

Note of Meeting – Cross- Party Group on Epilepsy, 24 January 2019

In Attendance:

Alasdair Allan MSP	Lorraine Mackenzie - Observer
Mary Antcsak – Epilepsy Connection People’s Forum	Pam Martis – NHS Lothian
Jean Barclay – Observer	Ann Maxwell OBE – Muir Maxwell Trust
Jeremy Balfour MSP	Shirley Maxwell – Epilepsy Connections
Helen Bongard – MSP staff	Tracey Millar – Epilepsy Scotland
Celia Brand – Paediatric Epilepsy Nurse RHSC	Clare Mills – Public Affairs Manager, Headway
Andrew Boyle – NHS Fife	Hillary Mounfield - Quarriers
Frances Brown – Epilepsy Scotland	Steven McAvoy - Enable
John Bruce – Epilepsy Connection People’s Forum	Barbara McCulloch - Observer
	Michael McCulloch - Observer
Sharon Cairney – Epilepsy Connections	Eilidh McIvor – Citizen’s Advice Scotland
Steven Connelly – Epilepsy Connections	
Magnus Corkish	Debra McKean – Epilepsy Connections
Norma Crawford - Quarriers	Linda Radcliffe - ESN
Heather Davies – Epilepsy Connections	Derek Robertson – NHS Lothian
Leigh Fell – Carita Neuro Solutions	Brian Rocks – West Dunbartonshire Epilepsy Support Group
Kenneth Gibson MSP	Ewen Roy – Epilepsy Connections
	Jane Stuart – NHS Lothian
Ann Greenall – ESN NHS Fife	Lori-Anne Telford - Quarriers
Alan Guild – Observer	Jim Thompson – Epilepsy Connections
Andrena Hughes - Observer	Kerry Thompson – Paediatric Epilepsy Nurse, Melrose
Raymond Hussain - WDSG	John Thomson – Eisai Ltd
Chris Jeans – SUDEP	Anissa Tonberg – Epilepsy Scotland
Rona Johnson – Epilepsy Scotland	Darren Wilkinson – ESN, Forth Valley
Barbara Jones – Epilepsy Connections	Lesslie Young – Epilepsy Scotland
Marie Kelly – RHSC	
Yvonne Leavy – ESN, NHS Lothian	
Rachel Lloyd – ESN	
Richard Lyle MSP	
Helen Macdonald – Lanarkshire Epilepsy	

Apologies:

Marilyn Bryce - Observer	Patricia Graham - Observer
Jo Campbell – NHS Grampian	Alan Guild – Observer
Elaine Collard – NHS Highlands	
Ian Forbes – UCB Pharma	
Jennifer Irvine – NHS Lanarkshire	
Dr Ailsa McLellan – NHS Lothian	
Gail Patrick - Observer	
Dr Aline Russell - Quarriers	
Dr Jay Shetty – NHS Lothian	
John Thomson – NHS Lanarkshire	

