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Note of Meeting – Cross Party Group on Epilepsy, 24 November 2011

In Attendance:

Jean Barclay, Epilepsy Scotland	Karen Lawrence, Paediatric ESN
Matt Barclay, Community Pharmacy Scot	Shirley Maxwell, Epilepsy Connections
Sheena Bevan, ESNA & NHS Grampian	Craig Millar, PA to Richard Simpson MSP
Thomas Binns, Observer	Claire Miller, Observer
June Blake, ESN	Nanette Milne MSP
Janet Casey, Observer	Hilary Mounfield, Quarriers
Shauna Casey, Observer	Dr Ailsa McLellan, SPEN
Patricia Findlay, Epilepsy Bereaved	Dr Ann O'Hara, Children's Hospital Aberdeen
Elizabeth Forgave, Observer	Allana Parker, Epilepsy Scotland
Gina Freeman, Epilepsy West Lothian	Dr Richard Roberts, Epilepsy Scotland
Kenneth Gibson MSP	Derek Robertson, ESN
Jane Hanna, Epilepsy Bereaved	Kerry Shearer, Epilepsy Scotland
Michael Heron, ESN	Dr Richard Simpson MSP
Lynne Ilias, Observer	Robert Stout, Epilepsy West Lothian
Markos Ilias, Observer	Anissa Tonberg, Epilepsy Scotland
Jennifer Irvine, ESN	Lesslie Young, Epilepsy Scotland
Christine Jeans, Observer	Humza Yousaf MSP

Apologies:

Declan Ahern, ESN	Yvonne Leavy, NHS Lothian
Lynne Allan, Paediatric ESN	Eileen McCubbin, ESN
Eleanor Arthur, Epilepsy Liaison Nurse	Jamie McGrigor MSP
Claire Baker MSP	Alison McInnes MSP
Marilyn Bryce, Epilepsy Scotland	Jan McKenzie, NHS Highland
Jo Campbell, NHS Grampian	Duncan McNeil MSP
Ruth Davidson MSP	Angela Norman, NHS Tayside
Laura Donaldson, Paediatric ESN	Pamela Parker, ESN
Susan Duncan, Neurologist	Willie Rennie MSP
Murdo Fraser MSP	John Scott MSP
Simon Glen, Headway Glasgow	Susan Sheridan, Scottish Epilepsy Initiative
Irene Hamill, ESN	Jennifer Simpson, Special Products
Jamie Hepburn MSP	Maureen Swannie, Orkney Health Care
Jane Holmes, Observer	John Toland, ESN
Jim Hume MSP	Sam Whitmore, Epilepsy Connections
Kevin Kelly, ESN	Susan Yule, NHS GGC
Lorraine Kennedy, Observer	

1. Convenor Kenneth Gibson MSP welcomed everyone and thanked Dr Richard Simpson MSP and Allana Parker for organising today's meeting. He especially thanked guest speakers Jane Hanna from Epilepsy Bereaved and Dr Richard Roberts for agreeing to deliver presentations on Sudden Unexpected Death in Epilepsy (SUDEP).

A special thanks for attendance was extended to the Casey family and the Illias family. These two families were involved in the recent FAI and have been tragically affected by SUDEP. He then updated everyone on activities since the last meeting:

