Support Group	Derek Robertson , Epilepsy Liaison Nurse
Andrena Hughes, Observer	Phil Robinson, Lanarkshire Epilepsy Support Group
Zareen Iqbal, Epilepsy Connections	Brian Rocks, West Dunbartonshire Epilepsy Support Group
Jen Irvine, ESN Lanarkshire	Richard Simpson MSP
Chris Jeans, SUDEP Action Scotland	Jacqui Telfer, Epilepsy Scotland
Gaye Kelly, EFW Quarriers	Sarah Wands, Observer
John Paul Leach, Consultant Neurologist	Gayle Weir, Epilepsy Connections
Helen Macdonald, Lanarkshire Epilepsy Support Group	Lesslie Young, Epilepsy Scotland

Apologies:

Cameron Buchanan MSP	Lorraine Mackenzie NHS Aberdeen
Jo Campbell, ESN Aberdeen	Eileen McCubbin, ESN Ayrshire & Arran
Cathy Dorian, Scottish Centre for Telehealth & Telecare	Peter Martin, Observer
Joanne Hill, ESN	Mary Nicol, Observer
Cara Hilton MSP	Michelle Small ESN NHS Lothian
Roberta James, SIGN	Jane Stuart, NHS Lothian
John Kinsella, SIGN	John Toland, ESN

1. Deputy-convener Richard Simpson MSP welcomed attendees to the meeting.
2. The draft note of the September 2014 meeting was approved. There was an update on activities:
 - Following recent ministerial changes, our Cross Party Group member MSP Jamie Hepburn has taken up the post of Minister for Sport, Health Improvement and Mental Health. We wish him well
 - There have been two Members Motions mentioning epilepsy since September raised by Siobhan McMahon MSP and Richard Simpson MSP. These respectively highlighted Hemiplegia Week in October and congratulated Epilepsy Scotland in November for its achievements over the last 60 years, including its work with the Crown Office and Police Scotland.
 - A Parliamentary Question has been submitted by Liam McArthur MSP. He asked about the number and percentage of further and higher education students with various health conditions. Details of the number of students with epilepsy were provided.
 - After the issue was raised in September that some GPs are charging patients to sign travel pass forms, Epilepsy Scotland asked its Facebook followers to give details of these occurrences. This, and similar information currently being gathered from Epilepsy Specialist Nurses and other epilepsy organisations, may help to indicate the scale of the problem.
3. The Deputy-convener introduced guest speaker Dr John Paul Leach, a consultant neurologist based in Glasgow, who is also the neurology speciality advisor to the Scottish Medical and Scientific Advisory Committee. Dr Leach gave a preview of some of the key points from the forthcoming revised SIGN guideline for diagnosis and epilepsy management in adults.
 - Dr Leach explained that the launch and implementation of SIGN epilepsy guidance will be in a few months' time and its implementation came through a huge amount of teamwork
 - The Scottish Intercollegiate Guideline Network (SIGN) was set up to provide written documented evidence, using proof from medical studies, to help guide various different aspects of medical practice. The initial 1997 SIGN epilepsy guidance in adults created a bit of a splash worldwide,

and pre-dated NICE guidance for England and Wales. SIGN guidance set out to be user friendly and its ready availability on the web has meant that people around the world use it as a baseline

