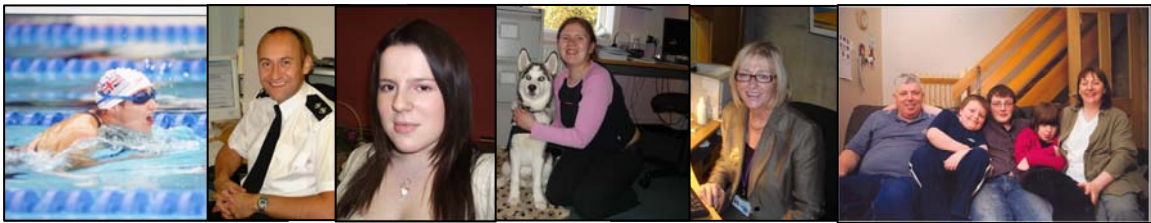


My active life



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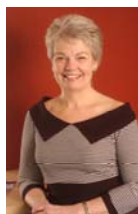
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Maggi McEleny

“Epilepsy Scotland has helped me over the years to stay positive through the bad times when my epilepsy was poorly controlled and also through the better times when it has been controlled by medication.

“Epilepsy Scotland has also helped me get my story across to many others through their publications about my successful Paralympics swimming career despite having epilepsy. Hopefully through this I have been able to inspire others that dreams can be achieved despite having epilepsy!”

From being paralysed to winning a gold medal at the Sydney Olympics, Maggi McEleny has seen all sides of epilepsy. The 42-year-old was diagnosed when she was 13 and the seizures led to her being paralysed from the chest down. By 18, she was using a wheelchair. A few years later she was introduced to the Port Glasgow Otter Club to swim and build up strength in her arms in the pool.

Maggi never meant to try the sport competitively, but her coach saw her potential. And she never looked back as she plunged through 15 years of international competition. She attended four Paralympics Games, winning a total of 15 medals. At the Sydney Paralympics in 2000, she was given the honour of being voted by her fellow athletes to carry Britain's flag for the opening ceremony. For this proud moment she was pushed in her wheelchair by her coach.

"There's no sport you can't do," she says. "Swimming is the most dangerous sport if you take a seizure. That's why I have a spotter, someone that watches out for me while I swim. If they saw any change in my stroke, they would alert the staff.

"There have been times at major international events that I have taken a seizure even an hour before a race, and the team doctor has wanted me to pull out. But my coach was able to say, 'give her 15 minutes and she will break the world record'. I've done it - 30 minutes after I came out of a seizure and I broke the world record!

"It's just getting that through to people. There's still a stigma attached to the condition. I wish we could break down those barriers faster."

Maggi retired two years ago from competitive swimming and now trains other people with disability to swim. Despite a medical setback, Maggi has become the first person in the world to swim with a tracheotomy. She says: "I told my consultant I had to get back into the water. I can only do it once a week, but at least it keeps my sanity.

"Don't let your epilepsy put you off doing anything. For any sport, go for it - make enquiries because there's ways around everything."



Cathy Peattie, MSP

“I was in denial when epilepsy was first diagnosed in April 2008. It was weeks before I could tell anybody other than my close family. I do have a busy lifestyle as an MSP. I cover a fairly wide constituency with big towns and many villages. I do lots of surgeries and home visits. I now have a notebook for conversations I’m having with constituents while we travel on buses. I’m not aware that I’m unable to do anything I used to do, except drive.

“I didn’t feel that I could say very much initially – but I can now! Thanks to Epilepsy Scotland, my family know a lot more about the condition, and they are incredibly supportive. I can get on with my life and I just happen to have epilepsy.”

Cathy Peattie has been a Member of the Scottish Parliament (MSP) since 1999. Here she tells us how it started and how being recently diagnosed with epilepsy has affected her life.

