
TX: 19.02.03 EPILEPSY CAMPAIGNERS “DISAPPOINTED” BY NEW GOVERNMENT ACTION PLAN TO REDUCE DEATHS

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ROBINSON
The Government has just produced its long awaited action plan to try to reduce the number of deaths from epilepsy. A thousand people die from epilepsy in the UK every year - that's more than from cot death and AIDS put together. Half of these deaths are sudden and unexplained, often young people are found to have died during seizures that happened while they were asleep. Last year the first national audit of epilepsy deaths concluded that many of those who died had received poor quality care.

Susan Allen's son Tim died suddenly at the age of 27.

SUSAN ALLEN

The family had absolutely no idea that anybody could die from epilepsy. So we just felt this tremendous sense of shock and grief and bewilderment - we couldn't understand how and why he had died. All the family had seen him just six days previously when he'd been best man at his older brother's wedding and he'd been the most relaxed and happy that I'd seen him for many weeks. So I really felt that he'd turned a corner in terms of his epilepsy.

I think we could have been told about the risks, especially as Tim had so many of the factors. We never were and I believe that only one per cent of relatives who've lost people through epilepsy have been warned that the condition can be fatal. I was astonished to discover that a very high risk factor for sudden death in epilepsy is having seizures in sleep. Tim had one seizure in the day, his very first seizure, after that he only ever had seizures in his sleep and I thought that made him safer - I thought he's not going to drown in his bath, he's not going to pour boiling water over himself when he's cooking, he's not going to fall over in the street and be knocked down by a car - at least he's in bed, he's safe. And after his death I found out that was the one factor that was more likely to have induced his death than any other and that was absolutely shattering information.

ROBINSON
Susan Allen. Epilepsy is a common condition and there are things that can be done to reduce the risk of death but, as we've just heard, few patients are even warned that it can be fatal. Simon Lees is epileptic but only found out about the risks when his brother died of the condition.

SIMON LEES
There are various steps that I take to reduce the risk of SUDEP, something that doctors do point out to their patients but unfortunately sometimes they don't explain the real reason why. Making sure that you have regular sleep, making sure that you don't drink too much alcohol, making sure, most important of all, that you take your medication on a regular basis. The communication has to be improved because nobody is warned about it initially when I feel that it should be spoken to the

patient about during the first few months of diagnosis, so at least they're aware that the condition can be fatal. Secondly, the time it takes to accurately diagnose the type of epilepsy a person has is very important. There is a massive amount of time that it takes between seeing your own GP and going for tests, such as scans, and then being referred to neurologists or epileptologists. The final point really is the difficulty, once diagnosis is achieved, it can take months, sometimes years, to find not only the right medication to suit an individual but also the correct levels which give the least side effects. Again the times between seeing consultants varies greatly, really there needs to be a better service to these people because, at the end of the day, we're talking about people's lives here.

ROBINSON
Simon Lees. The chief medical officer, Sir Liam Donaldson, drew up the epilepsy action plan and he joins us now. Sir Liam what's in it?

DONALDSON
Well the ball was started rolling on epilepsy when I produced an annual report last year where I highlighted my concerns about standards of care for people with epilepsy as one of the areas, the small number of areas, that I concentrated in the annual report. And following that I recommended that an action plan should be produced and the action plan has been produced. It covers a wide range of action - improving the NHS involvement in reviewing their present services for epilepsy and trying to improve them, we've tasked our modernisation agency specifically with taking action in that regard, setting standards of care for people with epilepsy which the National Institute for Clinical Excellence is doing, trying to improve the standard of medication and prescribing which we're doing through another initiative and also ensuring that we work closely with the charities - we've put £400,000 into the National Society for Epilepsy to get them to improve information and support for people with epilepsy and their families. So it's not enough but it's a very important start and we'll be building on this action over the next few years.

ROBINSON
You've pre-empted what was going to be my next question because it sounded to me, from what you were saying, like a lot of talking, a lot of consultation, a lot of lip service and yet the national audit of epilepsy deaths suggested that one third of those people who died had never even been referred to a specialist. Is there anything in the action plan which will create over time some more consultants in neurology?

DONALDSON
Well that's not the only answer and I think really, although you may call it lip service, by far the most important thing, when you're trying to improve a service, is to gain widespread commitment that something needs to be done and that's the first step. And I think epilepsy's a special case because it isn't just a case of attitudes within the health service and within the medical profession, it's the attitudes of society as a whole - epilepsy has been a condition which has created feelings of great fear and stigma in the past and people with epilepsy have been afraid, sometimes, to admit that they have this diagnosis. And we saw with the BBC drama recently about the problems with the Royal Family in the past and that particular Lost Prince, as he was called, now that's the first time that I've seen epilepsy seriously dramatised in a mass audience television programme. This is an important first step but we have to recognise that the disease needs to come out of the shadows, both publicly and professionally, if we're going to get that commitment to doing something about it.

ROBINSON
I'd like to bring Jane Hanna in here, she helped produce the audit of epilepsy deaths and she founded the charity Epilepsy Bereaved, we've just heard Sir Liam Donaldson say that more needs to be done, what else would you like to have seen in this action plan?

HANNA

Well I think we'd first like to say that we really do welcome the commitment, the personal commitment, that the chief medical officer has shown to actually raising the profile of epilepsy and SUDEP which has been so hidden from view. But we have to say that for our bereaved relatives many, many will be extremely disappointed because of a failure by the Government to invest in an action plan to reduce death. And what I mean by that is that the only investment in this plan that we can see that is ring fenced for epilepsy is the £400,000 to support an information network run by volunteers. And even in relation to that one of the big points in the audit was that risks were simply not being properly discussed and for that to happen there has to be an investment in communication by clinicians, it's not going to be sufficient to have leaflets given out by volunteers, these are complex issues and there needs to be a serious investment in training of professionals. There is a promise of 1.2 million for neurology - access to neurology - but it's not ring fenced and the Government isn't monitoring the spending of any of these funds.

ROBINSON
Jane Hanna from Epilepsy Bereaved I'm afraid we'll have to leave it there but I know it is a subject that we'll come back to, thanks too to the chief medical officer Sir Liam Donaldson.