- The guidance was updated in 2003 with a further update for epilepsy in children a few years later. By 2012 it was time to update the guidance again. Let's be clear, this guidance is not a set of mandatory instructions or minimal standards to which everyone has to adhere. It is a list of principals to which it is hoped most responsible clinicians adhere to in most cases, circumstances permitting. On the medical/legal front, deviation from SIGN guidance is often seen as being negligent or unacceptable. Of course, any deviation from guidance should be well documented and always be done in the patient's interest
- While the initial plan for a selective update to the guidance didn't quite come to fruition, the work by a wide range of medical specialties and the voluntary sector has been considerable in looking at epilepsy treatment, woman's issues, other social issues and the provision of psychiatric and psychological help. Wider questions by different sub groups such as 'what's the best treatment for someone who has new onset epilepsy?' or 'what's the best treatment once the first treatment has failed?' were modified to 'what treatments are going to be useful in newly diagnosed epilepsy' after a literature search and medical studies were not able to provide a definitive answer
- Information scientist Carolyn Sleith outlined all available papers for the sub groups to review and rank in terms of levels of evidence to their questions. The better the study, the higher the rating. Regarding the best treatment of epilepsy question, 157 systematic reviews were identified which attempted to minimise bias and give some clear cut answers. In fact, a further 45,496 identified and 1,519 check-listed observational studies were available in total across all the questions. The extensive epilepsy guidance produced in 2003 has now been added to and is hopefully improved. In terms of evidence, expert opinion is allowed but carries a lower ranking than research studies
- The new guidance indicates the strength of evidence behind a recommendation and not the strength of feeling for it. However, good practice points reflect a way forward where, as yet, there may not be substantial research evidence to support expert opinion. Stakeholders from the epilepsy community in Scotland and some representatives from the UK have contributed to and shaped the guideline which will be launched at an implementation meeting in June 2015. The guidance will hopefully be a springboard for improving services over the next decade
- Virtually all of the earlier guidance has been updated, completely revised or had new sections added. Here are some of the biggest challenges and the best improvements for patient care:
 - Outlining which patients should begin treatment after a first tonic-clonic seizure
 - Not switching anti-epileptic drugs for patients to provide stability and continuity of treatment. This is not in line with recent MHRA (the health regulatory authority) UK- wide advice regarding moving patients to different drugs depending on their pharmacological properties
 - New ways to administer emergency treatment for status epilepticus (very prolonged seizures)
 - Providing an EEG to monitor the brainwaves of all those with non-responsive status epilepticus so that clinicians can offer appropriate sedation levels
 - It should be said that an average district general hospital will have around 50 people admitted with generalised tonic-clonic seizures per year. Most of those patients will respond quickly to treatment but roughly 20-30 per cent do not and this may involve their further admission to non-specialist IT units where monitoring can be ad hoc
 - Access to an EEG in the new guidance may raise a few uncomfortable questions and pose logistical challenges to the medical infrastructure given the reduced and reducing number of consultant neurophysiologists and consultant neurophysiologists around the country. Glasgow has five (4.5 whole time consultant equivalents) and there is one consultant neurophysiologist in Aberdeen, Dundee, Edinburgh and Inverness, of which two are due to retire. The EEG itself can be done by a neurophysiology technician and there may be ways to get access to adequate neurophysiologist monitoring without necessarily furthering increasing the number of consultation neurophysiologists
 - In terms of various recommendations on women's health, the focus is to try and avoid any interaction between anti-epileptic drugs and contraceptive medication
 - Moreover, timely UK-wide research into mortality in pregnancy shows 24 deaths of women with epilepsy occurred between 2009-2012 (12 from conception to six weeks after delivery and another 12 deaths from 6-52 weeks after delivery.) The worry is that some women with epilepsy without pre-pregnancy counselling may be at risk during, before and after delivery, when they are sleep deprived and not paying quite as much attention to their own health because of other factors in their life. These new guidance points will potentially address this in the longer term

- A third of patients can have issues with either anxiety or depression. Therefore, screening for depression and suicide should be considered in all patients with epilepsy
- Mortality in epilepsy has become a driver for care. So patients aged 16-30 should be counselled about the risks of SUDEP (sudden and unexpected death in epilepsy) at an appropriate time for the patient and by an appropriate healthcare professional. The clinical focus is to assist patients to achieve seizure freedom/ good seizure control
- Feedback from the worldwide peer review of the draft SIGN guidance has been largely very favourable. The new guidance builds on progress from 2003. It poses some difficulties around implementation but also gives an opportunity to improve things for patients all around the country.

4. Dr Simpson thanked Dr Leach for his presentation and asked others to join in with questions:

Dr Richard Simpson commented that SIGN Guidelines were an incredibly valuable exercise not least because they define the levels and grading of evidence. He asked if part of the process involves making any recommendations about future research that might be undertaken in order to bolster or refute lower levels of evidence. Dr John Paul Leach agreed that SIGN regularly invited requests to highlight further areas of research work and this is mentioned in the new guidance.

At an earlier national meeting about the SIGN guidance, Ann Maxwell had mentioned the use of VNS as a treatment and the inclusion of epilepsy alarms in the mortality section. She wondered if there were any references to either of those points in the new guidance. Dr Leach thought one of the treatment sections does look at VNS, however, there was no firm guidance on how available this should be nor was it included in the key recommendations. Ann Maxwell asked about the reason for that and Dr Leach said the grading of evidence was not strong enough to put it high on the list of treatments. As for epilepsy alarms, these are mentioned in the section on mortality but they are not included in the key recommendations. He noted her concerns and acknowledged there are patients who have very much benefited from having epilepsy alarms. The new guidance states these can be useful in some situations but are not routinely recommended.

Ann Maxwell commented that even where patients are saying what they would like, whether in relation to SUDEP or epilepsy alarms, the absence of a recommendation in SIGN made it harder to get funding, in this case for epilepsy alarms. Dr Leach acknowledged not everything that people wanted will be in the new guideline. On balance, he felt that with the resources available and the evidence to hand the sub groups had made reasonable recommendations.

Dr Simpson wondered what happens when there isn't strong evidence for existing or new things to form part of a SIGN guideline and if further research can be identified in a commentary? Dr Leach took the view that if some of the group members thought that more work is needed on epilepsy alarms or electrical stimulation then it should go in the research recommendations.

Hilary Mounfield asked Dr Leach about his recommendation that status epileptic patients should all have an EEG and at the moment not everybody is. She enquired how that could be managed given various constraints on health funding and if he could envisage a solution to it? Dr Leach thought a relatively simple way was to have these tracings electronically reported to one neurophysiologist who would be on call across Scotland. Given the distances of rural populations and IT limitations, perhaps a more practical target would be that no patient was ever more than 24 hours away from an EEG. Other lesser intensive forms of brain function monitoring may be possible in communities without access to a full EEG. It would be a way forward and hopefully technicians could be trained up for that without having to grow a whole host of other consultants.