“My ‘funny feelings’ started three years ago and got worse. Last autumn, I was chairing the Cross Party Group for Asthma. I welcomed people but then stopped speaking. I had this funny feeling that they were having the same funny feeling that I have! Maybe a minute or so passed. Then I carried on with the discussion as if nothing had happened. This lapse bothered me a bit. I take thyroid medication and thought maybe the dose was too high because I’d lost a bit of weight.”

The second time this happened Cathy hosted International Womens' Day 2008 in the Parliament before 150 guests. Again she stammered and stopped, this time for around three minutes. Cathy was aware of people looking at her then picked up again and started to speak. She was quite shaken so her GP referred her to a neurologist and a week later she had tests. When the consultant confirmed the diagnosis of epilepsy, she was stunned. Ironically, that same afternoon, the Parliament had a debate on epilepsy.

“Since the diagnosis, so many people have spoken to me and said ‘someone in my family had this issue.’ Some expect me to have a seizure in front of them! But the majority of people I talk to will say ‘I know someone with epilepsy’ or they are surprised and ask me what it is.”

“I started my medication and it was really awful the first day or so. But since the medication has built up, I’ve been fine.”

As Cathy is the only one who drives in her family she was worried how she would be able to do her work without being able to drive. “First I used buses. One member of staff takes me to home visits. Another MSP gives me a lift home on Thursday nights. I was told the Scottish Parliament has a disability allowance which helps to pay for a driver for my car. Actually, I am managing much better than I thought I would.”

Cathy says she was impressed with the care she had from the health service. She found both the consultant and epilepsy specialist nurse very helpful. They spent time explaining what she should and shouldn’t be doing. “For example, I enjoy swimming so I can do this if someone is with me.”

“My family were worried but they are incredibly supportive. My daughters said I had to raise awareness so that other people would be more understanding. If the public is not aware of people with epilepsy, or not aware of what it is, they always think the worst of everything.

“I can get on with my life and I just happen to have epilepsy. But there are times when I really need to say to people ‘can you give me a lift?’ and explain why. I’ll try and tell them there are various levels with epilepsy and this is how it affects me. Some folk then say absolutely nothing or talk about the weather. I’m thinking ‘did you hear what I said?’ Others are quite interested and want to know how I am. I didn’t feel that I could say very much initially - but I can now!”



Ross Bennet

“I am always keen to raise awareness of epilepsy both in the Police Force and with the public. A few years ago, Fife Constabulary won Epilepsy Scotland's Employer of the Year award. We put our positive support for staff into practice.

“One of the many ways I share my experiences of epilepsy is by giving talks - including some to GPs, student doctors and nurses and at fundraising dinners. I have also helped raise issues with the Scottish Executive.

“I enjoy keeping fit and ran in this year's Glasgow half marathon for the Fife Epilepsy Network raising £1,000. I also play golf, squash and study karate. I have a wife and two young children and my epilepsy doesn't stop us from being a very active family.

“Since my seizures started, I have gained an MBA and Post Graduate Diploma. As a recent Epilepsy Scotland board member, I can be directly involved in their important work. As more people understand epilepsy, public attitudes will mature and any social stigma will disappear. I am extremely proud to be involved with Epilepsy Scotland. They have helped give me and my family the confidence to be who I am and live life to the full.”

Ross, aged 37, was a Detective Constable for Fife Constabulary when he had his first nocturnal seizure in 1997. He gave up driving immediately and realised he would likely be transferred to another job. What surprised him was the concern shown by his employers. Ross remarked: "I don't know how other Force Areas deal with such cases but I was given all the support I could possibly wish for."

Successive line managers and colleagues treated him as a valued officer. There is a definite culture of support at all levels. Fife Police won Epilepsy Scotland's Employer of the Year award in 2006 because it assists employees to reach their potential and to learn, mature and progress within the organisation without unfair discrimination and bias.

Ross remarked: "When I took a seizure and couldn't use my car for a year, I was advised that a driver would take me to meetings. While I was changing medication, I was allowed to work from home. This support is not unique but exemplifies how Human Resources and Occupational Health deal with this situation maturely. The practices are simple but matter significantly to someone with epilepsy."