- The inaugural Epilepsy CPG meeting was held on 29 June. The group was re-registered during recess. Its five office bearers include Convener Kenneth Gibson, Dr Richard Simpson and Alison McInness as joint Co-conveners, Jim Hume as Treasurer and Nanette Milne as Secretary. Copies of the note of the June meeting are available
 - The group now has 24 MSP members, including new member Humza Yousaf
 - The motion Kenneth Gibson proposed regarding epilepsy training for student teachers was debated in March 2011. Epilepsy Scotland will shortly meet with the General Teaching Council to discuss training
 - The Transitions event on 21 September in Parliament was well attended. The Cabinet Secretary Nicola Sturgeon agreed at the meeting that coordinated transition services for young people with difficult epilepsy was very important and necessary. Kenneth Gibson MSP added that he hopes all MSPs support Epilepsy Scotland's Control Transition campaign.
2. Kenneth Gibson introduced today's speakers. Dr Richard Robert outlined FAI reports and SUDEP along with the latest FAI recommendations (11):
- Dr Roberts defined SUDEP as 'Sudden, unexpected, witnessed or un-witnessed, non-traumatic and non-drowning death in individuals with epilepsy - with or without evidence of a seizure, and excluding documented status epilepticus, in which post-mortem examination does not reveal a toxicological or anatomic cause for death
 - The incidence was about 1 in 1,000, or about 50 SUDEP cases a year in Scotland
 - The recent FAI showed that SUDEP had not been discussed with the patients or their parents. Dr Roberts highlighted the one thing clinicians aim do to help prevent SUDEP is to try to achieve complete seizure control for patients (bearing in mind quality of life). Epileptic seizures are a symptom and occur with varying degrees of severity within different epilepsy syndromes. The incidence of SUDEP rises to 1 in 100 for young adults with certain drug-resistant seizures while some benign epilepsy syndromes carry a risk of death not significantly higher than the general population
 - Current SIGN guidelines for epilepsy are clear and the issue for SUDEP is about timing. They recommend a discussion about SUDEP with adults and similarly that families should be advised if their child is considered at risk. Dr Roberts believes discussion of SUDEP has to be in context, individualised, and the timing based on the perception of the person being ready to receive it. Sometimes it was withheld if there was a perceived risk to a patient or significant learning difficulties. When given a diagnosis of epilepsy, a person can be in shock and not be able to deal with the provision of more information at that point
 - The Sheriff's first recommendation was that the vast majority of patients with epilepsy, or their parents or carers where appropriate, should be advised of the risk of SUDEP on first diagnosis or if, in the particular circumstances of that patient, there are exceptional circumstances for delaying immediate provision of the information, then within a very short time thereafter. Advice about the risk of SUDEP should only be withheld if there is assessed to be, in the case of a particular patient, a risk of serious harm to the patient in providing the information or the patient has learning difficulties
 - Dr Roberts agreed with the second recommendation from the recent FAI that it was highly desirable that a decision not to inform should be recorded. The Sheriff wrote that a decision not to inform a patient or his or her family about SUDEP should be recorded in the patient's medical records along with an explanation, however brief, for the decision. Thirdly, after a consultation with an epilepsy patient the consultant

or, where appropriate, the specialist epilepsy nurse, should send a letter to the patient and to the patient's GP summarising the findings of the consultation and any care or treatment decisions taken

- Dr Roberts then outlined a checklist of eight key issues to be discussed following a diagnosis of epilepsy in a 30 minute consultation. After covering general epilepsy information, medication and treatment, seizure triggers, first aid, lifestyle, possible psychological impacts, sources of support and any issues for women, little time was left. He stressed the importance of Epilepsy Specialist Nurses (ESNs) to provide information. He also mentioned that registrars with a couple of years experience could be trained to provide SUDEP information
 - The Sheriff's next recommendations (4-6) were that information and advice about SUDEP should be provided directly by the consultant in charge of the patient's case or, where appropriate, by an epilepsy specialist nurse. Dr Roberts felt ESNs were most important as giving information packs was not enough and that patients needed face to face contact about SUDEP
 - Fifthly, all NHS boards should prioritise consideration of their arrangements for the care of epilepsy patients, whether a post of epilepsy specialist nurse is required, if not already in place, in any particular hospital and, if there is such a post, whether the current arrangements are adequate
 - The sixth recommendation called for a review of current arrangements for the provision of written information packs to newly-diagnosed epilepsy patients and their families to ensure that they are adequate and meet the needs of patients for information and access to services and support at a distressing time. Dr Roberts agreed that there was a need for more information and working out when and how it was transmitted
 - He outlined recommendation 8 which stated that consideration should be given to the feasibility of introducing a system in GP practices (possibly in conjunction with pharmacies) whereby the uptake of repeat prescriptions by patients can be monitored. The Sheriff recommended that where a patient is prescribed medication both the prescribing doctor and the dispensing pharmacist should provide the patient with clear and easily understood instructions as to how the medication is to be taken. If the regime of medication is relatively complex the doctor should take time to explain it and should, in particularly complex cases, provide written instructions. In the case of all prescriptions pharmacy labels should be clearly printed in easily read, jargon-free text
 - Dr Roberts reflected on what has been done in the last 25 years, with a three-fold increase in the number of appointed neurologists, the introduction of specialist epilepsy nurse posts, the creation of epilepsy clinics and first seizure clinics, improved options for investigations and drug treatment, a better knowledge of SUDEP - but more is needed
 - Possibilities include appointing more specialist nurses, support for the voluntary sector in the work they do with people with epilepsy, continuing to improve neurological services, the development of transition clinics/services and funding more research into SUDEP and what people with epilepsy want to know about it
 - Dr Roberts concluded with recommendation nine that those responsible for issuing guidelines on the care and management of epilepsy patients should consider the adequacy of existing guidelines. SIGN 81: Diagnosis and management of epilepsies in children and young people states that families should be advised if the child has an increased risk of SUDEP and can be reassured if the risk is considered to be low.
3. Attendees were invited to ask any questions:
Dr Richard Simpson asked if Epilepsy Scotland could refresh the list of current Epilepsy Specialist Nurses in Scotland as MSPs are aware that vacant posts are unfilled, and the ratio per population for patients to Specialist Nurses.

