

**DRAFT Note of Meeting – Cross Party Group on Epilepsy, 25 September 2014**

**In Attendance:**

Declan Ahern, ESNA, Epilepsy CNS	Pamela Martis, NHS Lothian
Jean Barclay, Observer	Mark McDonald MSP
Matt Barclay, Community Pharmacy Scotland	Nanette Milne MSP
Susan Chalk, speaker, Quality Improvement Officer, Aberdeenshire	Hilary Mounfield, Scottish Epilepsy Centre
Finn Dimelow, speaker, Primary 6, Kinnellar Primary	Josh Ogbu, speaker, Primary 6, Kinnellar Primary
Louise Dalgarno, speaker and class teacher, Kinnellar Primary School	Allana Parker, Epilepsy Scotland
Kenneth Gibson MSP	Ellie Paterson, speaker, Primary 6, Kinnellar Primary
John Heaney, West Dunbartonshire Epilepsy Support Group	Brian Rocks, West Dunbartonshire Epilepsy Support Group
Cara Hilton MSP	Jennifer Simpson, Special Products
Claire Leonard, Epilepsy Connections	Graeme Stephen, Health Safety & Wellbeing Team, Aberdeenshire
Ian Martin, MCN Manager	Eloise Williams, speaker, Primary 6, Kinnellar Primary

**Apologies:**

Clare Adamson MSP	Peter Martin, Observer
Celia Brand, PEN Consultant	Eileen McCubbin, ESN
Marilyn Bryce, Observer	Alison McInnes MSP
Jo Campbell, Roald Dahl, Children's Epilepsy Specialist Nurse	Phil Robinson, LESG
Andrena Hughes, Observer	Michelle Small, Paediatric ESN
Jen Irvine, Epilepsy Nurse Practitioner	Anissa Tonberg, Epilepsy Scotland
Gaye Kelly, Quarriers Fieldworker	Sam Whitmore, Epilepsy Connections
Helen Macdonald LESG	Lesslie Young, Epilepsy Scotland
Lorraine MacKenzie, Observer	

1. Convener Kenneth Gibson MSP welcomed attendees to today's meeting.
2. The draft note of the April 2014 meeting was approved. He then gave an update on activities:
  - Gil Paterson, Claire Adamson and Stewart Stevenson MSPs have joined this Cross Party Group
  - Since the last meeting there have been four Members Motions covering epilepsy. These included motions submitted by MSPs Richard Simpson and Kenneth Gibson to highlight National Epilepsy Week and its theme of transforming lives and tackling the stigma of epilepsy through education
  - A Members debate was secured by the Convener during National Epilepsy Week. Mr Gibson thanked fellow Cross-Party Group MSPs George Adam, Cara Hilton and Alison McInnes for their excellent contributions around the need for greater epilepsy education.
  - Many MSPs took part in National Epilepsy Week activities held in the Scottish Parliament. Quite a few visited the Epilepsy Consortium Scotland exhibition in the Garden Lobby. Many also signed their support to forthcoming SIGN guidelines for managing adults with epilepsy. This support attracted considerable local press coverage.
  - Attendees were reminded to complete the evaluation sheet for today's meeting.
3. The Convener introduced the guest speakers. First were primary six pupils Finn Dimelow, Josh Ogbu, Ellie Paterson and Eloise Williams from Kinnellar Primary School in Aberdeenshire and their class teacher Louise Dalgarno. Next were Aberdeenshire Council Education Department's Quality Improvement Officer Susan Chalk, with Senior Practitioner Graeme Stephen from the council's Health Safety and Wellbeing Team. Both officers would jointly share about the benefits and impact of combining first aid training and epilepsy awareness.