He remarked: "A colleague had a seizure four years ago and was fearful for his job. His concerns were listened to and acknowledged. He was moved to a station near his home and worked hours favourable to his circumstances. This approach was helpful and he has since been promoted. He is really grateful for the Force's support. Other public organisations could easily replicate these simple practices."

Ross is now a Chief Inspector with 18 years service on the Force. He was able to drive again for a while but then had more seizures. Each time he has to wait 12 months before he can drive again.

He is keen to raise awareness of epilepsy both within his Police Force and with the public. Ross is a board member and he fundraises for Epilepsy Scotland. He also assists Fife Epilepsy Network with information events.



Jane Williams

“Being able to volunteer with Epilepsy Scotland has, in a way, helped me deal with my epilepsy. From making speeches to politicians in the Scottish Parliament to doing the photocopying and the shredding in their office, Epilepsy Scotland has helped me turn my diagnosis into something positive.”

Teenager Jane Williams is a student at Strathclyde University. She was twelve when she had her first seizure. She was diagnosed with juvenile myoclonic epilepsy. Her form of epilepsy is very predictable. She gets some warning before she has a seizure. They normally happen when she’s just woken up or when she’s very tired.

Taking medication caused Jane to put on a lot of weight so she changed to other anti-epileptic drugs. They don’t control her seizures so well but she feels better about herself.

At school, her teachers knew very little about this condition. Jane said: “If school teachers knew more about epilepsy it would make a big difference. I lacked confidence and I remember one high school teacher shouting at me when I tried to explain I felt unwell and had to leave the classroom. Overnight trips were out as interrupted sleep may trigger a seizure. Another teacher was over-protective. My experience has shown me that not many of them know enough about epilepsy.”

Jane is passionate about raising awareness and she wants to end the stigma and fear associated with this condition. She commented: “Most classmates accept that epilepsy is something you have, not something you are.”

She agreed to be a guest speaker for Epilepsy Scotland at party political conference fringe meetings. Jane remarked: "The MSPs who were there couldn't believe how little teachers knew about epilepsy. Since then a councillor from my area has been in touch with me about talking to some of the local teachers about my experiences."

Jane has also spoken to the press about what it means to live with epilepsy. She said: "Epilepsy doesn't prevent me from doing anything but I couldn't continue with figure skating because the practice sessions were so early in the morning. I had a few seizures on the ice because I was really tired, so I had to give it up."

But the loss of ice-skating led Jane to writing. She hopes to be a publisher and eventually a full-time writer. She commented: "I would not let epilepsy stop me. You have epilepsy but you're no different than anyone else."



Dave Crozier

"Epilepsy Scotland has given me a chance to speak up about how I deal with having epilepsy in my everyday life. They have enabled me to speak to different groups of people including GPs, nurses and politicians. This has given me an opportunity to put a realistic perspective on where improvements in services can be made.

"The staff at Epilepsy Scotland are always willing to listen. They are keen to allow me to put across my point of view. I think I am now seen as someone who is willing to talk openly. Without these opportunities, and knowing that people are taking in what I'm saying, I may not be as confident as I am today."

Dave, aged 22, currently lives in Glasgow and has completed a degree in Community Education at Strathclyde University. He was seven years old when he had his first seizure. Doctors found a brain tumour and surgery to remove it was successful.

However, two years later Dave had another seizure and epilepsy was diagnosed. He has tried many different drugs to control both absence and tonic-clonic seizures. Although his seizures are more controlled now, nothing has helped him gain total control of the seizures yet.

Dave's family was very supportive of him but for obvious reasons they have also been slightly over-protective. His parents would worry about him taking seizures when he was out of the house. He said: "Basically, if I could have given them a timetable of where I would be, they would have gladly taken it and highlighted it!"

Fortunately his seizures were not very serious during primary school so there wasn't much of a concern. At secondary school, things were more difficult though. He remarked: "I felt my class teachers didn't know how to help me, except to send me home if I took a seizure. I relied on my friends to watch out for me. One time I was on the pavement after a seizure and passers-by accused me of being drunk!"

