

*From government to global campaign Mr John Bowis MEP*

Madam Chairman and ladies and gentlemen, 'l-ghodwa t-tajba', I'm sorry to say that those are the only Maltese words I will be using this morning. But teach me more, in fact Madam Chairman, if I remember rightly St. Paul was shipwrecked and I always thought that Malta was a country with many roads but no rivers. Last night on the way from the airport I discovered it's the other way round, plenty of rivers and no roads. So I perhaps the St. Paul suggestion is appropriate.

Well, ladies and gentlemen, everyone in this hall is here on a journey with epilepsy and although I am neither a doctor nor a specialist nor a family member or someone whose personally living with epilepsy. I want just one of those politicians who sometimes are part of the problem and sometimes part of the solution. What we learn and the way we learn is personal experience because believe it or not, politicians are also human beings. I take you back in a day in my youth when I was walking with a girl along a street in a Scottish city called Dundee and she suddenly fell at my feet. Wasn't the sort of thing I was used to, girls didn't usually fall at my feet. But on this occasion she was having an epileptic seizure and at that moment I felt all the frustrations and the anger and the incomprehension, and the fear that I was not understanding what was happening. Here was somebody that needed help and I did not know what to do. I didn't know if it was dangerous, I didn't know if I should have known and so I felt that shame. All the issues that come up and contribute to that awful word has been referred to as stigma.

Then many years later I was working in the city of London and I passed out, collapsed and went rigid and it was thought that I might have had a 'petit mal'. So I was taken to St. Bartholomew's Hospital and there they did all the tests and eventually they discovered it wasn't. But for that period I experienced what so many other people and so many of you would have experienced, the moment when you discover you have epilepsy. All your life passes in front of you not just your past life but your future life. What does it mean, what does it mean I can't do anything, does this mean I can't be able to drive again, does this mean my career is over. And again all those fears and worries that contribute to stigma I experienced. So again some years on when I found myself in government in the Department of Health, responsible for Neurology amongst other areas, I found myself in a position to do something about that experience.

When you go into government, I don't know if my friend and colleague here experience the same thing, you think you know it all and after a year you discover you don't and after two years you discover nobody else does either. That's when you actually can both enjoy being in government but also perhaps play a most useful part as a minister. You listen in government and you have all sorts of lobbyists coming to see you, maybe you talk about that in the workshop later, and some of them use the megaphone tactics of shouting at you, and doesn't really have an impact, except that you don't want to meet those people again. Some people embrace you so much that you're slightly embarrassed you probably give in, to get them out of the room. But some of them and one in particular came to see me, his name is Ted Reynolds, and he was an enthusiast. He was a

Neurologist dealing with epilepsy and he was an enthusiast who managed to spread his enthusiasm and it was infectious and that was one disease that I was very happy to take on board and to feel that enthusiasm for work in epilepsy. That led me finding out more it led me going and meeting many of the family NGO's, it led me even in going walking for epilepsy in charity walks. Indeed I have a certificate to prove not only that John Bowis walked for epilepsy but that Sandy Bowis walked for epilepsy. Sandy is not my son but my border terrier.

But getting to know people living with epilepsy getting to know the specialist getting to know what was possible getting to know the nurses that made a tremendous impact on me and later I had the opportunity to launch the Centre for Epilepsy at the Kings College in London and then the institute of Epileptology. Then it seemed to me that we needed to do something more in government. So I decided we should have a small initiative for epilepsy in our government and I tell if you are a minister and you have an idea you have to fight for it. All the other ministers have got ideas too and they want theirs to top the list. All the officials in the department and I'm sure my friend here will deny this that they don't want new initiatives because they have got quite enough on their plate for the time being. So my officials would say I don't think we can manage any more minister, there's no real money for this you know. I said no we are going to do it. Then one day they came into my office they said with glee on their face 'I'm terribly sorry minister, the Treasury has just told us we can't afford any new initiatives'. I went straight down to the House of Commons got a friendly colleague in parliament to put down a question in Parliament about when my initiative on epilepsy was going to be brought forward. That went through the officials said I suppose they've got to answer it now. I said yes they know its coming so they have got to announce it now and we announced it. Once it was announced you can't go back on it, and so we had an initiative for epilepsy.

On the basis of that we were able to do not tremendous amounts of money, a range of things we had a national epilepsy week. The theme of that appropriately for today was for youths with our chief medical officer, and the NGO's we launched this with a series of posters showing really what people could achieve if the rest of the world would let them. Sadly it was very difficult to persuade known personalities in politics the arts and whatever to come forward and say I live with epilepsy and look what I achieved. But we did find people who were sportsmen and barristers and so on who allowed their real faces to appear on posters and say look there's nothing wrong with epilepsy apart from your attitude to it. That was the message.