- Susan Chalk summarised the council's approach. Aberdeenshire has its own epilepsy awareness training and it also works with partners, the NHS and with charities. The council also works with Epilepsy Specialist Nurses and the children in the school who have a specific diagnosis of epilepsy. Her colleague Graeme Stephen would give information on general training to all schools. She invited the children to begin the presentation:
- The Kinnellar Primary School pupils read out their views in turn about epilepsy awareness:
  - o It was interesting to find out about epilepsy as the class didn't know about it before
  - o People with epilepsy can feel safer in school if others know about it and what to do
  - o Learning about epilepsy is good as it is helpful for other situations, like being out in the street or at football if someone has a seizure or was injured through taking one
  - o Pupils feel good knowing they can help with seizures and first aid, putting someone in the correct recovery position and when/how to make a call to the emergency services
  - o Pupils agreed it is important to learn about conditions such as epilepsy that could affect them or their friends, and thanked the Cross-Party Group for listening.
- Class teacher Louise Dalgarno agreed that teaching Primary 5 and 6 pupils to be aware about epilepsy has raised their confidence in dealing with a lot of matters. She thought skills like first aid were skills for life. It has been valuable to hear pupils talking confidently about what they would do in situations that could really put them under pressure.
- Susan Chalk provided some facts and figures. Aberdeenshire is very large geographical area. It has 150 primary schools, 17 secondary schools and four special schools which drives the need to work in partnership. The council provides its own training which is rolled out across all schools but it is very important to work with the NHS and charities to support learning for school children and staff. Over 52 schools currently have children with epilepsy, so it is very important that all staff have an awareness of epilepsy.
- Graeme Stephen reminded attendees of the legal requirement to make provision for first aid within the workplace. From 2013, the usual option of approved training by the Health and Safety Executive (HSE) changed. Aberdeenshire Council adopted the Scottish Qualifications Authority (SQA) vocational qualification with criteria that has to be met to become a first aider. Epilepsy and seizures is part of the criteria for two courses on offer; emergency first aid (two hours) and first aid at work (three days) which takes a more in-depth look at epilepsy. In 2013, a total of 549 people were trained in emergency first aid. Nearly a third (164) were school staff. Similarly for the first aid at work course, 13 of 32 people trained were school staff. So the take-up by schools is good. Although there is no legal requirement to provide training for everyone in schools, the council sees it as a moral obligation so pupil support assistants and administration staff are among those being trained.
- A specific section on the first aid at work course explains what epilepsy is. This information is provided by medical practitioners and first aid trainers. It categorises the main seizures so that a first aider can recognise what is actually happening. There is information about what to do for minor seizures and any treatment. For full (major) seizures there is an explanation of the different stages of the condition and how to help the person. The important bit of the course is what not to do as over the years lots of myths have developed about epilepsy. Candidates' learning is then assessed and there's a written test to pass before getting the qualification to become a first aider.
- The shorter course touches on seizures as a whole rather than on epilepsy as a single condition. It looks at varying things that can cause seizures. In terms of treatment, the important part is to recognise what's happening so staff can take the person through the recovery phase after the seizure lapses. It also covers contacting emergency services especially where staff are unsure of what to do. A manual is provided for the three day course and a condensed version is available for the emergency first aid course. The courses are open to all staff in Aberdeenshire Council.
- Susan Chalk mentioned that her son also has epilepsy. He is now at secondary school but was in a primary class when it developed. He did take a seizure at school. The staff had general training (rather than any provided by an NHS nurse) and they managed the situation very well. He was able to continue normally with his day which is the aim for rolling this training out across Aberdeenshire schools. The council wants to make epilepsy understood and not be feared so that 'it's business as usual' for the pupils because their awareness of epilepsy has been raised.
- Louise Dalgarno explained that no pupils in her class have epilepsy but they all go to several out-of-school clubs and are also in contact with lots of children. She mentioned that being aware of epilepsy takes the fear factor away because it is a scary situation to see someone this way and

have no idea of what is happening. She thought knowing the do's and the don'ts of epilepsy and first aid could make a real difference and is a valuable thing for pupils to be made aware of.

4. Kenneth Gibson MSP thanked all the speakers and invited questions. He welcomed one from Mark McDonald MSP who is here for the first time. Mr McDonald asked how long this training had been offered for schools and who or what made it happen?

Graham Stephen replied that first aid courses including epilepsy had been going for a long time (around 15 years) in Aberdeenshire. The type of training changed in October 2013 when schools adopted an emergency first aid course using the SQA assessment process based on a certificate of competence rather than a certificate of attendance. Knowing about seizures and epilepsy are set within the criteria which have to be met.

Susan Chalk mentioned that head teachers can also consider offering first aid training for school pupils on a three year rolling programme. This is separate to staff training. Louise Dalgano explained that in Primary 5, pupils get basic information such as seeing an accident and knowing what to do. In Primary 6 they go into a bit more depth about first aid and epilepsy and then learn even more in Primary 7. The children develop these skills as they go through the school. Mark McDonald asked about the number of schools involved and if this training approach to schools could be delivered jointly with other local councils like Aberdeen City? He will consider writing to his local education department to progress this.

Claire Leonard asked if St John's Ambulance provided this epilepsy awareness training to pupils? Graeme Stephen replied that several organisations did. The Health Safety and Wellbeing Team did not have the resources or remit to train pupils but made the decision to roll out emergency first aid and a two hour course for playground type injuries to primary schools. Once the staff are trained they are deemed competent by the Trainer Assessors. It would be perfectly acceptable for them to relay the course messages to children. They would have the documentation to hand. Here pupils are doing the broader spectrum of first aid with epilepsy awareness being part of it Louise Dalgarno agreed the majority of schools in Aberdeenshire are rolling out first aid and it is certificated so the children can work towards getting a certificate to take home. In her school St John's Ambulance service did the training over two days but there are other agencies to present it.

Declan Ahern asked if this practice is compulsory for school pupils or is first aid knowledge part of the national curriculum? Susan Chalk agreed it forms part of the Health and Wellbeing experience which now comes within curriculum for excellence. First aid would be studied but it would not have to be certified although this would be good practice Kenneth Gibson MSP concurred that the CPG on Epilepsy wants to extend good practice and see exceptional work happening across Scotland.