Dave is keen to raise awareness of epilepsy. He has spoken about how he lives with his condition during GP training days run by NHS Education Scotland. He has also conducted research for his degree course into public attitudes towards epilepsy. Earlier this year, his research findings appeared in 'The Scotsman'. The key message was that more informed attitudes towards epilepsy are still needed.



Doreen Jobson

“Epilepsy Scotland is a most important organisation for those who have epilepsy, and also their families and friends. When first diagnosed with epilepsy many years ago, I was anxious to gain as much information about the condition as I could. I contacted Epilepsy Scotland who were a great source of information and support, and continue to be today.

“I fully support the aims of Epilepsy Scotland to fight the discrimination and stigma often experienced by people with epilepsy. Epilepsy continues to be misunderstood by many people. However, I am pleased to say Epilepsy Scotland is always working to 'educate' the public. I am always happy to support Epilepsy Scotland in their valuable work.”

Doreen Jobson has just turned 70. Her three adult children and six grandchildren keep her busy. Doreen is also an active member of her local church teaching in Sunday School and helping with other activities. “I always thought that once you are retired you would struggle to fill your days with things to do. But that is not my experience. There is never enough time to do all the things I would like to do!”

Her first seizure happened when she was around 50. “For a couple of years before that seizure I'd had some strange feelings, a bit like déjà vu. I mentioned these to my doctor and was eventually referred to hospital for some tests. They didn't show up anything and I was told that it probably was the menopause or 'nerves'.”

That was until she had a bad tonic-clonic seizure during her sleep. She had bitten her tongue and was unconscious. Her husband, fearing the worst when he saw the blood from her mouth, called an ambulance. Doreen said: "I woke up in hospital and thought that I may have had a heart attack." After a second bad seizure, again during her sleep, she was referred to a consultant neurologist who told her she had epilepsy.

"I was totally shocked. As a medical secretary, I obviously had heard of epilepsy. But I thought epilepsy meant people suddenly falling down and twitching violently. My husband pointed out that this more or less had happened to me only I was doing this in my sleep in bed!

"I thought epilepsy was something you developed as a child. I didn't realise you could suddenly develop it in later life. If I am honest, I was horrified, and even a little ashamed. Epilepsy back then had a lot more stigma. When I telephoned my mother from hospital and told her, she was shocked and reacted quite badly. She felt the need to point out that no-one in our family ever had epilepsy. Partly because of her reaction I didn't tell many people for a long time." Doreen stresses that her husband and children however have always supported her.

Apart from the shock and shame she felt about her epilepsy diagnosis, Doreen's life was further turned upside down when she started having seizures while awake. This meant that she had to give up her driving licence. "It had a huge impact on my independence," she said.

After her diagnosis, Doreen contacted Epilepsy Scotland. "I got all the literature as the doctors at that time didn't really explain that much about epilepsy. I was lucky I could also talk to the doctors at my work, and they were very supportive. Had I not worked as a medical secretary I think I probably would have lost my job. Generally I kept the epilepsy all to myself and didn't talk to anyone about it."

Doreen is a member of her Church's Guild. They have guest speakers at their meetings on different subjects. In 2001 someone invited Epilepsy Scotland to come along. "After their talk I stood up and told everyone I had epilepsy. People were surprised and concerned to hear this. But since then, they've all been very supportive. In a way, Epilepsy Scotland helped me to 'come out' and be open about my epilepsy!"

After her diagnosis, Doreen started treatment with anti-epileptic medication. "I must have tried every drug that was available, in every possible combination over the next 20 years. Some of them worked better than others but my seizures were still frequent. I had practically resigned myself to the fact that I would have seizures for the rest of my life."

