

Editorial – Living, Caring, Learning: The nurse-patient relationship in bleeding disorders care

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Twenty-five years after transitioning from paediatric to adult care, I have been asked to pen this commentary by my former paediatric nurse. That should tell you everything you need to know about the lifelong relationships that are forged between nurses and their patients!

Whilst we think of haemophilia as a lifelong condition, we rarely stop to think about the lifelong impact on those caring for this incredible, indomitable, irrepressible community. Many healthcare professionals take great pride in caring for generations of families with haemophilia and other bleeding disorders. Equally, patients take great pride in being able to show nurses and their comprehensive care team what they have achieved with their support.

The 'Living, Caring, Learning' focus in *The Journal of Haemophilia Practice* over the last year has shone a light on what many, rightly, consider to be the most valuable relationship within the comprehensive care team – that of patient and nurse. In saying that, nurses within haemophilia never see patients – they see people, families, struggles, challenges and so much more. They endeavour to provide true comprehensive care to people and their families.



Clive Smith with Dr Kate Khair

Perhaps the strongest theme that has come out of this series of articles is that of education. Nurses are responsible for teaching parents about a new diagnosis, about the challenges of the first days at school, adolescence and much, much more. However, on reading the nurses' stories, it is impossible to ignore how much they have learned from their patients. As treatments have developed over recent decades, so have attitudes to what people with bleeding disorders

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can achieve – be it following their professional dreams, excellent joint health, sporting achievements or starting a family. That knowledge has allowed nurses to improve as individuals and provide even better care to the patients they look after.

A further aspect of this can be seen from the active self-development that nurses undertake in terms of study and research. Nurses are undoubtedly inspired by patients to be at the vanguard of research to help advance knowledge and standards of care for the community they serve.

Inevitably, this interdependent relationship provides ethical challenges for nurses. In the UK nurses are referred to as ‘sister’, stemming from medieval times when all nursing was undertaken by nuns. Many nurses and patients see each other as part of a family. However, they must resist the inevitable urge to become too dependent on each other and blur the professional boundary which must always be respected.

The stories shared by each of the nurses in this series set out how many rather fell into haemophilia care. Each describes the rich experience that a life spent caring for their patients has given them. Even after retirement, many continue to be involved. For so many the haemophilia community has become like the Hotel California – a place where you can check out, but never leave.

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