

Note of Meeting – Cross- Party Group on Epilepsy, 7 November 2019

In Attendance:

Alasdair Allan	Jeremy Balfour
Celia Brand - PENC	Karen Burke – NHS Lothian
Janette Buttle – NHS Greater Glasgow	Kirstyn Cameron – Epilepsy Scotland
Susan Duncan – Consultant Neurologist, Western General	Ian Forbes – UCB
Janice Fyall - RHSC	Ann Greenall, NHS Fife
Helen Grossi	Gillian Horsburgh – NHS Greater Glasgow
Raymond Hussain – West Dunbartonshire Epilepsy Group	Roberta James, SIGN
Chris Jeans – SUDEP	Rona Johnson – Epilepsy Scotland
Pamela Kirkpatrick, Robert Gordon University	Sylvia Lawrie
Aileen McCafferty – NHS Tayside	Caitlin McCallum - RHSC
Darren McCarthy - VNS	Ailsa McLellan – NHS Lothian
Emily Ord – EISAI	Elizabeth Pilley – SIGN Group
Linda Radcliffe – Epilepsy Scotland	Brian Rocks – West Dunbartonshire Epilepsy Group
Dr Alix Rolfe – University of Edinburgh	Graham Shepherd, UCB
Jay Shetty – NHS Lothian	Sarah Silk, NHS Lothian
Carolyn Sleith – Healthcare Improvement Scotland	Gillian Smith – University of Glasgow
Sharon Thinn – NHS Kirkcaldy	Anissa Tonberg – Epilepsy Scotland

Apologies:

Jean Barclay – Observer	Jo Campbell – ESN Aberdeen
Andrena Hughes – Observer	Helen Macdonald – Lanarkshire Epilepsy
Ann Maxwell OBE – Muir Maxwell Trust	Dr Clare Mills – Headway
Lesslie Young – Epilepsy Scotland	

1. Convener Alasdair Allan MSP welcomed attendees to today's meeting and gave an update since the last meeting in September:
 - Alasdair Allan's office and the Secretariat have drafted a letter to send to the Scottish Government, asking what they can do to support the national roll out of the epilepsy register currently being piloted in NHS Greater Glasgow and Clyde and NHS Tayside.
 - The publication of Scotland's first Neurological Action Plan has been delayed as a result of the General Election. Joe Fitzpatrick MSP, Minister for Public Health, Sport and Wellbeing, has advised the Neurological Alliance of Scotland that the plan will be published by the end of the year.
 - Epilepsy Scotland held their national conference Saturday 2nd November in Glasgow which focussed on individualised treatments for people with epilepsy. Several of Scotland's leading epilepsy specialists presented at the event.
 - The Scottish Government has published its analysis of the Disability Assistance in Scotland consultation responses, it can be found online.
 - Epidyolex now has its EU license and SMC have been in contact with the company regarding a submission seeking approval for its use in NHS Scotland.

Minutes from the September meeting were approved.

2. Alasdair Allan MSP introduced Dr Jay Shetty, Consultant Paediatric Neurologist, chair of the SIGN guideline group. He presented the key recommendations from new SIGN Scottish national guidelines on diagnosing and managing children and young people with epilepsy and include the following points:

Dr Jay Shetty: Said the SIGN guideline group is made up of paediatricians, paediatric neurologists, GPs, epilepsy specialist nurses, dieticians, voluntary sector and young person input.

Said childhood epilepsy is not one condition, it is often referred to as epilepsies. It manifests in different types of seizures and there are many different types of syndromes. As there are so many types it is very hard to find one way to manage epilepsy. There are more than 4,000 children with epilepsy in Scotland.

Said epilepsy is not just seizures, children can experience learning difficulties, behavioural problems and increased mortality. For some children epilepsy will be a lifelong condition. There is a managed clinical network across Scotland in managing children with epilepsy, which is published on the SPEN website.

Said a new guideline had to be developed as there are new ways to diagnose and manage patients e.g. carry out genetic testing and new anti-epileptic drugs. There are a number of AEDs however, one third of children will never achieve seizure freedom. Different treatment options then have to be considered e.g. surgery or ketogenic diet. In epilepsy there is a recognised increase in psychiatric comorbidity, need to update clinical practice to manage this better. As epilepsy is sometimes a lifelong condition, guidance had to be issued on how to manage a child's transition to adult services.

Said an evidence review is hard in paediatric epilepsy medicine. As epilepsy patients are so high risk, clinicians cannot compare the effectiveness of drugs against placebos or carry out randomised testing. Therefore, for the first time, clinicians used a mixed method review to evidence this guideline. This allowed them to look at a much wider range of evidence including qualitative evidence.

The guideline took over two years to develop, significant amount of work from several parties. The SIGN Guidelines are well respected internationally. Said strong recommendations were decided on strong evidence, and good clinical practice points were developed based on good evidence. Jay then summarised the key areas that the group provided recommendations on:

Neuroimaging – for the majority of children 1.5T scan is sufficient. However, children with drug resistant epilepsy 3T scan should be considered if the 1.5T scan showed no abnormalities. This high-tech imaging should be read by a person who is an expert in paediatric neurology. There is currently no paediatric 3T scan in NHS Scotland, there are some in research areas but this is often not appropriate. Once the children's hospital in Edinburgh is opened, it will have a 3T scanner but that will be the only resource in NHS Scotland which will impact waiting times.