However, a couple of years ago, her neurologist decided to add a new drug, Keppra, to the Epanutin she was already taking. "I was told that there may be unwanted side effects but I was willing to risk this. My seizures improved from four or more a month to only three seizures in a year. I was obviously delighted with this progress. My neurologist decided that there was still room for improvement and suggested that another drug, Pregabalin, be added to the others. This was in May 2007.

"It has had a dramatic effect, it stopped my seizures. I am so grateful to all the doctors and neurologists over the years and to my very supportive GP. I am also indebted to all those involved in epilepsy research. In April 2008, having been seizure free for one year, I applied to have my driving licence re-instated. This was agreed and I am now in possession of a full driving licence."

Doreen is keen to share her experience with others. She says: "From my history of epilepsy, I can relate to others with the condition. Epileptic seizures are very unpleasant, and at times it is difficult to cope with the condition. Sadly, as yet, there is no cure for epilepsy. But as my story demonstrates, even after many years of having seizures, there is indeed hope. Never give up hoping."



Marilyn

“Volunteering for Epilepsy Scotland has enabled me to contribute to wider awareness of epilepsy in Scotland. I value most the face-to-face interaction at Epilepsy Scotland's information events.

“I am glad to be part of a supportive network shaping positive attitudes throughout the world for present and future generations. Changing the world starts with one person so each individual input such as mine is valuable. Our work at Epilepsy Scotland brings a more enlightened, inclusive and confident future for people living with epilepsy here in Scotland.”

A few years ago Marilyn needed advice. She wanted to talk to someone and called Epilepsy Scotland's Helpline. She found the information very useful. She always remembered the difference it made to her life: “More than anything I wanted to talk to an understanding person about what was happening.”

After retraining as a medical secretary and with a law degree behind her, Marilyn saw the “Epilepsy News” magazine appeal for office volunteers. She was in between jobs. She looked at our website, then called our User Involvement Officer and offered to become a volunteer.

Since then, Marilyn has helped Epilepsy Scotland in many ways. She has come along to information events to talk to people about their epilepsy. She has proof-read and commented on a number of draft publications. She has written some information for our website. She is keen to raise awareness of epilepsy and ‘normalise’ the condition. Her contribution to Epilepsy Scotland's work has been greatly appreciated.



David Dundas

“Epilepsy Scotland gave me the opportunity to raise awareness about my employment situation. Thanks to them my story appeared in the Firefighters magazine. Sharing what happened has enabled a number of other firefighters who developed epilepsy to keep their jobs. The fire service later made a DVD about disability which included epilepsy. It was aimed at managers and I was able to explain how they could help.

“I feel it’s important to tell people about epilepsy so they understand more about it. I didn’t know much about the condition until it happened to me. That’s why I’m willing to share my story with the press and talk on local radio. My partner Liz and I have two young children so we lead a pretty active life. Our family is very grateful to Epilepsy Scotland for the advice and support they gave us. We believe if everyone knows about epilepsy, no-one needs to be scared of it.”

Glasgow firefighter David Dundas thought his career was over when he developed epilepsy. When he was eventually diagnosed, the Fire Brigade doctor recommended retirement from the service on medical grounds.

David and his union official challenged this decision. They contacted Epilepsy Scotland and were put in touch with a neurologist who could argue his case from a medical point of view.

Initially, Dave was transferred to desk duties. When he got his driving licence back after a year without further seizures, he wanted to return to his old job. He and his union argued that if DVLA (Driving Vehicle Licencing Authority) allowed him to drive again after 12 months being seizure free, so should his employer. In the end the Fire Brigade doctor agreed to this.

David agrees that the lack of knowledge about epilepsy was the drawback. He stressed that other firemen were not threatened with losing their jobs because they were taking medication to deal with chronic conditions like diabetes, angina and depression. David says that his case certainly changed the Fire Brigade doctor's attitude towards fire fighters with epilepsy. "He meant to retire me but changed his mind when he found out more about epilepsy from my neurologist and when he learned that other Scottish Brigades had fire fighters with epilepsy."

