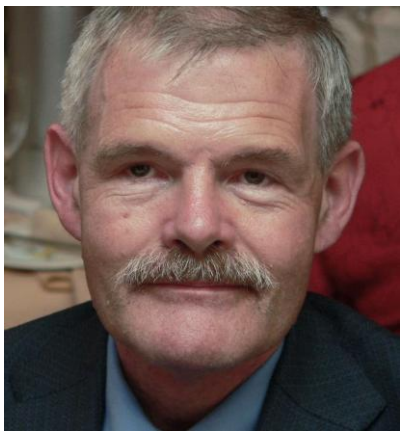
[*This story was read to participants at the Learning Institute on Health and Literacy: Constructing Curriculum for Health Care Providers by Jan Novitzky, Development Officer at National Institute of Adult and Continuing Education (NIACE) (UK). It was written by Stephen's sister, Ann Howe, who has given permission to share it in the hope that it might raise awareness among health care providers and others about the links between literacy and health and prevent tragedies similar to Stephen's*.]

Stephen's Story



My younger brother, Stephen, died suddenly and unexpectedly during May 2007, at the age of 53. The inquest returned a verdict of natural causes, a result of an epileptic seizure. That only tells part of the story.

Stephen had a number of difficulties. In addition to the epilepsy, which was diagnosed when he was two years old, he also had learning disabilities. Like many people with multiple challenges to face, he didn't have an easy life, but with the support of the family he made the best of things. He worked, latterly in sheltered employment, and he lived alone from choice, following mother's death in 2001.

In spite of all his difficulties, Stephen was in many ways an admirable man. He was hard working, honest, reliable and generous. At work he was popular, always cheerful and helpful to his workmates. His employment was necessarily low skilled, but it gave him a strong sense of self-worth, and he was proud of his money sense, saving regularly from his modest income.

Although he suffered grand mal seizures during his childhood and adolescence, as an adult his medication had kept him stable for over 25 years. Mother had trained him very well about the need to take his tablets, and we never had a moment's concern on that score. One of the elements of his behaviour was to act according to a routine; anything that affected his routine presented him with real difficulties. He took a long time to learn anything new.

His sudden death was caused by a change in his medication. Not in the obvious sense; as far as we know, the medical reasons for that change were sound. But the way the change was handled was to have fatal consequences.

You see, when Stephen attended his annual review with his GP, a number of literacy issues contributed to what was to be a tragic outcome. Even though the GP practice knew he had learning disabilities, no extra help was given to make sure he understood the changes. There was an assumption that telling him of the changes was sufficient; no doubt Stephen appeared to understand. He would have listened, but not have taken in all that he was told. The backup would have been the instructions on the pill containers, which he was unable to read. No one offered him information in a form that he could understand.

Stephen took 3 different tablets 3 times a day; the changed medication meant some were increased and some reduced. Anyone might have made a mistake in those circumstances; Stephen's problems made it almost impossible for him to cope. He needed reinforcement to make the necessary changes, and it had to be person to person, given his poor literacy. So, he under-dosed and he died.

There are a number of points at which Stephen's fate could have been averted. The Royal College of General Practitioners Curriculum Statement 14 *Care of People with Learning Disabilities* states that around 30% of those with Learning Disabilities also have epilepsy: that is approximately 60,000 people. The first curriculum statement in the above document is that GPs should:

> *Demonstrate an awareness that a significant minority of any practice population will include patients who have mild learning disabilities, who may need no particular special services, but who may have reading, writing and comprehension difficulties.*

In Stephen's case there was an awareness of Stephen's range of difficulties; but there needed to be a greater understanding of his problems with reading, writing and comprehension. There needed to be an awareness and understanding about just how difficult many routine tasks are for those with limited literacy and comprehension skills. Those engaged in the delivery of primary care services have a vital role in supporting those with difficulties such as those Stephen had to cope with. Those people deserve support in understanding the communication pitfalls, and in implementing strategies to address them with individuals. Some awareness-raising training can begin that process.

Nothing can change what happened to my brother, but my hope and that of my sister and brother, is that such a tragedy never happens again. Stephen was unable to read the instructions on pill containers. In this, and no doubt in other cases, literacy really is a matter of life and death.

Ann Howe