1. Convener Kenneth Gibson MSP welcomed attendees to today's Meeting and gave update since last Septembers meeting.
2. The Scottish Government is developing a Pregnancy and Neurology Working Group in which there will be a stream dedicated to epilepsy and pregnancy and there will be more news on this in coming months.
 - The British Paediatric Neurology Association have published guidance on the use of cannabis-based products for medicinal use in children and young people with epilepsy. In practice this appears currently restricted to children with Dravet or Lennox Gastaut Syndrome. It is thought the drug Epidiolex will be licenced later this year.
 - Since the last Cross Party Group, the Minister for Public Health talked about Scotland's first Neurological Action Plan this has now been published and is still open for consultation.
 - The draft General Standards for Neurological Care and Support from Healthcare Improvement Scotland have been published and received over 800 consultation responses which are currently being analysed.
 - Kenneth Gibson MSP introduced Frances Brown, Welfare Rights Officer for Epilepsy Scotland who gave an overview about her work in helping people with epilepsy access Personal Independence Payments and some of the issues they face under the current system run by the DWP:
3. The Scottish Government provided the funding for Epilepsy Scotland to employ a Welfare Rights Officer for one year to assist people with a diagnosis of epilepsy and their families/carers. Due to the demands and the success of the service, the post has been extended for a further year and Epilepsy Scotland has recently employed a further Welfare Rights Officer.
 - From the initial set up of the service in September 2017 to November 2018 Epilepsy Scotland have assisted 120 clients and around 615 people contacted the charity and over £700,000 confirmed Client Financial Gains.
 - A number of clients have been assisted with a number of different issues – advice and information, identifying entitlement to benefits and assistance throughout the claims process for Personal Independence Payment and Employment Support Allowance, this included assistance to challenge decisions and submitting Mandatory Reconsideration and Appeals requests. Representation was also provided at Tribunal Hearings along with undertaking complex casework, taking two cases to Upper Tribunal on behalf of clients, both these cases were successful.
 - A quality service is provided which is tailored to each client which means they can do office visits and home visits, this depends on what is best for each particular client. Epilepsy Scotland have travelled all over Dundee, Glenrothes, Falkirk, Edinburgh and down as far as Ayrshire.
 - A statement from a particular client was read out at his request:.
 - “At the age of 43 I had my first seizure then after a good while I was diagnosed with epilepsy, my life had been turned totally upside down and my mental health has also been affected. As a result of my epilepsy I lost both my jobs and was forced to give up (football) coaching as I took tonic clonic seizures in front of the boys.
 - Epilepsy Scotland helped me and gave me tremendous support, this is the first time I felt someone was showing any concern for my wellbeing especially in effect of the benefit system. I would not have managed to survive the ordeal of the queues endless form filling that was required to be filled in and appointments to attend without their support. This information and help should be readily available to people to be able to avoid the time and stress it takes to get benefits.”
 - Problems occur with Personal Independence Payments because there are descriptors that people need to meet and with a condition such as epilepsy that may be fluctuating then people do not automatically tick all the tick boxes and unless someone delves deeper and looks at the person in and around then no assessment is going to catch for that person.

- What has happened with a lot of people is that migration has started earlier than their DLA awards were going to be finish so the money that they thought they were going to have for another few years end, it gets taken off because they don't meet the points that criteria to get an award of PIP. There is also a link between epilepsy, Learning Disabilities and mental health problems.
- There were 6,330 decisions made on claims for people with epilepsy migrating from DLA to PIP and out of that figure 3,380 people did not receive any award on their transfer at the initial assessment stage, thankfully 1,120 people appealed the decision unfortunately the remainder did not appeal. Out of the 1,120 who appealed 870 were subsequently awarded PIP after their Tribunal. This means that over 53% of people living with epilepsy who previously had DLA were denied PIP, almost double the national average for all health conditions which is 27%, 33% of people who appealed the decision not to award them the PIP and of that 33% 77% were successful.
- There are some links between epilepsy, learning disabilities and mental health. About 1 in 3 people (32%) who have a mild to moderate learning disability as their main condition also are likely to have a diagnosis of epilepsy. Around 1 in 5 people (20%) with epilepsy as their main condition also have a learning disability. 33% of people with epilepsy report depression and up to 49% have anxiety disorders. Suicide rates in epilepsy are commonly 3-6 times higher than the general population, this is within 6 months of their diagnosis.
- The current benefit process does not seem to fully understand epilepsy as a condition. They only take into account the tonic clonic seizures and not the complex partial seizures or absences. They also do not consider the memory problems, low concentration, side effects of medication or the need for emergency medication. This lack of understanding means that people with epilepsy are not meeting the 50% rule – but in reality, they are. This was a question that was asked in Parliament to the Works and Pensions Minister in July 2018.
- One study found that out of 700 people with epilepsy 545 reported problems with memory. Mental Health is also under estimated in the assessment process, 33% of people with epilepsy report depression and up to 49% have anxiety disorders. As a result of two High Court rulings the DWP has changed its PIP assessment process in two areas – Safety and Supervision when carrying out activities (risk) and overwhelming psychological distress and journeys.
- Eleven benefits have been devolved under the new Social Security (Scotland) Bill including Personal Independence Payment, Disability Living Allowance and Attendance Allowance. The good thing is that the Bill enshrines in law the principle of treating benefits claimants fairly, with dignity and respect and will eventually end the compulsory assessments that all claimants must go through.
- Epilepsy Scotland welcomes the opportunity to be part of shaping and improving the future of the Social Security Scotland benefits system for our clients, their families and carers.

