

## **DEALING WITH A MISDIAGNOSIS OF EPILEPSY: A CARER'S STORY**

It's very important that from a carer's point of view to explain express some of the problems that arise when someone has been misdiagnosed over very many years.

We had not been married for too long and that was 1959, when Maria would collapse on the floor. I found it very scary. This went on for 40 years until the early nineties when she was diagnosed with Temporal Lobe Epilepsy. I couldn't make sense out of that because no one would take any notice of low blood pressure. Yet, low blood pressure was evident every time Maria collapsed.

The probability of sudden collapse without warning makes a tremendous difference to one's life. We couldn't go out and socialise so our social life was curtailed completely. I would come home from work not knowing whether Maria would be on the floor or not. When I turned 60 I had to go part time at work. I didn't want to go out and work part time but it became essential to care for my wife; she is so dear to me!

Of course it was only when it we got in touch with a cardiologist that he said "I think it's your heart that's stopping". Eventually the problem was diagnosed with an implantable monitor, and then put right with a pacemaker. That was 4 years ago, and hopefully we can look forward to a few years of happiness and a normal life.

When they say how has your life changed – well, what is your normal life? No social life at all, and that's bad news. Now, our life is greatly improved – we're still very tired and still suffer from a bit of depression but that's improving greatly.