David's situation and subsequent publicity has already helped other firefighters. "Maybe in the future people who have epilepsy will start applying to be a fire fighter which they never would have done before. However, we have won the argument for anyone who takes epilepsy while they are in the Brigade to stay in their post.

"My employer, which is now called Strathclyde Fire and Rescue, recently held an equality and diversity day. I was glad to see so many staff there and plenty of them were taking away Epilepsy Scotland's information. I'm glad that we are doing our bit so that even more people know what epilepsy is and how to help."



David Cherry with family

"I fully support all the work Epilepsy Scotland does. They are there for our family when we need any advice or support." (David's mum Shona)

Ever since he was little, David Cherry has been doing two things - acting, and caring for his family. Both became second nature to David as he leads a normal life, going to Woodfarm High School in East Renfrewshire and growing up like any teenager. But the 16-year-old has a dad with epilepsy and diabetes, a sister with epilepsy and severe learning difficulties and a brother with autism and learning difficulties. He shares caring responsibilities for them with his mum, Shona.

Sister Ruth, 15, can't feed herself and it's one of the main tasks David helps with, as well as lifting her and trying to communicate with her.

"Ruth can't speak at all," says David. "It's very hard for her and she can't use sign language. I've become reasonably good at gauging what she wants."

Care for any individual is as unique as the person themselves. David's dad, Iain, 44, rarely has seizures, but can't drive and isn't left alone with Ruth or Stuart in case a seizure leaves him disorientated and unable to look after them. Although Ruth has fewer seizures than she once did, her physical needs are largely met by her family. Caring for brother Stuart can be challenging. "With Stuart's learning difficulties, it's 24 hours a day," says David. "Epilepsy is just a worry at the back of your mind, but learning difficulties can be more tiring."

David says caring for his family has given him a unique and positive outlook on life. "If I was looking in at my life, I might see it as dumping a lot on me. But when it has come up, I have not known anything different. I'm used to it.

"The best thing is to look at the benefits of what you have got and what you're going to know before everyone else. It gives you a better insight than your peers. There's a lot worse off than me, and a lot younger carers who do more than me. In a way caring has given me a sense of maturity, though I hide it well!"

One of the best ways David has coped with his extra efforts has been Young Carers from the Princess Royal Trust. He says any young carer should seek out the local group in their area because it can give those breaks and time to relax with peers. Now David, who has been acting since he was three, aspires to study film, TV and theatre at Glasgow University. And his family are right behind him - just like he has been for them.



Helen Butler

“Epilepsy Scotland has allowed me to interact with people both socially and professionally. I have been a volunteer for almost two years doing some work on their intranet and administering their social networking sites. This has enabled me to add more work experience to my CV.

“Being allowed to bring my seizure response dog to the office has given me the opportunity to train him in an office based environment. I am always keen to raise awareness and have appeared in a number of newspapers and a television programme.”

Helen Butler is only 27 but has already achieved a lot in life. She is married to Craig and runs her own business designing websites. Helen was nine when she had her first seizure. Her epilepsy appears to be drug resistant, and she is now being assessed for brain surgery to help control her seizures.

When you see Helen you also get to meet Shadow. He attracts attention not just because he is a gorgeous Siberian husky but mainly because he wears a “service dog” jacket. This royal blue jacket puts Shadow into “work mode”. Helen explains why having this dog boosts her confidence and makes her a bit more independent, especially when Craig works away from home.

“My mother-in-law works in a doctor’s surgery and she heard about seizure dogs. I found a charity in Sheffield called Support Dogs, and I also did a lot of internet research on training seizure dogs. We wanted to get a pet anyway so I thought ‘why not combine the two?’ In the end, I decided to do the obedience training myself. He’s named after “me and my shadow, he follows me everywhere...”

Shadow has developed an instinct for knowing when Helen is about to have a seizure. She takes a warning aura first and her dog stays with her during and after a seizure. Helen explains: "One time I took him for a walk. I had a seizure, fell over and was totally out of it. I had no idea where I was. My nose was all bruised and there were cuts all over my face. Shadow took me all the way home, leading me to the back door of our house.

