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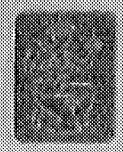

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Experts by Experience Column

The development of psychological support for the Wales Inherited Bleeding Disorder service

Lynne Kelly

I was a haemophilia carrier, my grandfather was a haemophiliac and I have three sons with haemophilia. Haemophilia describes a group of inherited bleeding disorders in which there is a missing or reduced clotting factor in the blood. It is a genetic condition, usually inherited, but one in three children are born into families where there is no family history.

Haemophilia can be classified as mild, moderate or severe, with symptoms including bruising, prolonged external bleeding and bleeding internally into joints and muscles. Haemophilia A is a deficiency in clotting factor VIII in the blood and haemophilia B is a deficiency of clotting factor IX. The treatment for haemophilia is an injection into the vein of the missing clotting factor VIII or IX. This increases clotting levels to a normal range, stops bleeding and prevents joint and muscle damage.

It has been known for a long time that families need assistance in finding appropriate care and multidisciplinary input to deal with the consequences of the condition. The concept of comprehensive care for haemophilia was developed in the 1960s, the idea being to treat the whole person and family through continuous supervision of all the medical and psychosocial aspects of bleeding disorders.

My grandfather was a haemophiliac and so his lifetime the only treatment available was whole blood transfusions and cryoprecipitate, but he lived until he was 76 years old. In the 1970s factor concentrates became available from pooled plasma imported from America. This revolutionised haemophilia care, but the new treatment carried HIV and hepatitis C and 5000 haemophiliacs, many as babies and children, became infected in the UK.

It is so stressful for a newly diagnosed family who have no knowledge of the condition learning how to administer intravenous factor as it is for older people who have haemophilia and are dealing with arthritis joint replacements and the effects of HIV and hepatitis C on patients, families and bereaved families.

When my first son was born with haemophilia in the late 1980s, the treatment was best tested, but we were advised that recombinant derived factor was being developed which would be much safer than blood products. With the support of haemophilia charities and our MPs, we succeeded in getting recombinant factor VIII in 1996 – one year before it was introduced in England.

This was a major breakthrough as it meant the new generations of people who had haemophilia were not exposed to the risks associated with blood products.

The next issue facing us was the loss of our Haemophilia Centre, which was merged with Adult Malignant Haematology – an unacceptable situation for everyone. Very poorly cancer patients undergoing chemotherapy treatment and noisy young children side by side, all added to the unsettledness of the hospital visit, which could often be daily, if you had a difficult bleed to treat.

It was obvious to clinicians and patients that this was unacceptable. We contacted our MPs and Welsh Assembly members and within two years, endless meetings and fundraising, the Arthur Bloom Haemophilia Centre in Cardiff was opened.

We thought we had achieved everything...

What could go wrong after we had managed to secure safe recombinant treatment and

comprehensive/multidisciplinary care. Then disaster struck, with the death of family and so many friends with hepatitis C and HIV, psychological support was now needed for everyone affected by haemophilia.

By talking to affected patients, families and bereaved families from all over Wales, I started gathering patient experiences.

Some patients had never spoken about their condition. Some young adults were so ashamed, they felt that nobody understood. Some couldn't even begin to talk about having a child with haemophilia; they themselves were frightened of going to the hospital. Many were so afraid of allowing their child to lead a normal life that they had become overly protective and blamed themselves for every bleed that their child had.

The difficulties encountered by children with needle phobia, Portacaths, inhibitors, and the effects on siblings and partners who felt that haemophilia took all the attention. Haemophilia seemed to interfere with everything.

Then there were older children and teenagers who were finding treatment regimes difficult. Most parents and carers learn to treat their child intravenously at home. This can be a huge step, to inject your child yourself, and needs a lot of support from haemophilia staff and cooperation from the child. Learning to self-administer treatment is extremely difficult to begin with, but fortunately, most families adapt to this, which helps cut down on hospital visits and disruption to family life. Lots of teenagers find treatment regimes difficult when they leave home and go to college or university. Many refuse to treat themselves and need help dealing with the consequences.

Some of the mums have dads, brothers or cousins who had died as a result of contaminated blood, and now have children with haemophilia themselves. Bereaved parents had lost children as young as seven to AIDS; some families had been split up and brothers and sisters separated and put into care when a parent died. Some families had lost up to three family members to HIV and hepatitis C. Some of the men with haemophilia who had contracted HIV had unknowingly infected their partners.