With a series of other conferences some on nursing some with NGO's sharing information, writing it up and decimating it, encouraging good practice, various projects with general practitioners getting them linked up to specialist services. Clinical audit projects and some grants for helplines to support families, grants for workshops on continuing care at home and work with the Royal College of General Practitioners to set up a fellowship and work on womens pack things like investigating information that carers need and want to make their lives more straight forward. All these things we were able to do but most important in a way we were able to send out whats called an executive letter to our health service. It went out accompanied by a specification for

services and that was drawn up by our epilepsy working party. That set out good practice and what we should have and it encouraged the establishment of specialist centers. It pushed for more specialist nurses and significantly it said in one point provision should be made in drug budgets for the higher cost of the newer anti epileptic drugs which can control seizures without the debilitating side effects of older drugs. Without that sort of direction people will always look for the cheapest option. Then it set out targets, reducing avoidable mortality insuring the 70% of patient seizure free, two years initial diagnosis and so forth and so on. In a range of areas including promotion, prevention and rehabilitation. That paid its part of pushing the agenda forward.

Then we moved on after a time my electors, as they do from time to time decided I needed more time with my family, or perhaps more time for working with epilepsy. So we changed government in Britain, and I was invited by the World Health Organisation to become involved with their two campaigns actually, one on the mental health and one on epilepsy out of the shadows. That of course led to the Heidelberg declaration and that led to the white paper that you have in front of you.

If you think why all this is necessary let me just spell out to you as I spelt out when we launched the white paper some of the reasons. You know in the British Museum we've got a 2000 BC Babilonian tablet that describes different types of epileptic seizures. It goes all that way back this diagnose. In 2000 AD we are seeing the same seizures and we are still looking for effective prevention ,treatment, cure and care. But it's really worse than that because says my good friend Regendra Pally, Indian Neurologist, now working as one of the editors of the British Medical Journal. The history of epilepsy can be summarised as 4000 years of ignorance, superstition and stigma, followed by 100 years of knowledge, superstition and stigma. That's the challenge that we have. Some 40 million people in our world live with epilepsy and some 32 million of them live with it with no treatment or drugs whatsoever and yet for comparatively small sums we could make such a difference. Some 80% of people could be living seizure free lives. In Europe we have 6 million people today with epilepsy and 15 million of us will do so at some point during our lifetime. In my country we have 420 thousand. The average GP has 10 to 15 people with active epilepsy on his or her list. The cost of Neurological disorders throughout Europe is rising. It is something over 300 billion euros per annum. That's the cost that comes from the doctors from the medication from the hospitals, nursing care the outpatient care and the family care. It doesn't take account of the lost earnings to people with epilepsy and their families and of course the lost revenues that would come from those earnings to exchequers.

Even in our age of accelerating advance in medical and social science in Europe, 2.5 million people in western Europe today are not treated appropriately to their condition. Children receive inadequate schooling. Jobs and promotion prospects are lost, people hide their condition, families are under pressure, people are dying prematurely three times more likely than other people of their age. The biggest issues are how we prevent accidents and suicides and sudden death and elderly people are unable to lead full and fulfilled lives. To add to these problems the pain the suffering the fear, the embarrassment of the condition, is added the burden of the most cruel and mindless of

these the stigma. Stigma is not just a feature of countries with their primitive traditions its no less a feature of our so called civilized western world. The cases shown by the WHO - - in Britain the law forbidding marriage to people with epilepsy was only finally repealed in 1970. A woman in the Netherlands in 1996 was whipped and put into isolation because her seizures were believed to be resulting from magic. In the US until 1956, 18 of the states sterilized people with epilepsy and until the 1970's people with epilepsy could legally be barred from restaurants, theatres and public buildings. In Germany and Italy today up to 20 % of people with epilepsy are unemployed and another 20 % retire early. Perhaps in my mind I think always of a congressman an American congressman Tony Coalo, who I met at the World's Epilepsy Congress in Dublin in 1998.

Here was a man who had wanted to join the priesthood and he had signed up to the Jesuit order in California. He had gone through all the process, all the education and at the end of it they said that's fine you passed with flying colours just go and have a medical and we're away. He had his medical and they diagnosed epilepsy. They said we are sorry you can't become a priest. He asked why and they said that under the canon law it is still deemed to be a condition possessed of devils.