"I don't know how Shadow knows when my seizure starts but he stops playing and immediately comes and sits with me. When I fall over, he licks my face and hands and stays there until I come round. I wouldn't say it has made a difference to the number of seizures I've had. But I definitely recover more quickly afterwards because I am more relaxed with Shadow there to look after me."

Helen has always been open about her epilepsy and is keen to raise awareness wherever she goes. She's encountered her fair share of prejudice and negative reactions but tries not to let this get the better of her. She points out that looking for work can be a problem. "When agencies or employers hear about my epilepsy and that I have a seizure dog, they say they need to check but often don't phone back." This is one of the reasons why Helen is self employed.

What's next for Helen? "I would like to do more awareness raising to change people's attitudes and bring epilepsy out of the shadows. I'm now thinking of writing a regular column for my local newspaper."



Aileen McGinty

“I have found Epilepsy Scotland to be particularly helpful. When I have had problems with services locally they have helped by being able to tell me what happens in other areas. This has allowed me to negotiate with healthcare staff in my area.

I have enjoyed being involved in many different ways with Epilepsy Scotland over the last ten years. It has allowed me the opportunity to use my experience to help others and to help reduce the stigma that is often found around epilepsy.”

Aileen McGinty, from Inverness, was diagnosed with epilepsy on her 17th birthday. Close friends wanted to know more about her seizures but nobody in Aileen's own family talked about it.

She studied and achieved two degrees, in art and law. She also experienced discrimination in finding employment because she had epilepsy. In between studying, she worked as a swimming instructor. Her employer knew about her condition but had no real worries because Aileen's epilepsy was well controlled, and other life guards knew what to do if she took a seizure.

When Aileen moved to the north of Scotland she could not get work as a poolside swimming teacher because her new GP maintained she was not safe to be in water more than waist deep.

Not holding a driving licence was also an employment issue. Potential employers wanted to know why Aileen didn't have one - even when a driving licence was unnecessary for the advertised post.

Based on her interview experiences, Aileen's decision to disclose her epilepsy depended largely on whether she intended to accept a job offer. She worked for several years as a solicitor and later in the health service. When interviewed by the Health Board, Aileen did not mention epilepsy to panel members but told the human resources officer in a separate interview. "If only all employers had such a policy of encouraging people with disabilities," she said.

Aileen became a volunteer for Epilepsy Scotland because she thought public awareness of epilepsy was important. "People can see that I have a good job and an ordinary life. Epilepsy doesn't have to stop you from doing things." She also contributed to NHS Highland's working group which was planning to develop local epilepsy services.

Aileen gives talks about epilepsy, including one at her daughter's primary school. She has also written a short guide to epilepsy for school pupils. Now a music therapist, Aileen believes it is important that people are made aware of the condition.

"I raise awareness because it helps other people. I would want others to do it for me. The more people understand epilepsy, the more it is improving things."



Lesslie Young

“As a result of either a viral encephalitis or an epileptic encephalopathy my daughter acquired, what was for 12 years, a difficult to manage epilepsy and moderate learning difficulties.

“Her acute illness, prolonged hospitalisation and the results of that illness were devastating in many ways. The effects of her illness continue to be seen and felt in a wide variety of ways.

“We were well supported by professional staff, and because of our medical backgrounds we could source information easily during the acute phase. This made dealing with the impact of an epilepsy diagnosis and prognosis much easier.

“However, following discharge from hospital a very different picture emerged. Nothing prepared us for dealing with a variety of potentially stressful situations, including the degree of anxiety and stigma that is associated with epilepsy, sourcing information as my daughter grew up, multidisciplinary reviews, manoeuvring through the complexities of the health and education systems and how much (or little) in the way of support or care one receives from either depending on financial constraints within these agencies.

“During this time I was not aware of the work of Epilepsy Scotland. My introduction to this organisation came at a much later stage.