Matt Barclay asked what drivers facilitate a buy-in by head teachers for epilepsy awareness and first aid training in schools? Susan Chalk replied that she takes a strategic approach to facilitate this. She is responsible for 23 schools and within them support for learning teachers and pupil support assistants may require training to assist pupils with epilepsy. Other specific conditions like diabetes help to raise overall general awareness of common long term conditions such as epilepsy. Kenneth Gibson agreed this strategic approach was important so that other schools gain from the practice in Aberdeenshire.

Hilary Mounfield remarked it was better that school pupils in small rural areas got to know about epilepsy even before they met a child with the condition so they could deal with it. Kenneth Gibson shared that when he was 10 he saw a boy in his class take a very severe seizure. In fact, the boy was taken away and no-one ever saw him again and no-one even knew he had epilepsy as no-one talked about it in the 70s. Things have moved on since then.

Claire Leonard commented that what Aberdeenshire was doing was absolutely brilliant by pitching epilepsy awareness at the right level for school pupils. In her role with Epilepsy Connections she finds young people, just like the pupils here today, are really open about it. There should be a lot less stigma towards epilepsy in the up and coming generation. In her experience, even pupils in Primary 1 can relate to epilepsy where they have seen someone take a full seizure at nursery.

Susan Chalk cited the valuable work of Epilepsy Specialist Nurses in Aberdeenshire. They visit schools when a child has a specific diagnosis of epilepsy and do the next level of awareness raising in whatever class the child is in. These nurses also hold monthly meetings in the hospital in Aberdeen which are attended by Aberdeenshire staff as well as parents of children with epilepsy.

John Heaney remarked that greater education and awareness about epilepsy was required for the emergency services to help people with epilepsy. The West Dunbartonshire Epilepsy Support Group is pursuing this matter with Police Scotland and the Fire Brigade locally. John Heaney and Brian Rocks would value the support of this Group on this issue. Kenneth Gibson replied that there was a discussion at this forum last year with Police Scotland and its efforts to reduce hate crime towards people with epilepsy. So this initiative is positive news. Perhaps The Group can take this matter forward and the Secretariat can contact Brian Rocks for more information.

Allana Parker mentioned that Aberdeenshire council responded to the Cross-Party Group information request and was one of a tiny few local authorities mentioning epilepsy awareness was combined with first aid training. She wondered if Susan Chalk had publicised or intended to promote Aberdeenshire council's good practice? Susan Chalk responded that sometimes people are unaware of delivering good practice until someone points it out. The tendency is to do things well and just keep your head down. She will consider promoting their practice to other councils.

5. Kenneth Gibson thanked everyone for their contributions today and spoke about forthcoming Parliamentary opportunities:

Epilepsy Scotland's Diamond Jubilee and Crown Office/Police Scotland reception for MSPs will take place on Wednesday 19 November from 6pm in Committee Room 2.

The launch of revised SIGN guidelines is provisionally this December, assisted by the Epilepsy Consortium Scotland at the Scottish Epilepsy Centre in Glasgow. Details will follow from the secretariat.

6. The Convener invited any updates from representative around the table:

Declan Ahern mentioned that he had canvassed the national epilepsy locality group with regards to GP charges for signing bus forms, care plans and things like that. BMA guidelines allow for charging although it is all fairly loose in terms of what is NHDS and non NHS work and what should and should not be charged for. The full extent of the problem is unknown with patchy details on where it occurs, though some nurses are aware of bus pass charges as high as £65 to those in an already disadvantaged group.

Kenneth Gibson agreed it was a really important issue. He thought it useful to try to find out how widespread the problem is, the effect it has on people's lives and any diversity across Scotland in terms of charging. The Group could then perhaps write to the Minister of Public Health in the first instance or indeed the BMA themselves to look at this practice. Ultimately, MSPs can even debate on the matter.

Declan Ahern said there could be difficulties in gathering the information countrywide from thousands of GPs and from patients. However, he will discuss ways of getting this kind of information and mention it at the October Epilepsy Specialist Nurses Association AGM to get a sense of how common it is and if there are any figures. Kenneth Gibson mentioned approaching BMA Scotland for information. Matt Barclay queried if it only has to be a GP who signs the bus pass? Declan Ahern said it can be a GP or specialist nurse and initially a neurologist could too.

Matt Barclay said that pharmacists are getting a lot more involved in terms of helping people with their medication. As an example, local GP's used to charge for passports but as a pharmacist, he quite happily did this free for his patients. Declan Ahern said the justification for charging seemed to be that a GP has to verify that the details on the form they sign are true. This would need a GP to review and check patient records and note the date of the last seizure. Allana Parker said that there may be patient feedback or information that could be gathered from epilepsy charities. Kenneth Gibson asked for an update on the matter at the next meeting.

Ian Martin introduced himself as the new Manager for the West of Scotland and Tayside epilepsy MCN. He gave his contact details and he is based at the Southern General Hospital and works part of the week.

7. The Convener then thanked everyone for attending. The next meeting of the Group will be **Thursday 29 January 2015** between 1 and 2pm in our larger venue, Committee Room 4. We hope to have a presentation outlining what the changes may be in the revised SIGN guidelines.