Sheena Bevan from ESNA answered that the requested information is already available, and she agreed to pass it to Dr Simpson.

Regarding recommendation 8, Dr Simpson added that the Government is introducing chronic prescribing. The Group should be encouraging every person with epilepsy who receives a prescription to register with their pharmacist for chronic condition prescribing because that would deal with recommendation 8 completely. The pharmacist is then responsible for working with the individual patient and to monitor, and they will be far more focused than a GP can be.

Sheena Bevan highlighted there is not enough funding or posts and there is a need for more epilepsy nurses. She also wanted to pick up on the point that ESNs often won't hear about patients who have died or been 'lost' from the system. She added that on the Primary and Secondary care data system there is already a process which highlights the death. This could be developed to inform medical and nursing staff involved in the deceased's care.

Dr Roberts replied that there will be monitoring to ascertain if the recommendations will take place. There is resistance to implementing the recommendations as they are not legally binding. He added that newly trained neurologists receive better training, especially regarding SUDEP and are better equipped to make the correct decisions to discuss SUDEP with patients directly. His view is SUDEP education is very important. Kenneth Gibson agreed that it is important that information is shared sooner and that communication on this issue is vital.

4. Epilepsy Bereaved Director Jane Hanna's presentation on SUDEP outlined these significant points:
 - The recent Fatal Accident Inquiry is a significant step for bereaved families in Scotland, the UK and throughout Europe - SUDEP was the main topic for the 2011 Epilepsy Congress
 - The Inquiry involves eight weeks of intense scrutiny before any decisions/findings. It is a high quality process, and the rest of the world looks to Scotland as it leads in this type of inquiry
 - Common recommendations for individuals with epilepsy in the 1990s included not swimming, not using ladders and other lifestyle changes. Most families felt the safest place for a person with epilepsy was at home in bed – a view that is still widely held.
 - Death by epilepsy and SUDEP is a public health issue. From 1993-2009 epilepsy deaths in the UK are increasing, at a time when deaths from other conditions had been falling. There was a peak in 2003 after a national audit was carried out
 - SUDEP is now being recorded on certificates as a cause of death. Better recording practices are being implemented, which is a great step forward
 - A good body of research is being established into SUDEP. If the research shows there is a possibility that a death can be prevented, we need to strive for this
 - There is a consensus in the research that the best possible outcome is seizure freedom, with timely repeats of anti-epileptic drugs prescriptions. One significant study showed people not taking their medication were three times more at risk than those who did
 - The earlier Findlay FAI on SUDEP highlighted the implementation of shared care plans with communication about these vital especially in areas where resources are scarce. Annual reviews were important too. It was also important to communicate the risks of SUDEP to individuals with epilepsy unless there is a significant reason not to. These epilepsy FAIs were about young people with existing conditions, but Ms Hanna asked is anyone looking at chronic conditions on an annual review basis?

