Cross-Party Group on Epilepsy

30th September 2021

Minute

Present

MSPs

Alasdair Allan MSP
Carol Mochan MSP
Collette Stevenson MSP
Jeremy Balfour MSP

Invited guests

Professor Tom McMillan

Non-MSP Group Members

Rona Johnson, Epilepsy Scotland
Anna Telfer, Epilepsy Scotland
Pauline Stansfield, Epilepsy Scotland
Chris Jeans, SUDEP Action Scotland
Jude Kilbee, Bial Pharma
Peter Dale, Epilepsy Connections
Jennifer Irvine, NHS Lanarkshire
Dr Susan Duncan
John Thomson, Eisai Ltd
Derek Robertson, NHS Lothian
Eleonora Saturmo, NHS Fife
Elaine Collard, NHS Highland
Shirley Maxwell, Epilepsy Connections
Mary Keenan, Epilepsy Connections
Andrea McKenna, Salvesen Mindroom Centre
Paul Gillon, Veriton Pharma
Jen Mutch, NHS Lothian
Pamela Martis, NHS Lothian

Apologies

Lorraine MacKenzie
Celia Brand, NHS Lothian
Jay Shetty, NHS Lothian
John Toland, NHS Fife

Kirsten Watson, GCHC
Lesslie Young, Epilepsy Scotland
Norma Crawford, Quarriers
Jo Campbell, NHS Grampian
Jean Barclay
Sylvia Lawrie
Helen MacDonald, Lanarkshire Epilepsy
Andrena Hughes

Agenda item 1. Convenor Alasdair Allan MSP welcomed attendees and commenced AGM with election of office bearers.

Rona Johnson introduced Alasdair Allan MSP standing for role of Convenor.
- Proposer Anna Telfer, Seconder Shirley Maxwell

Alasdair Allan introduced David Torrance MSP and Jeremy Balfour MSP as Deputy Co-Convenors
- Proposer Rona Johnson, Seconder Shirley Maxwell

Alasdair Allan asked if the group members were happy that Epilepsy Scotland continues to provide the Group Secretariat on behalf of Epilepsy Consortium Scotland.
- Proposer Shirley Maxwell, Seconder Chris Jeans

Alasdair Allan thanked members for the continued work to support the CPG.

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

Minutes of previous CPG on Epilepsy were approved.
- Proposer Rona Johnson, seconder Anna Telfer

Agenda item 2. Alasdair Allan MSP gave an update since the last meeting in February:

- The second round of funding for the Neurological Framework is now complete, with 22 projects funded across a variety of neurological conditions. It is likely the third round of funding will open Autumn/ Winter this year.
- The Patient Safety Commissioner consultation is now closed and we are expecting the consultation analysis to be published within the next couple of months.
- Following recommendations made in the Adult Social Care Review, the Scottish Government is currently consulting on the proposal for a National Care Service for Scotland. The consultation closes 2nd November, and we encourage people to submit their views.
- The Neurological Alliance of Scotland launched a survey about the use of virtual (phone and video) appointments for people with neurological conditions. The results from this are available on the Neurological Alliance of Scotland's website,

they have also been shared with the Scottish Government to inform guidance on virtual appointments.

Agenda item 3. Alasdair Allan welcomed Professor Tom McMillian to present research on Women with Brain Injury in Prison.

Professor Tom McMillan, Institute of Health and Wellbeing at the University of Glasgow

I will talk about the context of brain injury and the criminal justice system and background to the research programme.

In the world rankings of people incarcerated, Scotland is mid ranking, with about 136 per 100k in prison – about 8,000 inmates. The costs are high, to victims and families but also with a financial cost of custody per person about £40k per year. The reconviction rate of women is high, with 23% of women going back to custody within a year of leaving.

There was a steady rate of women in prison in Scotland over the last 10 years. In 2010 the United Nations mandated human rights for women in prisons, emphasising re-diversionary sentences. Despite this, the number of women in prisons worldwide hasn't gone down.

There are many concerns about the imprisonment of women. They have multi-morbid health problems, including mental health and drug dependency. History of abuse and risk of self-injury is very high. Health care which is provided by the NHS is not equivalent to care in the community. Damage to families from disruption of parental role and high rates of recidivism. Head injury isn't included in this list and the question is whether it should be considered. International studies found that 50-60% of prisoners have a history of head injury but studies in Scotland suggest 80%.

