

Note of Meeting – Cross- Party Group on Epilepsy, 28 March 2019

In Attendance:

Alastair Allan MSP	Michael Adair, Epilepsy Scotland
Jeremy Balfour MSP	Jean Barclay, Observer
Charlotte Bergqvist	Philip Bergqvist
Celia Brand, PENC, NHS Lothian	Kirstyn Cameron, Epilepsy Scotland
Richard Chin	Elaine Collard, NHS Highland
Dr Susan Duncan, NHS Lothian	Leigh Fell, Caritas Neuro Solutions
Kenneth Gibson MSP	Paul Gillon, Veriton Pharma
Pat Graham, PAMIS	Gillian Horsburgh, NHS Greater Glasgow & Clyde
Raymond Hussain, West Dumbartonshire Epilepsy Group	Jen Irvine, ENP, NHS North Lanarkshire
Chris Jeans, SUDEP	Rona Johnson, Epilepsy Scotland
Chloe Kippen, Edinburgh University	Yvonne Leavy, NHS Lothian
Rachel Lloyd, NHS Lothian	Richard Lyle MSP
Barbara McCulloch, Observer	Michael McCulloch, Observer
Ailsa McLellan, NHS Lothian	Kerry Mackay, Edinburgh University
Lorraine Mackenzie	Pamela Martis, NHS Lothian
Shirley Maxwell, Epilepsy Connections	Dr Gashirai Mbizvo
Fiona Moreton, NHS Lothian	Hilary Mounfield, SEC
Chalmers Mowbray	Julie O'Hara, Student Nurse Edinburgh Napier University
Derek Robertson, ELN, NHS Lothian	Brian Rocks, West Dumbartonshire Epilepsy Group
Jillian Rose	Dr Christian Schnier, Edinburgh University
Dr Shona Scott, NHS Lothian	Sharon Thinn, NHS Fife
David Torrance MSP	Liliana Wilson
Sam Whitmore, NHS Health Scotland	

Apologies:

Joanne Hill, Epilepsy Specialist Nurse Quarriers	Andrena Hughes, Observer
Jude Kilbee, Bial Pharma	Sylvia Lawrie
Anne Maxwell OBE, Muir Maxwell Trust	Dr Eleonora Saturno, Consultant Neurologist, NHS Fife
Jay Shetty, CPN, RHSC	Linda Stephen, West Glasgow ACH
Lesslie Young, Epilepsy Scotland	

1. Deputy Convener, Alastair Allan MSP, welcomed attendees to today's Meeting and gave an update since the last meeting in January.
2.
 - The Scottish Government's first Neurological Action Plan received over 150 responses during consultation which are being analysed just now. The final plan will be published shortly.

- NHS Healthcare Improvement Scotland has finalised the General Standards for Neurological Care and Support following public consultation. The new standards are being launched today and look forward to seeing their implementation.
 - The consultation on the Scottish Government's new approach to delivering Social Security Disability Assistance has been published and is open for consultation until the end of May. It sets out how disability benefits will work in Scotland once they are devolved.
 - Epilepsy Scotland have had a number of parliamentary questions answered at Westminster on epilepsy and social security. Figures show that 54% of people with epilepsy who previously had Disability Living Allowance are denied Personal Independence Payment and 66% of new claims from people with epilepsy are denied PIP. A motion submitted to the House of Commons highlighting concern about the high refusal rate for people with epilepsy received 31 signatures from across the political spectrum.
3. Alastair Allan MSP introduced Dr Susan Duncan, consultant epileptologist from NHS Lothian and Dr Gashirai Mbizvo, a clinical research fellow at the Muir Maxwell Epilepsy Centre. They presented a recent study covering seven years of Scottish epilepsy deaths which included the following points:

Dr Susan Duncan outlined the need for the study as some premature deaths in people with epilepsy are avoidable. She thanked her colleagues around the country for helping them gather the data. Thanked Epilepsy Scotland, Epilepsy Research UK and the Bergqvist Fund for their financial support. Said the study is already gaining attention and has received three awards so far. She asked for members and press in the meeting to respect the confidentiality of the case studies presented.

