

Epilepsy Consortium Scotland (ECS) Secretariat

Anissa Tonberg: 48 Govan Road, Glasgow G51 1JL

Tel: 0141 427 4911

atonberg@epilepsyscotland.org.uk

Note of Meeting – Cross- Party Group on Epilepsy, 7th September 2017

In Attendance:

Robert Bennett, West Dunbartonshire Support Group	Dr Pamela Martis, NHS Lothian
Celia Brand, NHS Lothian	Lorraine MacKenzie, Observer
John Bruce, Epilepsy Connections People's Forum	Caroline McKenna, West Dunbartonshire Support Group
Scott Coyne, Epilepsy Connections	Dr Ailsa McLelland, NHS Lothian
Michelle Dick, West Dunbartonshire Support Group	Heather McLelland, NHS Lothian
Danielle Dyason, NHS Lothian	Jack Middleton, NHS Lothian
Yasmin Erginsoy, Communications Manager to Kenneth Gibson MSP	Roslyn Neely, Edinburgh Children's Hospital Charity
Suzanne Felix, NHS Lothian	Anne Prentice, West Dunbartonshire Support Group
Bridie Fordham, West Dunbartonshire Support Group	Ronnie Prentice, West Dunbartonshire Support Group
Tam Fordham, West Dunbartonshire Support Group	Brian Rocks, West Dunbartonshire Support Group
Dr Catriona George, NHS Lothian	Emma Swift, Parliamentary Researcher to Lewis Macdonald MSP
Kenneth Gibson MSP	Elaine Tait, West Dunbartonshire Support Group
Rhoda Grant MSP	Anissa Tonberg, Epilepsy Scotland (CPG Secretariat)
Anne Gray, West Dunbartonshire Support Group	Dr Kirsten Verity, NHS Lothian
Andrena Hughes, Observer	Margaret Walker, West Dunbartonshire Support Group
Chris Jeans, SUDEP Action Scotland	Colleen Wilson, Epilepsy Connections
Lorraine Kennedy, Observer	Grant Wright, Epilepsy Scotland
Richard Lyle MSP	Lesslie Young, Epilepsy Scotland

Apologies:

Jane Cassidy, Observer	Carsten Mandt, Scottish Paediatric Epilepsy Network
Alex Cole-Hamilton MSP	Peter Martin, Observer
James Dornan MSP	Ann Maxwell, Muir Maxwell Trust
Dr Susan Duncan	Shirley Maxwell, Epilepsy Connections
Mary Fee MSP	Aline Russell, Quarriers, Scottish Epilepsy Centre
Neil Findlay MSP	Anas Sarwar MSP
Ann Greenall	Eleonora Saturno, NHS Lothian
Helen MacDonald, Lanarkshire Epilepsy Support Group	Sharon Thinn, NHS Lothian
Lewis Macdonald MSP	David Torrance MSP

1. Convener Kenneth Gibson MSP welcomed attendees to the meeting and AGM.
2. He gave a short update: no changes to the circulated April 2017 draft note, it was approved.
 - Since April, MSPs Sandra White, Claire Adamson, Graeme Dey and Gil Paterson have put forward Members Motions relating to epilepsy. These were collectively signed by 68 MSPs.
 - Following the presentation to the CPG in January by dieticians from the children's hospitals in Edinburgh and Glasgow about treating difficult epilepsy using ketogenic diets, we are happy to report that NHS Greater Glasgow and Clyde have accepted the business case proposed by the Glasgow service and will fund this ketogenic service for children for the foreseeable future. The service has been funded by a charity for three years, however the health board have now agreed to take this over.
 - At the last meeting we heard from the Minister for Public Health and Sport, Aileen Campbell, and CPG members again raised the issue of provision of EEG and

neurophysiology services in Scotland. We are pleased to report that a national summit, organised by the Scottish Government and involving NHS regional planners, service managers and neurophysiologists will take place on 1st November, with further action to follow. This is the first major step in finding a longer-term solution to the problem and is in significant part thanks to lobbying by the CPG over the past year.

- We are preparing to submit a Parliamentary Question regarding the lack of paediatric nursing in NHS Dumfries and Galloway. This is the last mainland health board in Scotland with no epilepsy specialist nursing for children.
- Please can people remember to complete the evaluation sheet for today's meeting.

3. **AGM** – Packs have been issued to all in attendance which includes a copy of the annual report and a financial report. The materials show how we are increasing the profile of epilepsy within the Parliament and how we try to assist the Scottish Government on policies relating to health and education issues. The Secretariat has drafted this year's Annual Return to the Parliament. If there is anything that needs amended or added to it please contact the Convener and Secretariat - also if anyone would like to be named as a Group member.

Nomination and Election of Officers –The Convener handed over to the Secretariat for the nomination and election of office bearers. The following individuals were re-elected:

- Kenneth Gibson MSP as Convener
- David Torrance as Deputy Co-Convener
- Mary Fee as Deputy Co-Convener

MSPs and attendees present agreed that Epilepsy Scotland continue to provide the Secretariat. The Convener thanked everyone for their valued support and contribution to the meetings. The convener then concluded the AGM.

