

Cross-Party Group on Epilepsy

29th September 2022

Minute

Present

MSPs

Alasdair Allan MSP
David Torrance MSP

Jeremy Balfour MSP

Invited guests

Dr Ailsa McLellan, Consultant Paediatric
Neurologist, NHS Lothian
Dr Kirsten Verity, Paediatric Clinical
Neuropsychologist, NHS Lothian

Sarah Whittaker, Clinical Associate in
Applied Psychology, NHS Lothian

Non-MSP Group Members

Anna Telfer, Epilepsy Scotland
Colleen Wilson, Epilepsy Connections
Derek Robertson
Elenora Saturno
Emily Beard, Epilepsy Connections
Helen MacDonald, Lanarkshire Epilepsy
Jan Campbell, UCB Pharma
John Thomson
Lesley Perkin, UCB Pharma
Lynne Young, Salvesen Mindroom Centre

Mary Keenan – Epilepsy Connections
Michael Durkan
Pamela Martis, Intellectual Disability
Specialist
Paul Gillon, Veriton Pharma
Ross Cunningham, Epilepsy Scotland
Stephen Bolan, Angelini Pharma
Susan Duncan
Vicki Burns, Epilepsy Scotland

Apologies

Audrey Nobel, Angelini Pharma
Chris Jeans SUDEP Action Scotland
Helen Reilly, ABPI

Hilary Mounfield
Kirsty McKenzie, Headway
Lorraine MacKenzie

Agenda item 2. Convenor Alasdair Allan MSP commenced AGM business

- Alasdair Allan MSP re-elected as Convenor of the CPG on Epilepsy
- Jeremy Balfour MSP re-elected as Deputy Co-convenor of the CPG on Epilepsy

- David Torrance MSP re-elected as Deputy Co-convenor of the CPG on Epilepsy
- Epilepsy Scotland confirmed to continue to provide the Group Secretariat on behalf of Epilepsy Consortium Scotland.

No income was received or spent directly by the Cross-Party Group on Epilepsy since the last AGM.

Minutes from the last meeting of the CPG on epilepsy (June 2022) were approved. Anna Telfer proposed and David Torrance Seconded.

Agenda item 2. Convenor Alasdair Allan MSP provided brief update on what has been happening since the last meeting.

- The Neurological Care and Support Framework published their midpoint progress report to mark the halfway point for the five-year framework. It highlights key achievements, challenges and future priorities as they implement the framework.
- Epilepsy Consortium Scotland commissioned new research on Epilepsy Specialist Nurses in Scotland. The research found that patients were very positive about the support offered by their Epilepsy Specialist Nurses, but that the nurses were facing extensive and potentially unmanageable workloads, with these pressures further compounded by the COVID-19 pandemic.
- Social Security Scotland has now rolled out Adult Disability Payment (ADP) across Scotland, replacing Personal Independence Payment (PIP). This means new applicants in Scotland must apply for ADP rather than PIP. Those already in receipt of PIP will see their awards being gradually changed over to ADP in the coming years.

Agenda item 4. Alasdair Allan welcomed guest speakers Dr Ailsa McLellan and Dr Kirsten Verity to present on PAVES.

Epilepsy and Mental Health

Children with epilepsy have higher rates of mental health comorbidities and their quality of life is lower than children who do not have epilepsy. Mental health problems impact the quality of life of children more than the epilepsy. Even though we are always trying to stop the seizures, it is the mental health problems that are going to more impact their quality of life. However, child mental health services are facing challenges across the UK. In Edinburgh for example, there might be a two year wait for CAMHS.

Typical Epilepsy Clinic Consultations Before PAVES

Prior to PAVES a typical consultation could look like: A girl, 13, with juvenile absence epilepsy. We would have 20 to 30 minutes to ask about seizure frequency, types of seizures and medications. She is 13 so I need to think about childbearing potential, what side effects she is having from her drugs, how she is getting on at school, what is going on in her life, perhaps talking to her about alcohol and drugs and about complications of epilepsy and consider when we last had a conversation about SUDEP. I have 20 to 30 minutes to cover everything and quite typically in these consultations, just as the family are leaving, parents might say something like, she doesn't seem quite herself. Where do I go with that in my busy clinic, knowing there is a two year wait to be seen by CAMHS?