Dr Gashirai Mbizvo said there are 60,000 deaths in Scotland per year. Said the death certification process is different in Scotland compared to England and Wales – first cause of death is identified by a GP or junior doctor, that then goes to National Records of Scotland to be scrutinised, results in a final amended death certificate. The classification of death uses an international code so that it can be interpreted internationally. Said the initial cause of death and final cause of death very different, highlighted the importance of the National Records of Scotland process. Said the study uses this administrative data from death certificates as well as hospitalisation records and primary care data.

The research question for the study was; what are the rates, causes and risk factors for epilepsy related deaths and what percentage are preventable. The study uses a Scotland wide retrospective cohort study to identify the rates and causes. Uses a case control study to identify risk factors. They linked various administrative sets together to produce their dataset.

Said that epilepsy is common around 60,000 people have the condition in Scotland. Although it is common, mortality has never been looked at nationally until now. Said there is an assumption about what epilepsy related deaths are e.g. SDEP or drowning. Said that there are other reasons why people with epilepsy die e.g. respiratory problems, people with epilepsy are seven times more likely to die from pneumonia compared to the general population.

Said the study period runs 2009-2016 covering adults (16+) where either; epilepsy appears on the death record, epilepsy is documented on someone's medical record, a person has been prescribed anti-epileptic drugs or have been admitted to hospital as a result of epilepsy. Said the CHI number in Scotland made gathering this data possible. Said they compared this to people with epilepsy of the same age who have not passed away and then compared it to the national

average. They hoped to find a risk prediction with mortality in people with epilepsy to target those who have a higher risk of death and take measures to avoid it.

Said they analysed just over 2,000 deaths in that study period and said the deaths are consistent across population of areas. The study shows that mortality has not reduced 2009-2016 despite advances in medical care. Said when compared to the general population for the age bracket 16-24 they would expect to see two deaths but in epilepsy they found ten. Said those aged 16-54 are two to six times more likely to die compared to someone who has not been diagnosed with epilepsy. Overall mortality is not reducing, and people are dying young.

Said for the 16-54 age bracket there were 579 deaths. Out of those 54% had been admitted to hospital, over 90% were on AED and 60% were from Scotland's most deprived areas.

Outlined some of the main causes of these deaths and said that Sudden Unexpected Death in Epilepsy (SUDEP) was the highest cause, respiratory problems second, circulatory diseases (cardiac arrests), mental behavioural disorders which were largely alcohol related and drowning. Found that people with epilepsy are generally dying of different causes compared to general populations.

Said they found that nearly 80% of deaths in their study were avoidable. Went on to discuss case studies that cannot be documented in the minutes due to confidentiality. Highlighted the need for rapid access clinics for people with stable epilepsy who suddenly experience seizures as these are the people that are likely to die. Highlighted the problem of mental health and that 36% of the cohort had indicators of depression compared to 11% of the general population.

Thanked Dr Susan Duncan and Dr Richard Chin and the donors for their support of the study.

Dr Susan Duncan then outlined the need for services for people with chronic disease. Stated that waiting list targets has created long waiting times for people with a chronic condition. Wants an urgent clinic and drop in clinic to be developed. Said there needs to be an enhanced mental health provision, with a mental health screening programme implemented to prevent suicide. Said that third sector education important. Discussed the pharmacist's role in making sure people have the right doses and type of medication. Highlighted the possible benefits of creating a tissue bank to analyse genetic causes of deaths.

4. Dr Alastair Allan MSP thanked Dr Susan Duncan and Dr Gashirai Mbizvo for their informative presentations and opened the meeting to questions and comments:

Brian Rocks – West Dumbartonshire Council – Highlighted an instance where he was admitted for surgery which was then cancelled due to the lack of clarity regarding his medication, said there was confusion with what his GP prescribed him and hospital records.

Dr Susan Duncan – Highlighted her own experience of surgery with her epilepsy. Said she took her drugs with her and wrote her doses down. Said the third sector has a role to play to outline what exactly you need to bring with you in cases like these.

Anissa Tonberg, Epilepsy Scotland – Highlighted work from Parkinson's UK about promoting the importance of people receiving their medication in any setting – thinks this will be a good thing to develop for epilepsy.

Alastair Allan MSP – Highlighted his own experience of having epilepsy and said he cannot remember the last time he spoke to a medical professional about his condition or prescription. Said there is no proactive system to remind people to come in for their review.