4. The Convener thanked Frances for her presentation and invited questions.

Michael McCullough, Observer – Thanked Frances for her comprehensive description of the problems and complexity when applying for PIP and the effect it has on people of all descriptions.

Alastair Allan MSP – Asked about how the new Social Security system can protect people from suicide who have just been diagnosed with epilepsy.

Frances Brown, Epilepsy Scotland – Said the system must review the condition as a whole. Seizures are just one part of the condition; most people say the memory and anxiety/depression cause the most problems for them. It is about understanding all effects of the condition and ensuring that person is treated with fairness and dignity.

Hilary Mounfield, Scottish Epilepsy Centre – Asked what training assessors get in epilepsy.

Frances Brown, Epilepsy Scotland – Advised that from personal experience, through attending assessments with clients, said not very much. Said there doesn't seem to be a wide understanding on how the condition affects people.

5. The Convener introduced Cabinet Secretary for Social Security and Older People, Shirley-Anne Somerville MSP, to speak about the up and coming changes in Social Security and positive impacts this will hopefully have for people with epilepsy.

Shirley-Anne Somerville MSP – Thanked members for inviting her to the CPG.

Said the Scottish Government are trying to do things very differently which is summed up in the Social Security Act because it enshrines Social Security as a human right, meaning there should be no stigma to claiming it.

Said this is a joint project with the DWP, so the timetable is not entirely up to the Scottish Government. Noted 15% of benefits are being devolved to Scotland, with the rest in Westminster meaning that a strong link remains with the DWP.

The Social Security Agency headquarters have been set up in Dundee, with the first payments being made last year; two payments of the Carers allowance supplement totalling around £33.3 million. The new system is being designed through experience panels. This means the system is designed with people, not for them, and ensures that it works for everyone all the time.

Notes the concern, gained through her work as a constituency MSP, that people have about the disability benefits system and that the current system is broken. Said that the government are particularly focussed on PIP and it will be designed an exceptionally different way. Said mental health and fluctuating conditions are examples where the current system does not work. The current culture of needing to prove that you are not lying will change under the new system.

The form to apply for benefits needs to change, this will be designed by people with lived experience of the current system. Said the government needs to remove repetition and the complexity of forms. Also said that the burden to provide extra information needs to be taken away from the individual so that it is the agency that has the responsibility for gathering evidence. Also stressed the importance to exhaust existing information first before asking claimants to repeat themselves or ask for new information.

Said she recognises that face to face assessments have become default under the new system and this is extremely traumatic for people and it affects people's mental and physical health. Under the new system they will move away from face to face assessments in general, there needs to be more flexibility in the new system with the option of home assessments where appropriate.

When face to face assessments have to happen, they must be carried out in a way so that it works for the individual and they do not feel like they are on trial.

Audio recordings will be introduced to stop the inconsistencies between what happens in the assessment room and what is documented on the form. People can opt out of this however, this default practice should help restore trust in the system.

This work should help reduce the number of appeals as decisions will be correct in the first instance.

Said dignity, fairness and respect is at the heart of the new system. Understands that it is going to be difficult to restore trust in people but hopes that all the changes she outlined will help begin to build that trust up again.

Barbara McCulloch – thanked the Cabinet Secretary for providing clarity and told the group her daughter's experience of transitioning from DLA to PIP and how taking away her independence affected her physical and mental health.

Anne Maxwell, Muir Maxwell Trust – said that there are failures in the current system as every piece of information provided by the claimant is not considered and this affects point scoring. She said her son's Blue Badge renewal is currently in doubt as the PIP decision maker could not see all the documents supplied by her and awarded him less mobility points.

Shirley-Anne Somerville MSP – noted that this was a good example of how the current system is broken and the Scottish Government are determined to ensure that these errors do not happen under the new system. There will never be a point where claimants have given out something that they have deemed as important and someone else has decided it's not.

Anne Maxwell, Muir Maxwell Trust – Said they didn't deem it unimportant they just couldn't physically access it.