Neurophysiology – clinical diagnosis is the gold standard; an EEG is used more to confirm the clinical diagnosis.

Genetic testing – important an experienced professional discusses this with the family before genetic testing is considered. Certain groups benefit more from genetic testing in specific diagnoses and treatment.

AEDs – NICE have already recommended on first line drug treatment. Final decision on an AED should be made with the clinician and the families as side effects and efficacy have to be considered/discussed. Syndromes should be managed in a specialised centre as there are a number of aspects that need to be considered. Jay listed several drugs that the group recommended, can be found when the guideline is published. If AEDs do not work, other treatment options should be considered.

Ketogenic diet – proven to be very effective in some children. There are some epilepsies which react well to the diet, min three months on the diet and requires dietician support.

Surgery – underutilised at present, surgery is often the best treatment option for children with drug resistant epilepsy. Recommended that children with drug resistant epilepsy should be referred for surgery early – centres in Edinburgh and Glasgow. NSD funded service.

Mental health – children with epilepsy have significant psychological and behavioural problems. Increased diagnosis of autistic spectrum disorder and ADHD. Clinicians need to be aware of these issues and work with other clinical teams to ensure early assessment e.g. screening

technique. CAMHS has a serious waiting list, could be up to 12 months, clinicians are very anxious about this.

Transition – clinicians need to have a planned, structured and educational approach to transition. More time will be needed for clinicians and nurses to make sure transition is handled properly.

Mortality – information should be provided to young people and parents as close to diagnosis as possible. SUDEP and safety should be discussed periodically with young people and families, face to face. Health professionals should discuss the pros and cons of SUDEP monitoring to help families make an individualised choice.

Said a patient version of the guideline is being developed. Jay thanked Epilepsy Scotland, the young people involved in the guideline, the SIGN and SPEN teams and the clinical guideline group. Noted that the clinical team did everything for the new guideline in their spare time.

Alasdair Allan MSP thanked Jay Shetty for his presentation and opened the floor to members for questions.

Anissa Tonberg, Epilepsy Scotland – asked what MSPs can do to help encourage the implementation of the guideline.

Jay Shetty – said the health boards need to recognise that the guidelines are developed on a wide range of evidence. Said waiting times are slowing progress in treatment e.g. access to neurophysiology has significant waiting times which slows diagnoses and treatment as a result.

Alasdair Allan – asked if an Action Plan has been put in place to support the implementation of the guideline.

Jay Shetty – said once the guideline is completed the SIGN team will be looking towards an implementation strategy for each individual health board.

Alasdair Allan – said MSP action can be prompted by the clinicians. Said they can write to health boards to ask whether they have reactions to what is being proposed.

Rona Johnson, Epilepsy Scotland – asked when the guideline will be published.

Jay Shetty – said that the guideline is nearly finished, only some wording and editorial decisions need to be made. Believes it will be published soon.

Susan Duncan – said she helped design the adult guideline on epilepsy, so knows how much work the team puts in. Noted that the current implementation process relies on clinicians monitoring the process via various forms, believes this is the pitfall of implementation. Said the implementation of SIGN guidelines needs to be delivered by someone else other than the clinicians as they are too busy.

Ailsa McLellan – said that everything recommended in the new guideline, if it were to be implemented, would cost a lot of money. Asked for the political view on the guideline. Asked if the government would get involved if health boards are not delivering on the SIGN guidelines.

Alasdair Allan – asked who these guidelines are made for.

Jay Shetty – said they are for people who look after children with epilepsy.

Alasdair Allan – said the opportunity exists to exert usual questions and pressure on health boards and the Health Minister to implement the guidelines.

Ailsa McLellan – said she would take Alasdair up on that offer.

Brian Rocks – asked how they are dealing with memory problems in education.

Jay Shetty – said this needs to be diagnosed very early on. Said a neuropsychologist assessment would be helpful. Clinicians will work with families to recognise this problem early on

and then write to schools. They then need to decide if the problem is related to the child's epilepsy or their medication.

Anissa Tonberg – said previous guidelines have been very statistical based. However, this guideline focusses a lot on qualitative data. Asked how this change will be received in the medical community.

Jay Shetty – said they could have never looked at it solely from randomised trials as they would have not been able to give many recommendations. Mental health for example needs a more nuanced approach in this context. Noted that trials are very expensive. Said he thinks clinicians will welcome this method.

Gillian Smith - said access to services and reasonable adjustments are more difficult for children with learning disability.

Jay Shetty – said access to other services are really poor e.g. CAMHS. Said there are pockets of good practice. Need to work with schools, families and communities.

Alasdair Allan handed over to the Secretariat, Anissa Tonberg.

The Secretariat thanked Jay and members for their discussion. Noted that there is opportunity for the Cross-Party Group to ask MSPs to write to health boards and ask what they are doing to implement the new SIGN guideline.

Jay Shetty – noted that professionals have worked together with families to produce this. Believes this empowers families to ask questions to their health boards and MSPs about the care their child receives.

The Secretariat stated that:

- The next CPG on epilepsy will be held 27th February 2020 and the subject will be out of area placements.

She thanked all for their attendance and closed the meeting.