Dr Susan Duncan – Said the Quality Outcomes Framework (QOF) used to make sure that GPs called people in for their reviews, but said this has now been done away with. Said it is the 30% of people who do not respond to drugs who are most at risk of premature death. Said these are the cohort that needs close monitoring compared to people with long term well controlled epilepsy. Highlighted that there is one Motor Neurone nurse per 25 patients, compared to two epilepsy specialist nurses per 4000 patients in Lothian. Said a new recall system should be developed to bring back this regular phase of reviews.

Michael McCulloch, Observer – Highlighted issues of getting information to hospital staff. Said he created a box for his daughter with all of her medications and prescriptions, said this has helped significantly when she has to go to hospital.

Anissa Tonberg, Epilepsy Scotland – Asked about mental health screening and the feasibility of rolling out the Lothian scheme which was piloted in paediatric epilepsy care. Asked if this was the type of mental health screening that Dr Susan Duncan would like to see.

Dr Susan Duncan – Said it would be some kind of screening model. Said adult services have traditionally not been well funded for neuropsychiatry and psychology and would like to see a screening model put in place.

Alastair Allan MSP – Highlighted the danger for people with epilepsy switching brands of medication and how it resulted in a death within the study. Asked what steps the Scottish Government can take to avoid this situation during Brexit.

Dr Susan Duncan – Said in the first instance generic substitution must be resisted. If generic substitution comes about then it is vital that the milligrams taken are correct. Said any changes in someone's condition must be highlighted to neurologists.

Dr Gashirai Mbizvo – Highlighted instances in asthma where brands are prescribed, not the molecule. Wondered if this would be made available to GPs for people with epilepsy as pharmacies are then bound to provide that specific brand.

Kenneth Gibson MSP – Said this is an important point to reinforce and that even small changes in medication can have a significant impact on someone's condition.

Chris Jeans, SUDEP Action – Thanked Dr Duncan and Dr Mbizvo for the study. Highlighted that she lost her son to SUDEP and this type of research is important.

Lorraine McKenzie, parent – Found the study very interesting and encouraged by people willing to carry out these type of studies. Noted that other conditions receive more attention and called on the Scottish Government to carry out a campaign to try and help reduce avoidable deaths.

Pat Graham, PAMIS – Asked about whether there is a category for learning disability within the study.

Dr Gashirai Mbizvo – Said it had been difficult to capture this data as that particular disability may not have been captured on the death certificate. Said if he looked on the primary care data, he should be able to find some information.

Kenneth Gibson MSP – asked why death in epilepsy seems to be occurring so young and declines significantly as someone gets older.

Dr Gashirai Mbizvo – Said he is not entirely sure why. Theorised that since the background data of mortality when someone gets older is so large, it cancels out the instances. Whereas death in young people is generally much lower which is why the instances are significantly higher.

Dr Susan Duncan – Said she believes that if someone develops epilepsy when they are older it is a different type of epilepsy and they respond very well to medication. Said this is a phenomenon that should be researched better in the future.

Rona Johnson, Epilepsy Scotland – Asked what needs to be done to establish a prospective database on epilepsy deaths.

Dr Susan Duncan – Said a lot of work has to be done. Said it should start off in a small concept way in one of the health boards. Said collecting the deaths would not be hard as the death certification process in Scotland is so good. Noted that collecting data is time consuming and they must be sure about the quality of the input data. Hoped to develop a database like this in the next couple of years.

Anissa Tonberg, Epilepsy Scotland – Asked for opinions on the link between deaths and deprivation and if there is wider health inequality work that this can be linked into.

Kenneth Gibson MSP – Said that the Scottish Government are very aware that death is linked to deprivation. Noted that this difference is experienced in other areas too. Said they are trying to tackle inequality in every which way it can.

Alastair Allan MSP – Noted that some of this is caused by health but argued that there are several other contributing factors to inequality as well.

5. Alastair Allan thanked Dr Susan Duncan and Dr Gashirai Mbizvo again for their engaging presentation. Asked members if there was any other parliamentary work that they wanted to be highlighted.

The Deputy Convenor stated that:

- The next CPG on epilepsy will be held in 22nd June and the subject will be learning disability.

He thanked all for their attendance and closed the meeting.