Dr Simpson agreed it was a challenge and something the Epilepsy Group may take forward. Having some indication of the location of EEGs, the current level of technician neurophysiologists and whether data is capable of being electronically transmitted would be helpful. His view was that rather than having people interpreting this data across the country it might be centrally based. There may be a huge potential to offer these kinds of services to countries like Malawi and other places. He asked the Group and the feeling was this was something they wanted the Secretariat to take forward. Current waiting times for EEGs could also be an issue. Dr Leach believed that in Glasgow, Ayrshire, and Lanarkshire the wait would be between two hours and three days for an acute EEG. However, there could be longer waits around the country, if in fact the technology is available at all. Dr Simpson agreed to work with Convener Kenneth Gibson and the Secretariat to undertake a Freedom of Information Act request.

Shirley Maxwell welcomed the new guidelines, particularly the inclusion of psychiatric comorbidities and epilepsy and sleep. She asked Dr Leach how the guidelines are going to be implemented. Dr Leach hopes there will be an implementation meeting along with the National Neurology Advisory Group (NNAG) and a wide range of representation and stakeholders. The

NNAG is keen to have some practical guidance to stimulate the way forward and to assist all the neurology centres in Scotland. Beatrice Cant mentioned that the joint implementation meeting is taking place on 18 June.

Dr Simpson enquired if there were any things that would be stopping because they are not evidence-based under the new guideline. He asked where resources might be re-deployed? Kenneth Gibson MSP, who is also Convener of Finance Committee, agreed a major plank of budget expenditure was to look at how government disinvestment could lead to re-investment elsewhere for better outcomes.

Dr Leach found it very difficult to imagine ways to cut back on epilepsy care. Traditionally, it suffered badly from under investment despite being one of the more common neurological conditions with serious consequences. He thought it would be difficult to step back from some of the investigations and treatment. There may be some aspects for EEG, such as diverting resources from routine EEG into more acute EEG. Drug treatments are relatively inexpensive for epilepsy and certainly the newer drugs, which are proportionally if not absolutely expensive, are usually used only by recognised specialists. Epilepsy surgery provision in Scotland is reasonable and there is a national network for arranging operations. There are people who may get operations later than they could do, or who might have access to operations who currently don't. Mr Gibson mentioned he did not necessarily mean having to dis-invest in epilepsy as re-investment could come from other (health) areas. Dr Leach responded that from a nursing, medical and community point of view, it would be tough to draw back further given very little resources have been put into epilepsy care historically.

Lesslie Young cited the switching of generic and branded epilepsy medications as a really good example of not dis-investing but re-investing because some switching could lead to unnecessary admissions to hospital. Dr Simpson said it was important to have proper studies on the issue first rather than have wholesale switching which is not sensible. In his time as a doctor of a practice with high generic drug use, he tended not to switch epilepsy patients to different medication because he found patients destabilised. It was anecdotal evidence, given low patient numbers, and Ann Maxwell agreed anecdotal evidence is important, as with VNS.

Dr Leach reminded the Group that if the role of the guidelines is to take on board evidence, then the manufacturer of these devices has had more than 20 years to show evidence that these devices make a significant difference. While not completely dismissing anecdotal evidence, the job of the guidelines is to put it in context and in proportion to other evidence. The sub groups have done as honest and as fair a job as they could in trying to rank that. Dr Simpson was aware of doctors prescribing medicines they thought were good until a proper study showed these treatments were less than effective. His view was that new treatments are not discarded just because they are new and without sufficient evidence. It was more that things have to proceed on the basis of rating whatever evidence is available so far. Ann Maxwell thought this could be harder with some technologies and Dr Simpson was not sure he agreed.

Allana Parker said that Epilepsy Action, on behalf of the Joint Epilepsy Council, is asking relevant organisations to explain to their patient groups that those experiencing any problems with epilepsy medication being switched should get in touch with their GP. All adverse reports on this are being processed. Brian Rocks mentioned he is testing a body system which is proving useful. Dr Simpson agreed that gathering case study information on new things like alarms is helpful in planning the next SIGN review. Beatrice Cant agreed there is a refresher process for the guidelines which keeps the information updated as and when evidence becomes available.

5. Dr Richard Simpson thanked Dr Leach for his presentation and invited any updates:

Ann Maxwell explained that Great Ormond Street Hospital in conjunction with the Muir Maxwell Epilepsy Centre and Edinburgh University are holding clinical trials on medical marijuana for children with intractable epilepsy. Dr Simpson asked the Secretariat to email the research link.

6. Future parliamentary opportunities include:
 - National Epilepsy Week (17 - 23 May) and the Epilepsy Consortium Scotland has an exhibition in the Garden Lobby, sponsored by Kenneth Gibson MSP, to which MSPs are invited. Details on this and a photo call will be emailed to all MSPs
 - There will be an opportunity for some awareness training specifically for MSPs and their staff, and details on that will also be circulated
7. The next meeting is on Thursday 30 April 2015 in Committee Room 2 at 1pm where attendees hope to learn more about integrated health and social care for epilepsy.