

Epilepsy Consortium Scotland (ECS) Secretariat **DRAFT**

Allana Parker: 48 Govan Road, Glasgow G51 1JL

Tel: 0141 419 1701 Fax: 0141 419 1709 Email: aparker@epilepsyscotland.org.uk

Note of Meeting – Cross- Party Group on Epilepsy, 28 January 2016

In Attendance:

Declan Ahern, Epilepsy CNS NHS Lothian & ESNA	Brian Nisbett, Scottish Government
Jean Barclay, Observer	Alex Osland, SUDEP Action Scotland
Lorne Berkley, SEC Quarriers	Allana Parker, Epilepsy Scotland
Celia Brand, ESN NHS Lothian	Gil Paterson MSP
Cameron Buchanan MSP	Dennis Robertson MSP
Jane Cassidy, Observer	
Kenneth Gibson MSP	Derek Robertson, ESN NHS Lothian
John Heaney, West Dumbartonshire Support Group	Phil Robinson, Lanarkshire Epilepsy Support Group
Jamie Hepburn MSP, Minister for Sport, Health Improvement and Mental Health	Brian Rocks, West Dumbartonshire Support Group
Jane Holmes, Observer	Harry Stevenson, Chief Officer South Lanarkshire Health & Social Care Partnership
Andrena Hughes, Observer	Anissa Tonberg, Epilepsy Scotland
Carsen Mandt, SPEN Programme Manager	Colin Urquhart, Scottish Government
Pamela Martis, Assoc. Specialist Learning Disability	Jean Urquhart MSP
Shirley Maxwell, Epilepsy Connections	Lesslie Young, Epilepsy Scotland
Brett Millett, Epilepsy Connections	
Helen MacDonald Lanarkshire Support Group	

Apologies:

Matt Barclay, Community Pharmacy Scotland	Ann Maxwell OBE, Muir Maxwell Trust
Jo Campbell, ESN NHS Highlands	Nanette Milne MSP
Hugh Henry MSP	Eileen McCubbin, ESN Ayrshire & Arran
Danniella Higgins	Alison McInnes MSP
Fiona Hughes, ESN NHS Forth Valley	Anne McTaggart MSP
Jim Hume MSP	Lorraine Mackenzie, Observer
Chris Jeans, SUDEP Action Scotland	Hilary Mounfield SEC
James Kelly MSP	Jacqui Telfer, Epilepsy Scotland

1. Convener Kenneth Gibson MSP welcomed attendees to today's meeting.
2. The draft note of the September 2015 meeting was approved. An update was given on activities:
 - Since October 15, Siobhan McMahon MSP has put forward a Members Motion for Hemiplegia Awareness Week that related to epilepsy.
 - Six Parliamentary Questions have also been submitted. Elaine Smith MSP asked what advice the Scottish Government gives to pregnant mothers about the possible side effects of using sodium valproate for treating epilepsy. Graeme Pearson MSP wanted to know the number of epilepsy specialist nurses in NHS Ayrshire and Arran. Our Deputy convener, Alison McInnes MSP asked the Health Improvement Minister four related questions about the number of hours that health boards deploy epilepsy specialist nurses to clinical shifts on wards, and on increasing the number of ESNs. Alison has since sent a Freedom of Information request to health boards to find out how much time ESNs have been taken off their regular duties in the last year. If you wish to see the answers to the six PQs, our Secretariat, Allana has a copy.
 - A summary paper showing health board provision and the location of EEG services has just been circulated by the Secretariat. All the health boards responded to our Freedom of Information request asking about EEG resources. One key finding is that it seems only NHS Greater Glasgow and Clyde provide an EEG service after 5pm and at weekends. The expected demand for EEGs is likely to increase as a result of revised SIGN guidelines for the diagnosis and management of adults with epilepsy. Several health boards have vacancies for either a consultant neurophysiologist or a neurophysiology technician. Some boards said recruitment to posts is a problem.

