

# Editorial – Living, Caring, Learning: How patients shape the specialist haemophilia nurse

Kate Khair

## KATE KHAIR

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I am delighted that for International Nurses Day 2023 we are, through *The Journal of Haemophilia Practice*, able to reflect and shine a light on the important and often unseen role of nurses in haemophilia and allied bleeding disorder care. Today, and over the coming months, our Living, Caring, Learning series will share stories from individual nurses who have spent many years of their lives caring for people with bleeding disorders and their families.

My first encounter with a person with haemophilia, about 35 years ago, was with Tom (a pseudonym). I nursed Tom when he was diagnosed with cancer and found him so different from the other young men in the ward. He had a different view of life, often leading a recce party to the local pub, and on one occasion being brought back well after closing time by the police – a young man, no hair, under the influence, with a cannula which he freely stated was 'to give my drugs'. Sadly, Tom's cancer was fatal; he knew that was the case. What lives on with me – and something I have seen numerous times since – is that indomitable spirit that those with haemophilia have.

Haemophilia gets under your skin (not just those new-fangled therapies). Central to this, and evident in many conversations I have had with nurses over the



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years is the impact that individual patients and families have on us. In *Living, Caring, Learning*, we see how this shapes the interactions we have with others and influences our practice. These personal reflections also

show many different aspects of nursing care, from the early days when treatment was limited, to today where nurses are supporting people with bleeding disorders to make informed decisions about new treatment options. Our role continues to evolve as advances in treatment bring about new ways of working.

The theme for International Nurses Day 2023 is 'Our Nurses. Our Future'. Dr Pamela Cipriano, president of the International Council of Nurses, said this theme will 'shine the light on nurses and on a brighter future, moving nurses from invisible to invaluable in the eyes of policy makers, the public, and all those who make decisions affecting the delivery and financing of health care' [1]. I hope that she is right – the role of the haemophilia nurse deserves much greater recognition.

From where I sit, nurses are the shining stars of haemophilia care. I am honoured to know all of you and to have been able to ask you to share your stories for International Nurses Day

## ACKNOWLEDGEMENTS

Kate Khair is an employee and shareholder of Haemnet Ltd and Editor-in-Chief of *The Journal of Haemophilia Practice*.

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