That was America within our lifetime. His parents rejected him on the grounds that no son of mine could have this condition and so he was almost destroyed as a person. But he built himself up again and he became a congressman. On one occasion he found himself leading a delegation to the Vatican. He knew he was going to meet the Pope and its very scripted what you are allowed to say when you meet the Pope. When he met the Pope he said to himself if I don't say something I shall never live with myself. So he raised this point in the audience and the Pope responded to all the points that were made except that, didn't say a thing. He said oh dear I blotted my copybook now. But as he was going out, at the door the Pope reached and pulled him across and said I heard what you said. That's what it took a brave man to speak out. That's what we are faced with and yet we know that people like Julius Ceaser, Peter the Great, Dostoyevski, Byron are just a few of the many figures from history and the arts, who lived and achieved despite their epilepsy. It is very sad that too many people today who are achieving in their chosen fields keep quiet about their epilepsy because of their fear of reaction to it.

So stigma, we must fight, we must fight it as politicians as health professionals as journalists and as NGO's. We will achieve that if we can do what this white paper sets out to persuade us to do, which is to educate people more on the truth of epilepsy. Education means that the general public certainly it means patience, so that they know what they are living with and what the options are. It means family so that they can be more assured and they can work with others in that condition. It means teachers in schools, it means youth club organizers, it means everybody it means the media, it means everybody understanding the truth of epilepsy and then we can remove the dross, the stuff we don't need to have in our minds and concentrate on what is possible. We need to legislate where appropriate to remove obstacles to normal work, travel leisure and living. Of course we need resources and resources of course come from government, from health services, budgets for specialist clinics, nurses, drugs and research. But they also come of course directly and indirectly from the public. That is why it is so important we raise the profile of epilepsy with the public. If the public understands the need for greater

investment in epilepsy services they will put pressure on their elected representatives to insist that their government provide these. That is the indirect power of the public.

The direct power is through their own giving . If they are seen giving to the research and treatment and care and charities of a particular condition that in itself impresses government and health services decision makers. If the public is not giving it is probably not putting pressure on politicians and health services managers to provide. In my country, which I suspect is typical of Europe, we give 300 times more to cancer charities than we give to epilepsy. We give nearly ten times more to leprosy charities, a disease that is virtually unknown in Western Europe in our lifetime, than we do for epilepsy, where 15 million or more will be affected. When it comes to service provision not only just cancer receives so much more. But a condition like the one I live with, diabetes, has ten times more specialist centers, clinics and 20 times more specialist nurses. So that is the challenge we have, it is ignorance on all fronts and it is not just the public, it is often among those who are working in the health and social care for youths. Yet we know the cost of do not doing nothing, we know the vast increasing costs to our governments and tax payers. Yet we don't want vast sums to make a difference, to launch an initiative in each country of Europe it doesn't cost an enormous amount. If you think that in Europe we spend each year something like 5 billion pounds on cosmetics and we spend something like 11 billion euros on ice-cream. Then surely we can find a fraction of those sums to make a difference to those 15 million of our fellow citizens. Madam chairman I think that as a politicians we have to say that we will use every weapon at our disposal in our several parliaments to promote policy advance on epilepsy both collectively and individually. I think we are talking about 15 million people of our constituents and their families who face the prospect of a life lived with epilepsy. They deserve our support in ensuring that they are helped to cope with care and with treatment backed by medical knowledge and public understanding. So thus far as it is humanly possible their lives can both be free of seizures and unburdened by stigma. Prince John this program has been mentioned both by our chairman and the president, I think made a big impact in recent weeks. That's a lesson at the highest family of my country, where somebody had a condition, but the family just didn't understand couldn't cope with. Were frightened to some extent and so they put him away. The only person who looked after him was his brother, his little brother who became the Duke of Kent. Little George if you ever see the film, watch it, because very often it is children who have the real message for us. It is adults who are not listening children who at school, like the case we heard about earlier, will be interested in supporting their fellow student. They can teach us so much and my favourite quote of the moment is one that as politicians we are always faced with impossible decisions and impossible priorities, apparent choices which no clear easy is the answer, and the easy way sometimes is to move on and do something else and close the book on something like epilepsy and go off and deal perhaps with heart disease or something where the public understands and everything else seems to want action. That's not good enough. I always say to myself that quote ' that those who make difficult choices in life often make lots of mistakes but those who avoid difficult choices make the biggest mistake of all'. I say that in the spirit of Caritas, which I had the pleasure of meeting last time when I was here in Malta, who are responsible for so much of today's activities. But the word caritas as the President said that word from the faith hope and

charity, faith hope and love, caritas – love . That is what we are all here about, compassion compatio, suffering along side, understanding listening. If we understand we take action. If we take action then some 15 million people, currently within our Europe will benefit and countless millions in the future will think back to what we are about to do and they will say thank you because you listened and cared, you made the difference.