- All Cross Party Groups will cease to exist when the Scottish Parliament is dissolved on Thursday 24 March 2016. I sincerely hope the CPG on Epilepsy will be re-established and continue its good work in the next parliament.
3. Let me now introduce today's speakers, we welcome Jamie Hepburn the Minister for Sport, Health Improvement and Mental Health to our Group. He will discuss the provision of integrated health and social care for people with epilepsy. Following the Minister's presentation, I will ask Harry Stevenson who is the Chief Officer with South Lanarkshire Health and Social Care Partnership to expand on this important topic.
- Mr Jamie Hepburn MSP thanked members for inviting him to address the Cross-Party Group. As the Minister for Sport, Health Improvement and Mental Health, epilepsy is one of his responsibilities. He very much hoped there will be a re-convened Cross- Party Group on Epilepsy. Such a Cross- Party Group is very helpful in casting light on some areas the Scottish Government needs to continue to improve. The Group also highlights good practice where it happens. His primary purpose today is to discuss health and social care integration and share some positive examples of the work taken forward within partnerships across the country.
 - The Minister acknowledged how common epilepsy is as a condition that touches many families including his own. It was important to recognise how it presents and the range of behaviour changes that can accompany seizures. Sometimes the social effects of epilepsy, the isolation or lack of confidence a person may feel can be as much of a burden as the actual medical effects of the condition and seizures themselves. People may worry that they might be judged or misunderstood from something over which they have no control.
 - This administration has a long and close working relationship with charities including Epilepsy Scotland and Quarriers. Our vision is for everyone in Scotland to be treated fairly and equitably and have the chance to fulfil their potential in all aspects of life. This clearly extends to people who have a diagnosis of epilepsy. For many years the third sector has led the way in combating prejudices and misconceptions that exist and in tackling epilepsy discrimination. His officials are currently exploring a range of options for taking forward epilepsy-related projects over the next year including talking with third sector colleagues about what the priorities should be. The invitation is there for the Cross-Party Group to be involved in this process following its re-establishment post-election.
 - People in Scotland who live with epilepsy should be able to access the best possible care and support and benefit from safe and effective services which put the patient at the centre. The integration of health and social care responds to the evolving health and care needs of our communities. Public services which are joined up afford a better outcome for service delivery and for the service user. Legislation to bring about this radical re-alignment is there to support the growing numbers of people in Scotland who have complex care requirements and sometimes multiple different care requirements. It also ensures the sustainability of the health and social care system in the face of increased demand and demographic changes. Among the Scottish Government's top priorities are preventative care and a greater focus on community based care.
 - Integration is about improving peoples' lives and making sure that those working in health and social care are better equipped to use their own skills and resources. Closer partnership working improves outcomes for individual patients so people can get the right care in the right place at the right time. There is evidence in Scotland and beyond of where this approach has been taken. Planning is required for the needs of people across the entire pathway of care to meet individual aspects of their care in different places at different times with different teams. Two priorities are key here; better outcomes for the people using the service and supporting the workforce into and through the process of implementing that integration.
 - Substantial resources are being brought together to try and empower health and social care professionals working within the community to design and deliver effective, efficient services that will better meet the needs of increasing numbers of people who have long term complex conditions. From April this year, health and social care partnerships will go live across Scotland. A crucial message is that the third and independent sectors have to be crucially involved and the Scottish Government has legislated for this. The third sector has a recognised wealth of experience in terms of developing innovative solutions and services in comparison with the NHS. It links into the formal system of working with healthcare professionals, GPs and other clinicians but also ensuring that individuals, their carers and families are involved in that process as well.