The PAVES Programme

PAVES (Psychology Adding Value - Epilepsy Screening) is a pragmatic way for neuropsychologists and neurologists to meet some of the mental health issues seen in children and young people with epilepsy. PAVES allows us to screen for mental health presentations before children, young people and their families walk into our epilepsy clinics.

The web-based screening gives a traffic light to the child or young person. It will support the neurologist or epilepsy specialist nurse in discussing mental health in the epilepsy clinic by flagging any issues. We then have a structure of stepped interventions which are provided according to need. Those interventions comprise of, at the highest end, psychology groups or workshops through to partnership working with third sector organisations and signposting for community resources. For clinicians, it is like having a psychologist in their desk drawer.

This stems from frustrations about meeting the needs of kids with mental health problems who we see in clinic who we don't have a way of supporting. Edinburgh Children's Hospital Charity funded a clinical psychology post and an assistant psychology post, or at least parts of that, to allow us to start developing PAVES. We were then funded subsequently by Realistic Medicine who continued with the staffing funding and money to develop the software to make it more seamless. Since then, we've been funded from Edinburgh Community Mental Health and Wellbeing grant and more recently, we successfully put in a bid for the CAMHS Mental Health Recovery Fund, which is hopefully going to be recurrent and is funding our half time clinical psychology sessions.

The PAVES Pathway

Before an epilepsy clinic, families are asked to complete our PAVES questionnaire online and the PDF results are sent to the clinicians. They have the traffic light in the clinic and can see the information about the young person. If the child is over the age of 11, they'll also complete a self-report. The traffic light would then be discussed – the PDF identifies level of concern, but also allows the clinician to see what area is problematic according to the report from the family or young person. They can explore it in more detail in clinic and on the back of that discussion, the clinician can then decide what is a good idea in terms of interventions or support. There is no psychologist here at this point, only the neurologist or epilepsy specialist nurse working with the family and young person or child, but they can guide safely to what resources might be useful. The clinician can access information about what community resources might be available on a shared drive called the Community Resource Decision Tree (this was built by someone who knows what is out there in the community and are CAMHS ratified resources that are available for children and young people across Lothian. It is taken by area, by need identified and by age and it is colour coded. This means a non-psychologist clinician can find the relevant resources and pass this information on to the family). They also have access to self-help material looking at, say, anxiety or sleep problems or headaches, that they can then give to the child and family in clinic. On top of that, they also have condition specific stepped care interventions to offer. The child or young person and families are given these resources in the clinic and when they come back into clinic they are invited to complete the questionnaire again which means the clinician can monitor how things are going with their mental health needs.

The Amber Group might be offered self-help materials if there's a specific area of difficulty. They might be given information about support services like Epilepsy Scotland, third sector organisations that could support them, or information about specific aspects of epilepsy or

difficulties. The Amber Group might be offered gentle prompting and some things that they can take away and think about. If the clinician feels that the child or young person is a red, they could discuss the concerns with the psychologist, so they can triage any level of risk. The Red Group is slightly more prescriptive because we want to make sure we engage them into the resources that we know would be useful. They would have the same sources of information, the same direction, but perhaps the clinician would get consent and make a referral. We also have the highest tariff groups such as the PIE group (a group for teenagers with epilepsy run between psychology and the epilepsy specialist nurse within the hospital – it is an evidence-based intervention designed to manage some of the sorts of difficulties that we might see in this red group. It is quite a high level of intervention, but we have found it to be incredibly effective and is received by young people and their families).

