

IN MY VIEW

Nurses should become more involved in haemophilia research

Jenny Bryan

Brian O'Mahony, Chief Executive of the Irish Haemophilia Society and President of the European Haemophilia Consortium, tells Jenny Bryan about the special role that nurses play within the haemophilia community

What was your early experience of haemophilia nursing?

As someone with severe haemophilia B, my first experience of a comprehensive haemophilia care centre was in Dublin in the mid 1970s, and I've been involved with the Irish Haemophilia Society since the early 80s. In the early days, there was just a haematologist and a nurse and, from the beginning, it was the nurse who played a pivotal role not just in advising patients and families, but in coordinating, organising and delivering care.

In Ireland, one of these nurses was Margaret King, who encapsulated the importance of the haemophilia nurse with her common-sense advice and support for patients. After she retired, she joined the Irish Haemophilia Society and she became chief counselor and confidant. In those days, Irish men – like British men – didn't talk about their emotions and wouldn't normally speak to a counselor. But they'd talk to Margaret.

There were – and still are – a lot of Margarets and they perform a very special role within the haemophilia community.

What makes haemophilia nurses different from other nurses?

Haemophilia nurses build a special relationship with their patients because they are treating them week-in week-out, month after month, year after year. I'm not suggesting that nurses working in other



Brian O'Mahony represents the Irish Haemophilia Society on the statutory National Haemophilia Council and as Vice Chairman of the Tender Commission established by the Irish Government. He previously served as Chair of the Irish Haemophilia Society for 17 years and as President of the WFH for 10 years from 1994 to 2004

"Haemophilia nurses are well-placed to carry out surveys on local, regional national and international issues that can help to inform future best practice"

fields aren't dedicated to their patients, but they don't have the same level of continuing contact with their patients. Haemophilia nurses have developed a unique level of expertise, and many people with haemophilia prefer to talk to the nurse they know really well, than to a junior doctor. One of the attractions of the job is being able to really get to know the condition and the group of patients you are following. It's a long-term commitment.

As past-president of the World Federation of Hemophilia, what differences in

haemophilia nursing have you seen worldwide?

So much depends on the status of the nursing profession in a country. In South Africa, where they are highly regarded, nurses are superb at finding and diagnosing people with haemophilia, and they organise outreach services into neighbouring countries and regions, such as Botswana and Lesotho. In other parts of Africa, such as Zimbabwe and Zambia, nurses have very little involvement in decision making. In other countries, for example Vietnam, they play a more supportive role. Here in Ireland, haemophilia nurses have taken on a much bigger role in service development and national policy.

What developments in haemophilia nursing would you like to see in the future?

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