“Firstly, as a direct approach from me for information to help me deal with a particular challenge, which was readily provided. I then became involved professionally providing sessional training and I am now the Training Manager.

“From a mothers’ perspective I can say that some of the situations I’ve dealt with in the past would have been made easier had I had the support Epilepsy Scotland provides. From a professional stance I can see that as a stand alone agency or by working with other professionals the work that Epilepsy Scotland does can only help to make the lives of those with epilepsy easier.

“My daughter, the most important person in all of this, is enjoying good health at present. She has a great zest for life and enjoys horse riding, skiing and many other activities. She is progressing well and is benefiting from the work of Epilepsy Scotland directly and indirectly.

“It is our hope that by sharing our experience through Epilepsy Scotland, we can help others who find themselves in similar situations.”



Mary Nicol

“Epilepsy Scotland does a great job in helping to promote the fact that epilepsy is nothing to be frightened about and making people aware that it can affect folk in all walks of life and all levels of employment. Our relationship with Epilepsy Scotland has certainly helped us to raise awareness of the condition in this organisation. We are willing to do whatever we can to provide any support needed.

“On a personal level, Epilepsy Scotland has helped me to accept that I am not alone in having this condition. They have enabled me to participate in Scottish Parliament cross party groups and make contact with others at award ceremonies. As I progress (very quickly) towards retirement, I shall get involved in some voluntary work with Epilepsy Scotland to try to repay its support.”

Mary developed epilepsy at the age of 38. Her first seizure happened out of the blue. “It was quite a shock. I was chairing an interview panel and I started to babble and rock back and forward in my seat. Fortunately, the candidate had left the room.” Mary had tests but was not put on medication. Then following a couple of seizures nine years later, she finally was diagnosed with epilepsy.

“My seizures settled down for a while after being on different drugs, but then started to come back again. At the time I was working for the Scottish Parliament. Their health scheme paid for me to see a consultant privately. I was really pleased with my employer for doing this, as it brought forward an appointment with a neurologist by several months.”

“Mary is now Deputy Head of Personnel at the parliament. Everyone in her office has been trained in epilepsy and how to recognise it. The parliament also organised a general awareness session for all staff, which was well attended. A refresher course is planned.

Mary explains that every new member of staff in the Personnel office is told with her permission that she has epilepsy. They also get a one-to-one on what to do if she has a seizure. This is just one of the many ways the parliament supports Mary.

“When colleagues from other departments come into my office for the first time, they quite often comment on how dark it is. This gives me a chance to explain about my epilepsy. I tell them that very bright light can make my epilepsy worse. I have my own room with natural light. And I am allowed to have uplighters instead of fluorescent lighting.

“Because I am in a room on my own, people check on me regularly. The last person to leave the office makes sure we go together. If I do want to work in the office on my own I have to report to the security staff and let them know where I am. They check on me periodically. I also have a personal emergency evacuation plan. If the fire alarm is activated, a designated person will make sure that I get out of the building.

After a seizure, Mary says she feels very confused for days afterwards. She has a bad headache and usually has to go to bed. “If it happens in the office, I am sent home in a taxi with someone to accompany me, and they will sit with me until I feel comfortable to be left on my own.”

Her epilepsy has affected her confidence quite a bit. She says this seems to be getting worse as she gets older. She stresses that there is nothing else her employer could do to support her at work. “I am already allowed to work reduced hours. I can work from home. I am allowed to come in late if I wake up in the morning and don’t feel too great.”

One of the other side effects of her seizures is that it affects Mary’s short term memory. “Everyone here including senior managers knows about this. They make allowances for it, and I don’t get criticised when I forget things.”

She is quick to point out that her experience at the Parliament has only ever been positive. “It hasn’t stood in the way of my promotion. I consciously tell everyone, including the senior management team and the directors. Even the Chief Executive knows I have epilepsy.

“I feel comfortable about disclosing this to colleagues. I have never been treated any differently from anyone else here who works in the Parliament.”