- The foundation of this approach and the over-arching legislation for integrated care is about trying to take forward a co-production model, one where people work together to tackle challenges in innovative ways. All this will help to ensure an integrated holistic person-centred experience and achieve best use of services. Involving other parts of the public sector in integrated health and social care, such as housing and local government, can also make a crucial contribution
- The Minister recognised it was not an easy or straightforward process. However, he was confident that having set up the structures and by involving organisations such as those around this table, was part of the equation to get it right.
- The Self Directed Support Strategy has hopefully demonstrated the administration's commitment to enable individuals, carers and their families to have flexibility, choice and control over the support services they receive which brings greater independence. The Minister wanted to see innovation here too, with people individually, and local authorities too, learning from one another. The new integrated arrangements will be involved in helping to support people including those with epilepsy which is of primary importance to this administration. The Minister was determined to make it a practical and effective reality on the ground for everyone across Scotland.
- Guest speaker Harry Stevenson outlined the approach taken in South Lanarkshire by the Health and Social Care Partnership and mentioned ways to influence progress at a local level. His presentation (attached) also included a short DVD entitled "John's story" shown to attendees.
- The main differences from the past include the joint responsibility between health boards in Scotland and local government. There is financial authority for decision making and for utilising delegated budgets. Strengthening communities is important through early intervention, prevention, and various local schemes (eg good neighbours or helping hands). Further developing of services required the input of third sector organisations, as well as the private sector, who are key partners in relation to the delivery of high quality care, including improved support to carers and unpaid carers
- Co-ordination of services so the person receiving care or support enjoys continuity is well illustrated in "John's story". Making the best use of the resources and expertise to ensure people are working at the things they do best while not duplicating is important because the issue of resources will remain for a number of years. Mr Stevenson does not believe that his team have ironed out the inefficiencies in the system and believes more can be done to help address some of the issues of our ageing population and other needs that exist within our communities.
- Targeting those energies and sharing that knowledge with others is an important issue. Care can be a seven day service for people and this focus is being addressed by the Parliament.
- In terms of commissioning, it can be the leader for change. By looking at the money that is locked up in services perhaps dealing with inappropriate presentations or admissions to A&E, the question is how do you shift that to bridge the front end of things? A lot of people who need it do live in residential care and nursing home care within Scotland and receive good support. Our Joint Improvement Team, working alongside government and other partners have a process of planning, reviewing, analysing to make sure we get it right. Having and meeting clear outcomes helps because things do move on and shift. Too often monies stay in one place and don't move to where they might be needed and therefore it is not always about getting new money.
- Integrated bodies have areas of responsibility. This slide shows delegated functions for local government covering mental health, drug and alcohol, homecare, residential care and day care, occupational therapy and housing support service. This is a huge amount of things. Other local council services like leisure facilities and the education system, in terms of how we prepare young people for the future and support them, are also part of the combined strength that a local government organisation can bring to that work that we do within our communities. It is not just about the social work service.
- In the Lanarkshire context, there are a number of hosted services. In working with primary care services and GPs, there is the development of a new contract that will come into place in 2017. Pharmacy is another important area where we hope to get more of these particular skills in relation to how we best support people.
- The structure in South Lanarkshire will be similar to elsewhere across Scotland. It started with an NHS board and a council, then a shadow Transition Board till 1 April when it is a fully-fledged organisation with a Management Group and a Strategic Planning Group. A number of themes have been identified locally as important: mental health, learning disabilities, older people, long term conditions, health improvement and substance misuse. This slide shows how our four

localities in South Lanarkshire are really important and are involved in the process of how commissioning plans are shaped. Commission plans are for 3 years initially, and need approval by the joint boards. Every partnership will be currently in consultation, and if you go online in your area you will find out how to contribute to that and get yourself involved. For national organisations, the importance of speaking to Government and then taking that message back to local groups is important.

- For strategic commissioning groups there is a limit to how many people can participate and be effective but this interface is an important group for the third sector. In South Lanarkshire an organisation called ASLAN's chief executive attends the board and this gives direct access for carers. Locality planning offer a great opportunity, even to smaller groups, to work alongside public partnerships, the private sector, carers, health council and others by being involved in discussions on how to shape services for the health needs of our population. This is where to make the case for the importance of epilepsy and the work and the advocacy undertaken on behalf of individuals. In our area, our strategic priorities came from what people told us on accessing health and care services. Carers support models of self-care and self-management and we find ways to offer out of hours support when there are worries about someone having a seizure. Intermediate care helps ensure people leave hospital safely, quickly and confident to be home again. The option of flexible housing is a big issue too for those who may need it.
 - There is one epilepsy nurse for adults in the whole of Lanarkshire with a population over 600,000. There are two paediatric nurses, with one working in learning disability services. There is a key need for more diagnostic services as well as transitions care for young people moving on from the school education system into the adult world. This is about them being confident and being supported to become independent, which is important for their family as well. The same holds true for adults with learning disabilities. Access to information is crucial, including employment information as many people with epilepsy are working. Adjustment issues around developing epilepsy are important too. It seems social stigma linked with epilepsy is still a big issue.
 - Mr Stevenson saw his role as educating other staff to understand epilepsy, and the impact it has on individuals. Easier access to clinics is needed given a high number of no shows by patients. The Lanarkshire Epilepsy Support Group has submitted a grant request to help develop grass route services. The no-shows are not due to people not caring about their health. If clinics in South Lanarkshire were held more locally it may help attendance.
4. The Convener thanked the Minister and Harry Stevenson and invited questions.