Why is head injury important in prisoners? Head injury causes cognitive problems: difficulties with concentration, planning, organisation, memory, and problem solving. It has an effect on personality and behaviour: it can affect impulsivity, irritability, egocentricity, poorer self-control and judgement. You can see how someone who is impaired in these ways could be at more risk of offending and of reoffending and not learning from the past. Also be more likely to be caught if they are offending.

How did this initiative start in Scotland? A report was requested by the Cabinet Secretary for Justice in 2015. The report came with a number of recommendations to develop a system within the criminal justice system which would help manage and help people with head injury. The particular thing that got interest was to determine the prevalence of disability in prisoners from head injury including further

investigation of head injury in women prisoners. The resulting study on head injury and multi-morbidity in women in prison in Scotland was published in Lancet Psychiatry in June 2021. Aims of programme were to create services within the Criminal Justice System that will alert professionals to the occurrence of head injury in prisoners, to triage prisoners including via training of staff and to provide support and intervention that is part of health care systems for other conditions (rather than having a separate system). In prisons, the plan would be to have a simple question about head injury history within the routine NHS assessment.

Head injury in women prisoners: We know there are multiple health problems common in women in prisons. Prevalence of head injury in women in prison is high and women in prison with brain injury is relatively neglected by research. Only about 5% of prisoners are women so it is difficult to get sufficient numbers for studies. What hasn't been discovered in the past is if head injury has persisting disabling effects in these women. Can disability in these women be explained by other factors (physical or mental health problems for example) and are women in prison with head injury more prone to violent offending?

At any time there are about 425 women in Scottish Prisons (about 5% of prison population). We interviewed ¼ of them. We were interested in the outcomes cognitive function, disability and offending and wanted to look at predictors – they looked at history of significant head injury, substance misuse, trauma and chronic physical health problems. They also looked at current predictors of physical health, PTSD, anxiety and depression. The sample was demographically representative of the female prison population in Scotland, so findings could be generalised. The group were two thirds from high deprivation areas, with high levels of disruption in schooling and with additional support needs.

Health

- Two thirds reported a chronic physical health condition. 92% reported mental health problems, 95% had a history of abuse, 70% anxiety and/or depression, 16% personality disorder. None had only one mental health condition. 83% had history of problematic drug or alcohol use.
- Looking at disability from any cause, the rate was 80%.
- The study wasn't about epilepsy in particular but they did ask about epilepsy. 17% had been diagnosed with epilepsy and there was no difference in prevalence between significant head injury and no head injury group, but the numbers are very small to detect.

Head injury prevalence

- 78% of women had significant head injury. Moderate-severe head injury in about 30%. Significant head injury with loss of consciousness before the age of 15 was 69%.
- Multiple repeat significant head injury was very common – 67% of the whole sample and 84% of those with significant head injury.

- The most common cause was domestic abuse (89%). The median duration of repeat head injury was 7 years. We know that repeated head injury within a short period of time is likely to have an accumulative affect, causing brain damage.

Head injury and outcomes

- In terms of cognitive function, there was no group difference between significant head injury and no significant head injury.
- Significant head injury associated disability – moderate to severe disability attributed to significant head injury was found in 40% of the women in the significant head injury group – not all of the women tended to be disabled by the significant head injury (which is often assumed in the literature).
- People were 5x more likely to have current PTSD, 9x more likely to have history of alcohol or drug abuse and 3x more likely to have a history of abuse if they were disabled by head injury.

Trauma and significant head injury

- High proportions of these women have suffered abuse with lengthy duration and often being knocked on the head. This highlights the complexity of the health morbidity in these women.
- These women have experienced: Child physical abuse 41%; Child sexual abuse 56%; Domestic abuse 81%; Adult sexual abuse 47%; Adult assault by stranger 44%
- Abuse as adult or child in 99% of significant head injury group, and 83% in no significant head injury groups. Repeat abuse as adult or child is more common in significant head injury group.
- Women in prison with significant head injury have high levels of comorbidity with mental health problems including anxiety and PTSD.
- A significant proportion of women in prison are disabled by significant head injury.
- What about head injury and offending? There was a three fold risk of significant head injury in violent offenders and women in prison had spent about 3x longer in prison

To round off we go back to the United Nations handbook on women and imprisonment. They recommend alternatives to custodial sentences for women and prevention of reoffending. This stems from the recognition of vulnerabilities of women offenders in relation to mental health needs. Our research argues that a history of significant head injury needs to be added to the list of vulnerabilities given the high prevalence of occurrence, disability and association with violent offending. There is a need for routine assessment of head injury and for it to become part of formulation for mental health and criminal justice interventions. There is also a need for community organisations working with female victims of abuse or ex-offenders to be aware of the association with significant head injury and its significance. There is also a need for training of professionals and support workers re the above.