PAVES Going Forward

The PAVES programme enables timely interventions, the immediate provision of self-help materials and immediate signposting to existing relevant resources. PAVES is not instead of CAMHS, but is complementary – some young people will still need to go to CAMHS, but we have shown a reduction in referrals to CAMHS – in our initial pilot there was a 62% reduction. We have done some cost benefit analysis showing that this is cost saving, but we do need a small amount of CAMHS resource and this is important for triage, dealing with concerns and to support and run the parent groups and PIE groups.

Agenda item 5. Alasdair Allan thanked speakers and opened up for questions and comments.

Ross Cunningham: Does the 62% reduction in referrals to CAMHS mean the children and families have decided that they didn't want to go through with the referrals to CAMHS after this intervention.

Ailsa McLellan: This figure was from looking at historic data, how many children and young people previously went from the epilepsy clinic to CAMHS and then we looked after we had PAVES in place, how many people we then felt it necessary to send to CAMHS. We are collecting data as time goes on about how the screening changes over time and when kids are coming back to the clinic months later we can see them moving off red into amber and even children moving off red into green just from the PAVES intervention.

Kirsten Verity: I think if we would talk to the epilepsy clinicians on how many children they're referring to CAMHS, it is in single figures because we have a way of meeting so many of the needs, other than the most high tariff.

Ross Cunningham: Are there any opportunities to use this same model in adult services?

Susan Duncan: In Lothian there is an adult screening programme going on. It mirrors these ideas closely and we are doing something similar in terms of screening patients and then making the results of the screening available to the adult clinicians and in the adult epilepsy clinics and then using a traffic light system offering our patients certain treatment options. One is a wellbeing course with Epilepsy Scotland, which has been extremely well received. Our preliminary work suggests that it reduces referrals onto neuropsychology and neuropsychiatry. We are in discussions to get it done electronically and we have also had discussions with another health board about rolling it out there. So yes, it shows great promise in adults.

Alasdair Allan: To what extent are other parts of the country picking up on this?

Ailsa McLellan: The Scottish Paediatric Epilepsy Network has been a great supporter and at our annual members day we are going to have a whole session on mental health because we are keen to roll out the programme to a couple of other health boards in Scotland. But what we have got to bear in mind is there is a small cost to it, there will need to be a PAVES champion keeping everything updated in terms of the Community Decision Tree and it needs some oversight probably nationally – someone who can support as people are trying to move their own PAVES project forward. We've got a manual, we've got things that will help services, but it will need a little bit of local funding to help move it forward. We also think it is not just specific to epilepsy, even though children and young people with epilepsy have higher rates of mental health problems than children with other chronic conditions. We just started a pilot in Edinburgh in diabetes.

Kirsten Verity: We have had interest from NHS England Children and Young People Epilepsy Mental Health task force who asked us to talk along with Great Ormond St who have a similar method of looking at meeting mental health needs for children and people with epilepsy. It's similar at the front end but quite different in terms of the stepped intervention. There might be a meshed approach but that feels on the slow burn whereas there has always been a huge amount of interest and support from clinicians and services in Scotland. It's just how to practically and pragmatically make it happen because engaging clinical psychologists, even within CAMHS, isn't an easy thing. We need to think about how we would have sessions in a particular area, how we would link them in with existing CAMHS services in the way that PAVES is. It has to be built from the ground up in different areas to provide a bespoke resource for children and young people.

Alasdair Allan: You are talking about solutions that are based around knowing that there is an intervention in a certain area. Does this make the case for a different way of engaging with young people with neurological conditions in a much more localised way? Does it imply wider change in the way we engage with patients?

Sarah Whitaker: We understand in CAMHS that if young people can have their needs met in the community, it is both empowering for the family but also brings a lot of normalisation around it. If they're going to a local youth club or they are accessing support through school, it doesn't feel as big and scary as maybe having to go to CAMHS or having to go see a psychologist. For young people with epilepsy, they might be used to feeling a bit different whereas this makes everything so much more local and practical for them and they are building relationships with trusted adults in their community.

Agenda item 6. Close