- After 2002, the Government wrote to all health boards and there was a short increase in interest and more ESNs, but there was no monitoring after this
- CEMACH statistics on UK Maternal Deaths in 2011 reveal that 57% of patients with epilepsy are not referred to an epilepsy expert and have no pre-conception counselling, there was a lack of understanding by non-specialists of epilepsy medication in pregnancy, and staff did not appear to perceive maternal epilepsy as a high risk condition. Epilepsy Bereaved would like to hear the views of the ESNs regarding maternal epilepsy, and welcomes any feedback
- As a result of this latest FAI, Ms Hanna asked if this Group can work with the Police Force to establish that the location where SUDEP occurs is not referred to or treated like a crime scene, which unfortunately happened to the Ilias family
- The recent Inquiry made several recommendations about clinical practice and this should not be viewed solely a tick box exercise. The Sheriff stated that the FAI should come to the attention of senior ministers and agencies. Ms Hanna asked if the Group can help by asking if there will be a Government action plan in response to the Inquiry, how it will be monitored and will the Government involve the agencies listed by the Sheriff, and Epilepsy Bereaved and other stakeholders?
- Epilepsy Bereaved is heavily involved in research and education, and is particularly interested in genetics research
- As well as influencing and supporting change, Epilepsy Bereaved are specialists in supporting and involving the bereaved. The charity sees one of its major task as supporting families and has assisted 74 families in Scotland during 2011. Ms Hanna asked if the Group will ask the Government what action it could take for signposting families to Epilepsy Bereaved.

5. Kenneth Gibson thanked both speakers for their very interesting presentations. While the scheduled meeting had also run on due to technical difficulties, with other MSPs having to leave to be in the chamber, he invited attendees to ask questions:

Sheena Bevan thanked Dr Roberts for acknowledging the importance of ESNs. She stated she would like MSPs to take back to the chamber that there are not enough ESNs or funding. She added that as an ESN she has received support from Epilepsy Scotland and Epilepsy Action but maintains there are not enough ESNs to deliver what Dr Roberts and Jane Hanna have said today. She mentioned it is often the ESN who discusses SUDEP with patients and who makes a point of documenting that the information has been shared. There is an appropriate time to disclose information about SUDEP, to recognise the individual's choice, respect their privacy and protect their right to withhold SUDEP information from their parents (covered by an Act of Parliament). She also cited an example of a young person with uncontrolled seizures who had hardly slept for several months after being given information about SUDEP. Kenneth Gibson MSP thanked Sheena Bevan for her statement.

Patricia Findlay responded that it was not wise to make policy out of isolated examples. It was important to create conditions where information was available. Two FAIs had generated attention but without monitoring she couldn't tell whether good changes or not had taken place. Patricia Findlay added that she felt that it is important to monitor what is working and what isn't, working together and sharing information. Kenneth Gibson MSP agreed with this point.

Dr Roberts added that younger, newly trained doctors are in receipt of better training, and specialised courses which cover all aspects of SUDEP. Neurologists who have not specialised in epilepsy and have been in post a lot longer will find it most difficult to change. There is a process, and things will get better.

Kenneth Gibson MSP agreed that there has to be a rapid change, as opposed to a glacial change; if lessons need to be learned they should be learned quickly to stop these kind of bereavements. Communication for moving forward with this is vital. The Parliament will focus over the next three years on a preventative agenda, and involve all departments in the government, local authorities and health boards. The Group can feed into the government process about areas where prevention can be enhanced in order to mitigate against things that can be prevented.

Ailsa McLellan raised a point about the efficacy of alarms, and night time supervision so that epilepsy deaths can be prevented. It was an area of concern due to lack of evidence. Jane Hanna cited a 2005 study which suggested a link and the Sheriff had recognised there was some debate about the benefits of these alarms. Dr Roberts said it was a difficult balance; there was no indisputable evidence that such alarms keep someone safe. Some patients have died while wearing a monitor and this intervention may not in itself prevent death.

Lesslie Young shared that Epilepsy Scotland is working with a multi agency group, with every agency from the justice system represented. Every police probationer will receive an epilepsy awareness talk, quarterly training is being delivered to deputy procurator fiscals, reaching over 300 individuals so far. SUDEP isn't a large part of this training, it is mostly information for identifying a seizure and appropriate first aid. Jane Hanna noted that this was really interesting and asked to be involved in adding a SUDEP element to what Epilepsy Scotland has established.

Sheena Bevan mentioned the Peer Review of Health Improvement Scotland (HIS) Clinical Neurology Standards for adults taking place in January/February 2012.

6. Kenneth Gibson MSP moved onto parliamentary business, and suggested meeting with the Secretariat to discuss how to take epilepsy issues forward to the parliament and feedback to the group any future issues from the Health department.
7. The date of the next meeting is Thursday 26 January 2012, Committee Room 2. The Topic is not confirmed but is likely to be genetics. Kenneth Gibson MSP thanked everyone for coming and advised all to feel free to give feedback to the Secretariat.