4. The Convener introduced guest speakers Dr Kirsten Verity, Clinical Neuropsychologist (KV) and Dr Catriona George, Clinical Psychologist, (CG) both from NHS Lothian. The speakers described a current screening project for mental wellbeing in children and young people with epilepsy. The presentation included the following points:

There is growing evidence over the past 20 years that physical health conditions are associated with poor outcomes regarding mental health. For example, we know that in children with diabetes, asthma and eczema there is an increased risk of mental health difficulties. There is a lot of evidence within the literature of the past 10 years that children with epilepsy have even higher risk of mental health difficulties/comorbidities and lower quality of life measures than children with other chronic health conditions.

Anxiety and depression in this group are up to 5x higher than the general population, and there are significantly higher levels of attention problems which affect individuals both academically and socially/emotionally. For example, the rate of ADHD in children/young people with epilepsy is up to 10 times the population average. There is a notably increased suicide risk in adults with epilepsy; children with epilepsy and mental health problems will potentially take these with them into adulthood. Children with epilepsy are more likely to have fatigue and sleep disorders, and these are associated with difficulties with attainment at school and mental processing. A significant number of children with epilepsy will have learning disability or a condition such as autism which will impact on all areas of their life.

The CHES study of 85 participants from 40 schools found that 50% of those not on the Special Education Needs register (so effectively unidentified) were underachieving in at least

one area. 60% met criteria for behavioural disorder (only 20% had been previously identified) and over 50% had deficits in memory and/or processing speed.

The reasons behind the development of these problems are complex; seizures contribute to difficulties but are not the 'be all and end all'. For example, the more epilepsy medications a child is taking, the more chance they will experience side effects which affect learning, behaviour and concentration. There may be underlying neurological factors where something in the individual's brain is not working in a standard way which could impact on their attention, behaviour, attainment and emotional processing. Having epilepsy is in itself stigmatising for many young people and this can compound and affect comorbidities like anxiety depression, low self-esteem etc.

Quality of life in children with epilepsy and in their parents has been found to be significantly lower than general population. These kinds of problems are predictors of poor outcomes in adult life.

There is now an increasing recognition that mental health is important in people with physical illnesses. This is reflected in various reports and policy documents such as the SIGN and NICE guidelines for epilepsy, the Epilepsy12 audit and RCPCH report on the state of child health and the Scottish Government's new mental health strategy.

In the UK approximately 1 in 220 children and young people are diagnosed with epilepsy and there are approximately 1000 children in Lothian with active epilepsy. Cognitive and mental health difficulties often go unrecognised in the early stages. If problems are identified, it can be difficult to refer to CAMHS as they are overwhelmed with demand and are therefore dealing with high tariff cases. CAMHS staff are doing everything they can to support many very difficult cases – so without greater resource they have to maintain a high threshold for referral. Often clinicians have to watch and wait – they know the individual's difficulties will get worse but have to wait until that happens and it reaches the threshold for referral to CAMHS. This can leave families feeling powerless.

One of the aims of the project is to consider how to get involved earlier and give early intervention to prevent some of these individuals ending up in CAMHS, which would also help remove some of the pressure from CAMHS. An aim is to prevent children growing up with difficulties, and into difficulties, ending up with severe chronic mental health problems which also affect their economic potential and create stressors on services etc.

In 2015 the speakers were in discussion with the Scottish Paediatric Epilepsy Network to develop a way of charting children and young people with epilepsy's mental health over time and across clinics. It needed to be something to slot into what people were already doing in services and not add any extra pressure, and to be a way of finding out about the mental health of children without having to have a psychologist present at every appointment. The Edinburgh Children's Hospital Charity kindly agreed to support a two-year project and fund a Band 7 Clinical Psychologist and Band 5 Assistant Psychologist for 2 days per week to develop a screening pathway in NHS Lothian.

The project is seeking to find a method for clinicians to screen children in their clinic without a psychologist present and then signpost what needs to happen next if there is a concern, such as an early intervention. In year one the team has developed a screening methodology to use within the neurology outpatient department and test its feasibility, acceptability and validity. In year two they plan to develop an early intervention pathway and begin to move to electronic methods of screening.

The project has been screening young people aged 5-18 who attend mainstream school. People in non-mainstream schools were excluded since they are potentially already receiving increased support and it is more likely that professionals are aware of their difficulties. Of the 166 remaining cases, 19% of those were further excluded as they were already engaged with

CAMHS services and a further 10% for various other reasons e.g. DNA. This leaves a cohort of 80 children who have been screened so far, using the Strengths and Difficulties Questionnaire at a routine neurology outpatient appointment. The questionnaire has been validated with this population however the team is also trialling other questionnaires alongside to determine which is most useful in terms of providing additional information.

