

Public Health Minister Shona Robison MSP
Speaking at the National Epilepsy Week Scottish Parliament Reception (2010)

Thanks very much Mary (Mulligan MSP) and can I welcome you all to the Scottish Parliament. Can I also praise Allana (Parker, Epilepsy Scotland) for organising tonight's event. It's good to see you all here and I hope you all have a really good and interesting evening.

I'm sorry this is, as Mary said, only a brief visit. I do have another engagement that I have to go on to but I did want to spend a little bit of time with you. My particular apologies to the young people who are going to tell us about their own experiences but I will get some feedback on these.

I know the main purpose of the event is to launch two children's booklets about epilepsy, one reflecting a child's own experience and the other from a parent's point of view. These kinds of first-hand accounts, I think, can't be beaten at all. I think they are so, so important in really helping us to understand people's concerns and the sorts of services and supports that they are looking for.

We often think that long term conditions only affect older people so it's good to be reminded that they affect children and young people too. Of all the long term conditions, epilepsy is the one that needs lots of information. That's probably because it's a complex condition and because the people who don't have it often get a hold of odd ideas about it. There is a sort of perception out there and some myths.

Many years ago it was a lot worse than it is now and terrible things were done to people who had epilepsy. There is still misunderstanding and fear around the condition and a lot of work has been done to overcome that, but I think it's fair to say that we still have a bit of a way to go. We need to make sure that everyone gets really good information about what it's like to live with the condition. That applies to doctors and nurses as well as children and their parents. I know this is something that Epilepsy Scotland does very well and I'm pleased that the Government has been able to give them a bit of money to help with that part of their work and some of it may have gone into these two booklets.

The other people who are really good at providing information and support are the people involved in the Scottish Paediatric Epilepsy Network. It's one of the things we expect any network to do, to make helpful information available to people when they need it. They also provide other kinds of support too, so that people feel that they are not having to cope on their own without any help from anyone else. I saw on the network's website that they have very good links to all the information that Epilepsy Action have put together about the sort of things that youngsters and their parents need to know about.

The other really important people in all of this are the Epilepsy Specialist Nurses, especially the ones for children and young people. I know that there have been concerns raised about protecting their time, and indeed, this was raised with me at the Cross Party Group on Epilepsy a couple of weeks ago and I promised I would look into the issue. I have taken this up with NHS boards and I will be getting back to the Cross Party Group once I have been able to check out the position more fully.

We are also aware of how important it is that young people make a good transition from child services to adult services. The network has developed a transition care process. It is essential that all teenagers who can do so are able to take part in discussions about their care and they are involved in that transition process. I think the network is also quite right to want to be able offer them the chance to be seen on their own if there are issues that they want to discuss privately.

We've now got clinical standards from NHS Quality Improvement Scotland. It's set out what all the elements of a good epilepsy service are. They are something that all boards are going to have to meet and that will be a tough challenge. They apply to people with epilepsy whatever their age may be, but we need to be clear that they should be used in a way that has maximum benefit to children and young people. We will be taking that forward with boards and monitoring how they implement those standards.

At the end of the day, this is an evening for celebrating what young people with epilepsy can achieve. It also shows how their passion and enthusiasm to take things forward will eventually bring about the changes needed for a fairer society. So enjoy the evening, and I'm sorry I can't be with you for the whole event but I'm sure it will be productive and I'll hear all about it. Thanks very much for the invitation.