The stigma of those affected by HIV and hepatitis C means that there is still great secrecy and mistrust in the haemophilia community. Progress would have been impossible without the support of haemophilia clinicians from all over Wales. I had to ensure that we were all asking for the same issues to be addressed. I then asked all the patients, families and bereaved families I knew to contact their MPs and Welsh Assembly Members and tell their story.

And by accident we became a lobby group

In 2009 a group of us went to see the Health Minister Edwina Hart to outline the difficulties we were encountering.

Our Assembly Members continued to ask questions about the gaps in haemophilia care in Wales in the Welsh Assembly to keep haemophilia on the agenda. And then the Cross Party Group on Haemophilia and Contaminated Blood was established at the Welsh Assembly to keep up the pressure.

In 2011, the Health Minister set up a Ministerial Task and Finish Group to review haemophilia care in Wales. Chaired by Dr Chris Jones, Deputy Chief Medical Director for the Welsh Government, the group consisted of haemophilia centre directors, haemophilia nurses, physiotherapists, clinical psychologists, social workers and Welsh commissioners (the Welsh Health Specialised Services Committee or WHSSC), with patient representatives from all over Wales.

The following gaps in service provision were identified by the Task and Finish Group:

1. Psychological and counselling support.
2. Physiotherapy throughout Wales.
3. Consultant hepatology support for haemophiliacs with hepatitis C.

Funding was then allocated to psychological support by the Welsh Government. Four psychologists were to be appointed for inherited bleeding disorders. The All Wales Advisory Group, consisting of haemophilia doctors, nurses, physiotherapists, local health board and patient representatives, and chaired by the Welsh commissioners (WHSSC) were to ensure that the recommendations were implemented.

However, it became evident that progress was going to be impossible without continued engagement from politicians, clinicians and patients. We had further meetings with the Health Minister to impress upon her the urgency of appointing the psychologists. The funding had been allocated to the commissioners but it wasn't being utilised. The commissioners were blaming local health boards for lack of progress, and vice versa. The clinicians had no leverage, and again we had to go back to MP's and Assembly Members to ask for further meetings with the Health Minister.

Finally, after much pressure, interviews were arranged and four psychologists were appointed. Dr Anna Beaver leads the Cardiff Inherited Bleeding Disorder Service, with Dr Zoe Moss providing outreach to Abergavenny. Alison Gorman is based at Swansea Haemophilia Centre and Sali Burns at Bangor.

In conclusion

What I have learned on my family journey is that as a parent it is essential to learn as much as possible about your condition to ensure you are well informed.

Parents need to engage with other parents and carers, at the hospital or through a patient support group or charity. It is so important to meet with others in the same situation. There is strength in numbers and there is no substitute for talking to others in the same situation.

It is essential to foster a good relationship with clinicians. I always have instilled this in my children – we used to say that the haemophilia doctors, nurses and physios were our friends. And I feel that this helped build mutual trust.

Working collaboratively with clinicians to ensure that we always have a clear message to take to decision makers about what we are asking for.

Quality of life for patients and their families is greatly improved when physical and psychological needs are met through comprehensive care/multidisciplinary care and we should make this our goal to ensure that patients have the best quality and most productive life.

Clinicians' input is often ignored by commissioners/health boards/government as they see the cost of the service increasing. We need to ensure that patients are involved throughout the commissioning process.

And finally, we need continued engagement with patients to ensure that the service is fulfilling their needs.

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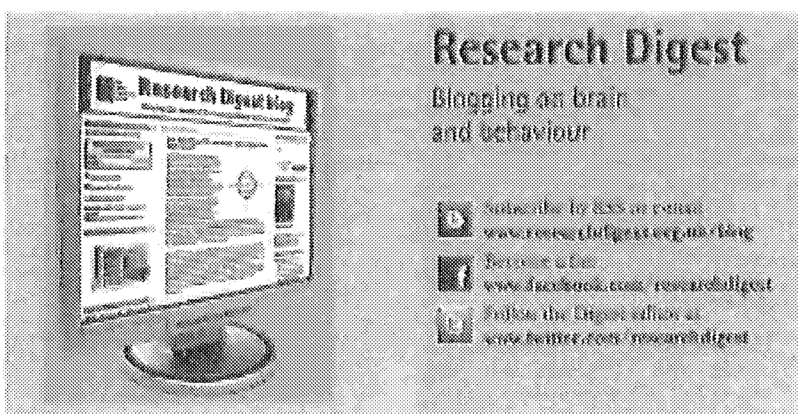

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