Lesslie Young thanked the Minister for acknowledging the ability of the third sector to be more innovative. However, given evidence in the recent Audit Scotland report with regards to the intervention of health and social care, a degree of frustration was noted formally about the perceived exclusion of the third sector in the build up to the development of the integration process. She wondered after what has been said today, how that is going to be addressed.

The Minister agreed it an interesting report which was being taken very seriously. However, the wider question was possibly around how to legislate for the involvement of the third sector. Not every third sector body can be directly involved on the integration of the board and sub structures could possibly happen. The Scottish Government did not intend micro managing the process of integration but he would deal with a specific concern if people raised it directly. There is a regular dialogue with all the integrated bodies and all the territory health boards and indeed COSLA.

Lesslie Young responded that communication was probably the integral part which the third sector wanted to be play and to be given the opportunity to take part in those conversations. The Minister agreed this was critical in going forward.

Brian Rocks asked the Minister about tackling misunderstanding of epilepsy through education. He sits on a support group and tried to attend a learning disability class to share more about the support group. He was thrown out because he took several seizures and wondered how to tackle the continuing stigma of epilepsy.

The Minister responded that this was something he took away from Harry Stevenson's presentation. In terms of mental health stigmatisation, the Scottish Government has done a lot in challenging misconceptions to bring about an improved environment. Maybe this is something that he could discuss with Epilepsy Scotland and some of the other national organisations. More needs to be done in relation to this, perhaps even wider than with epilepsy, about how do we challenge misconceptions that lead to stigmatisation. He was very disappointed to hear about Mr Rocks personal experience. Brian suggested that early education about epilepsy might help.

The Minister acknowledged it was a challenge in trying to educate the young but thought it probably goes wider than that. See Me, which the Scottish Government funded, has done great work. Perhaps expanding that approach could apply in different areas of life as well.

Anissa Tonberg asked the Minister for an update on any decision regarding the future of the National Neurology Advisory Group. It sits within the context of there being a wider plan about neurology in Scotland that the Scottish Government were hoping to share early this year.

The Minister acknowledged a review of the work of that particular group and advisory groups across the health portfolio that all play an important role. It was very important to have a neurological advisory group. He confirmed he will be making further announcements about that imminently. In terms of other work, the Minister mentioned that the Scottish Government did triple the amount of money made available for neurological conditions in terms of innovation and new approaches. His office had a dialogue with the neurological alliance around that and there is now a work stream with the wider health and social care alliance in relation to neurological conditions. He was happy to maintain that dialogue and if people have concerns about this approach he will listen and hopefully either put those concerns at ease. Or if it is recognised that something else could be done he will listen to that and act accordingly.

Carsten Mandt asked about the key mechanisms for sharing information with others from any strategic management as outlined in the presentations. The Minister used the example of South Lanarkshire and NHS Lanarkshire which could share good practice with neighbouring North Lanarkshire and NHS Greater Glasgow and Clyde. There were a number of integrated partnerships and as an administration, the Scottish Government is the obvious point of contact for all these bodies. He is looking to see what's been working most effectively and help to roll out that learning across the various partnership areas.

The Convener thanked both speakers again for their presentations. The Secretariat has copies of Mr Stevenson's presentation should anyone require a copy.

Kenneth Gibson MSP will be hosting a Parliamentary Reception on 9th March in the Members' Restaurant from 6pm onwards and he hoped that members could all come along to that. The Minister will be the key speaker at the event sponsored by Epilepsy Scotland and NHS Dumfries and Galloway. Drinks and buffet would provide a much more informal event lasting a couple of hours and give the Group the opportunity to meet, chat and network with people. Anyone wishing to come along should confirm their attendance by 22nd February to Epilepsy Scotland.

The Convener thanked everyone for attending and details of future meetings will be circulated in due course.