Agenda item 4. Alasdair Allan MSP thanked Professor Tom McMillan for the presentation and invited questions.

Alasdair Allan MSP: Given these statistics and what you have said about prevalence in prisons of regular head injuries, you mentioned at the beginning that women weren't receiving equivalent care and also said there was a need for routine assessment. Can you say a little more about why you feel there is an inequality in care these women are receiving and about what we can do better to triage and identify and offer more help to these women?

Professor Tom McMillan: When we asked women about care they were receiving, for example in relation to the trauma most of them had, not one of them said they had support for that. There has been in the last few years some emphasis on developing mental health services in prisons, so I think that is developing and improving, but it is limited. One of the worries I have is that in discovering these problems there isn't really a very satisfactory pathway for them to get support from the NHS in the prisons because the service itself is too small. The second thing is there is a need to triage a range of different interventions – these could range from education of prisoners (i.e., not knowing the effect of head injury) to guided self-help. One of the big issues for people in prison is stress and anxiety and a way of trying to help that would be through guided self-help, where the prisoner themselves are involved in a supervised way. However, in a pilot study about this they found the prison staff felt overburdened with work, and although initially keen to get involved with guided self-help, they weren't able to maintain that.

The first issue is about developing the health service in prisons in Scotland (it is the same across the UK). The second issue is when people are leaving prison and being sure they are given adequate support and they are linked up to organisations that are able to take on board complex health needs, particularly in women. I think sometimes the problem is that in various points in the criminal justice system, some of these issues are discovered but are not passed from one part of the service to another. There are attempts at the moment to have a more unified database system but it doesn't exist at the moment.

Collette Stevenson MSP: I sit on the Criminal Justice Committee and I used to be an Independent Prison Monitor at Shotts so I was really keen to hear this. Sitting on the Criminal Justice Committee, we recently visited HMP Edinburgh where there is an estate with women in it. One of the things which stood out for me was that women could access, from an NHS point of view, psychologist services but they couldn't access occupational health. I don't know if that is a rule from within that prison estate but we as the Criminal Justice Committee are keen to explore because based on the evidence you have provided today, I suppose services like that would go hand in hand in offering them support, especially with a head injury.

Professor Tom McMillan: I think you're right, I think that what would be more ideal would be a unified assessment that could be passed on and with recommendations and guidance on management and areas of risk, which incorporate these health issues. Some of these women clearly are at high risk of further significant head injury, going back to the same environment and the same things happening again, and increasing the likelihood of them returning to prison.

Rona Johnson: How are the Scottish Government implementing the findings of this research because there is clearly a massive issue in prisons in Scotland in the way in which women are being treated.

Professor Tom McMillan: I think there have been one or two aspects which have started to be implemented. The NHS assessment when people are in reception, the software for that is being revised, which will include a question on head injury. There is a need also for staff training so they are trying to encourage development of training modules and things which could be incorporated in standard training and also available if somebody was working with someone with a history of head injury. NHS Education Scotland are quite keen to develop this but are looking for funding so the Scottish Government would need to have interest in developing these packages. At the moment where they have got to with that is that I am doing a webinar which will then be uploaded on the web and used a stopgap.

Agenda item 5.

Alasdair Allan MSP asked if there were opportunities for parliamentary working from today's meeting and suggested the CPG write (via the Convenor) to the Cabinet Secretary for Health and Social Care about some of the issues talked about today. To ask what action is being taken on the back of this research, but also specifically about some of the areas mentioned (i.e., around occupational health and the identification of women with head injury on a more routine basis).

Agenda item 6.

Alasdair Allan MSP thanked group. The next meeting will take place Thursday 25th November,1-2pm where we will welcome the Scottish Government who will provide an update on the Patient Safety Commissioner consultation and how the Cumberlege Review recommendations are being implemented in Scotland. The Secretariat will be in touch in due course with further details.

Epilepsy Consortium Scotland (ECS) Secretariat Rona Johnson: 48 Govan Road, Glasgow G51 1JL
Tel: 0141 427 4911
Email: rjohnson@epilepsyscotland.org.uk