In terms of how the pilot has been working, the parent, and where appropriate the child, first completes the questionnaire in the clinic waiting room. The questionnaire is then scored while the patient is in their appointment. After the appointment, the psychologist goes over the questionnaire results with the patient and parent and offers feedback and, where appropriate, self-help materials. At the end of the clinic the psychologist has a post-clinic meeting with the neurologist where they compare the results of the questionnaire against the neurologist's own perceived level of concern for the patient (if any), to see if the questionnaire results are in agreement and can offer any further insight. Patients coded green are considered to be causing no concern. Patients coded amber 1 & 2 are of mild concern and may have self-help materials provided. Patients coded amber 3 are of higher concern and may receive self-help materials plus potentially a further low-level intervention or a third sector referral. Those coded red are of more significant concern and may be offered further intervention up to and including in some cases a CAMHS referral.

50% of those screened identified a problem of at least amber level (44% of primary and 64% of secondary school children). One would expect to find a problem of amber level 1 and 2 in only 10% of general population and amber 3 and red in only 5%. So far, the pilot has identified 40 children with developing problems – 30 of whom are at significant risk of developing persisting problems and possible CAMHS referral. 32 of the overall cohort were already engaged with CAMHS, so it appears that 43% of those in mainstream education and between 5 – 18 are experiencing difficulties.

Those considered in the Amber 3 and Red categories are at particular risk of developing more persistent problems. Not all problems are amenable to change through intervention e.g. Complex family situations, ASD related, ADHD which may be better addressed within another service, however clinicians considered 18 out of the 30 amber/reds to be appropriate for intervention.

The next steps for the project includes developing further interventions such as one-off seminars and workshops for parents; involvement in the Psychosocial Interventions for Epilepsy group trial; referrals to existing voluntary sector resources and self-management training. The idea is to make the most of resources already available as well as creating new ones.

There are a number of wider implications already emerging from the pilot data including:

- The need to develop a clear pathway/stepped care approach from screening to early intervention – CAMHS is not always the answer
- The need for joined up working between psychology, neurology, education and third sector services
- The potential to roll the project out more widely following the completion of the pilot in NHS Lothian.
- The need for such work to be sustainable – the team hopes to develop and trial interventions as part of the project, but there are currently insufficient resources available to enable a pathway to be sustained if these interventions are found to be helpful.

5. The Convenor thanked both speakers for their presentation and invited questions from the attendees.

Lorraine Mackenzie said she was the parent of a young man with difficult epilepsy and asked whether the tool could be used to assess adults, such as people born with brain injuries? She felt there is a danger these individuals are missed and that there is little place to give psychological help unless the person is at crisis point. She said she was referring to people their 30s and 40s who have not received support.

KV said that the tool was primarily designed for children and young people, however pointed out that if professionals are able to get in at this early stage then we may be able to prevent some of the entrenched problems in the adult population. KV commented that this kind of pilot has not been done before – if it is liked by clinicians and service users and by those in control of health board budgets then potentially it could be used in the adult population. It would depend on all services liking using it. It could potentially also be rolled out to non-epilepsy patients.

Anissa Tonberg commented that although this project is looking at alternatives to CAMHS, this is partly through necessity as CAMHS has a high symptom threshold and lack of confidence around epilepsy – so to what extent would easier access to CAMHS improve the overall situation? KV replied that it would definitely help children with epilepsy; this intervention is an arm of CAMHS in some ways, in general CAMHS is very overstretched and it would be great if services could accept referrals at a lower threshold. KV commented that anyone lobbying for CAMHS knows that we need more as services are massively overstretched and we would like to give more to this vulnerable population.

Kenneth Gibson MSP asked, on the subject of resources, what would the team need after November 2018 to roll this out across Scotland? KV replied that they have been thinking about that and that other regions work differently and are resourced differently. Some of this approach will need psychological input, but not all of it – there are self-help measures which can be supported and specialist nurses (not necessarily epilepsy ones) could 'straddle' psychology and epilepsy clinics. For example, in paediatric psychology they have a 'changing faces' practitioner, who helps manage the wider implications for children who have maxillofacial injuries or conditions, and their families – however also have a mental health qualification which they can tap into. Having an epilepsy specialist nurse or community health worker with some mental health specialism on the ground could be very helpful.

Chris Jeans commented that her family member had had many of the issues KV and CG had talked about but had never received support for them – sadly in his case things had to get a lot worse before the family received any help, so she felt it important to keep highlighting this. Colleen Wilson commented that she felt parents of adult children with epilepsy would welcome these early interventions in order to avoid later crises. KV agreed and said that it is clearly always better to intervene before things develop too far.

Kenneth Gibson MSP said that one of the reasons the CPG exists is to push things forward politically and cited the group's success regarding the EEG issue – he asked the speakers if there was anything practical that the CPG could do to support them? KV answered that this is a pilot post and therefore if it is successful, the CPG could help to pressure boards for similar posts elsewhere. Dr Ailsa McLellan commented that an important that the CPG kept the issue active – that is was such a large problem and it was important to keep it on the agenda, politically. It was suggested we could work towards a parliamentary debate – perhaps on the slightly broader topic of epilepsy and mental health – and that it might be good to aim for National Epilepsy Week in May.

6. Kenneth Gibson MSP thanked the speakers again and the attendees, and reminded group members that the next CPG meeting will be on Thursday 25th January 2018 at 1pm.