Shirley-Anne Somerville MSP – Said somebody took the decision to not include it and that is wrong.

Andrena Hughes, Observer – said that she works for the DWP and at the end of the assessment clients should be asked if they have anything else they want to add and this should ensure that information is not lost. She also noted that the DWP staff are simply following rules set and do not have a say.

Frances Brown, Epilepsy Scotland – Said she has gone to assessments with clients and advised they do not normally get asked that question at the end. She disagrees that the DWP staff are only following the process because she believes if they followed the process and applied the law and descriptors correctly then people would get their points would not have to go to appeal.

Andrena Hughes – Said that is why it is essential that people appeal.

Shirley-Anne Somerville MSP – Notes that the staff that currently work for the DWP are good and many now work in the Social Security Agency. Said that legislation, guidance, training and culture of staff all need to be right to ensure that people have the best opportunity for a fair assessment and get the benefits they are entitled to.

Eilidh McIvor, Citizen's Advice Scotland – asks how the emphasis on providing medical evidence will be taken away from the claimant.

Claire Mills, Headway – asks for assurance that the Third Sector training materials that are provided will be used and that there will be an evidence trial for that.

Shirley Maxwell, Epilepsy Connections – asks how the new system will change in terms of constantly filling out forms, waiting for results and then going for reassessment. Notes that people are constantly worrying.

Shirley-Anne Somerville MSP – said they are still working on the details on how to claim existing information, they are looking seriously at gathering evidence from other sources like family and friends. Advises that they are currently consulting with the NHS to make sure the new process is sensible and will work in practice.

Emphasises the importance of ensuring that the training of staff is right. Notes that under the new system applicants are tested on their dignity, fairness and respect aptitudes. Once passing this, staff go through a full induction which includes training from the Third Sector. Advises that the Agency already works with a number of sub sector partners to deliver training – encourages other training providers to make the same link with the Social Security Scotland Agency.

Said that this constant wheel that people are on in regard to reviews, fighting the system just has to stop. The Scottish Government are seriously looking at review times and why re-assessments are taking place when someone's condition has not changed. Advised they need to get away from the constant worry that people have.

Brian Rocks, West Dumbartonshire Epilepsy Support Group – asks about the effectiveness of the points-based system to assess fluctuating conditions.

Steven McAvoy, Enable – Suggests that the new Scottish system should adopt a failsafe piece of legislation, similar to Employment Support Allowance (ESA), where if a claimant does not have enough points but they still cannot live independently, then this legislation should still grant them the benefit, despite not qualifying through the points system.

John Nesbie – highlighted an instance with his partner where the report and what happened in the assessment did not match up.

Kenneth Gibson MSP – said that the Cabinet Secretary mentioned earlier that assessments under the new system will be recorded.

Carol McNeil, Epilepsy Connections – Said that the current descriptors in the PIP application are unfair to people with epilepsy. Advised they only measure how many seizures whereas in reality there is a risk of seizure all the time and they can cause very serious injuries.

Shirley-Anne Sommerville MSP – Said that this situation is not fair and that is why the Scottish Government are instilling a different culture and ethos surrounding PIP. Notes that they are working hard on getting the assessment right and fair for all. Encourages members to take part in the consultation about disability benefit to make sure they get regulation and guidance right.

Said that the point raised around the exemption and what happens in ESA is something which she would encourage people to feed into what they are doing with the new system, said her officials will have noted the suggestions made.

Notes concern about the lack of protection under the current system for people with fluctuating conditions. Reiterates the need to have a system that is fair, and people can trust. Invites people to the experience panels, notes that those who have lived experience of the system will ensure they get it right and so that everyone can be proud of the new system in Scotland.

Kenneth Gibson MSP – Thanked the Cabinet Secretary and Frances Brown for their excellent presentations.

5. The Convenor reminded attendees that if members of the group have any further questions or issues they wish to raise in relation to the meeting, they can send them to Anissa Tonberg the CPG Secretariat who will pass them on to the Cabinet Secretary.
6. The Convener reminded members that the next CPG meeting will be on Thursday 28 March 2019 and it will be on Death and epilepsy and a new study about identifying trends and potentially preventable deaths.