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**THE ROLE OF THE NURSE IN THE HOSPITAL  
AND HOME MANAGEMENT OF THE  
HEMOPHILIAC PATIENT**

The transformation of haemophilia from a life-threatening disease into a long-term manageable condition is changing the role of the haemophilia nurse specialist. It will likely be less clinically focused and have a greater emphasis on psychosocial support, including motivation, shared decision-making, support and self-advocacy for patients. Placing the person in all his complexity at the center of the treatment process is the main objective that the entire health system must achieve: it is no longer possible to reason in pharmacocentric terms, but the patient's needs must be given priority. It is

important to introduce valuable services, such as patient support programs, aimed at significantly improving the quality of life of the patient and of those who assist him and which, at the same time, involve and respond to the needs of the clinician who remains the primary reference for the patient.

Within these support programs, the contribution of the community nurse is particularly important at key moments in the patient and family journey, such as immediately after diagnosis, when prophylaxis is started, during joint health monitoring and in pharmacokinetic studies up to the teaching of self-infusion. Better diagnosis and comprehensive care have increased lifetime utilization and reduced bleeding rates and joint impairment for people with hemophilia. There is now much more emphasis on preventing major bleeding and teaching and supporting self-management. Models of haemophilia care are evolving and specialist nurses will play a leading role in their implementation. The revolution in haemophilia care presents exciting opportunities and challenges for nurses engaged in haemophilia, and there is ample scope to find different ways to deliver nurse-led care. Hemophilia nurses need to look beyond their own hospital or hemophilia center and share research and best practices with fellow nurses nationally and globally to improve the care they provide

