NURSE FOCUS

Living, Caring, Learning – Early education, active lives and tailored treatment in haemophilia care

Josipa Belev

JOSIPA BELEV is Head Nurse in the Department of Thrombosis, Haemostasis and Benign Haematological Diseases, University Hospital of Zagreb, Croatia

Josipa, a haemophilia nurse in Croatia, describes how meeting 18-year-old twins with severe haemophilia A changed her views around joint health and activity in people with haemophilia. The twins had started prophylaxis at a young age, learning to self-infuse at a haemophilia summer camp, and were both sporty and active. Neither had experienced joint damage and, 20 years later, they continue to live active lives. Josipa reflects on her own experience of volunteering at a haemophilia summer camp and teaching young people with haemophilia to self-infuse. She highlights the importance of talking with patients about their lives and understanding their lifestyle and circumstances to provide a treatment regimen tailored to the needs of the individual. Reflecting on the benefit of activity and exercise to joint health in people with haemophilia, Josipa describes how this has also inspired her to become a Nordic walking coach. She notes that access to more effective treatments has enabled a focus on quality of life in haemophilia care, and the importance of maintaining good physical health in an ageing haemophilia population.

Keywords: *Haemophilia; Joint health; Physical activity; Therapeutic relationship; Nurses; Professional practice*

I have worked in haematology for over 20 years, initially in the bone marrow transplantation team at the University Hospital of Zagreb in Croatia. I liked working with young patients but I wanted to move away from working with haematological malignancies and focus on patients with chronic disease. A few years after I joined, I moved to the Department of Thrombosis, Haemostasis and Benign Haematological Diseases as Head Nurse – and from that moment, I had new energy and ideas for organising healthcare for people with bleeding disorders.

Croatia has a population of about four million including approximately 400 people with bleeding

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License (*https://creativecommons.org/licenses/by-nc-nd/3.0/*) which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial, and no modifications or adaptations are made. Copyright is retained by the authors.

J Haem Pract 2023; 10(1). doi: 10.2478/jhp-2023-0007

disorders. We have one treatment centre for adults and one for children, each with two nurses specialising in bleeding disorders. Our facility offers multidisciplinary care including haematological and orthopaedic specialists, and access to physiotherapy and psychology and to a social worker. I work with adults and spend a lot of my day educating patients and their families, as well as organising hospitalisations, diagnostics, treatment and logistical activities, including clinical trial coordination. We have been involved in a number of clinical trials, including for subcutaneous treatments. None of our patients have had gene therapy but we hope this will be possible in the future.

At nursing school in Croatia, there is almost no information about haemophilia in the curriculum. At best, it is a small part of what we are taught about haematology or genetic diseases. However, my experience has shown how interesting and fulfilling it is to be a nurse working with people with bleeding disorders. My patients are my motivation and my inspiration!

DISCOVERING ACTIVE HAEMOPHILIA PATIENTS WITH HEALTHY JOINTS

Twin brothers, Luka and Marko (pseudonyms), were 18 when I first met them, and they changed my view about what we can achieve when we work in partnership with people with severe haemophilia. At the time when they came for their first adult consultation at the Haemophilia Treatment Centre (HTC), we were still regularly seeing a lot of people with haemophilia who were bleeding profusely and had permanent joint damage. Luka and Marko were different – they were happy, healthy, and they showed that it was possible for people with haemophilia to have a significantly better quality of life than I had learned about. They didn't have any joint damage and they were both very active. As well as being part of a traditional Croatian dance group, both were football referees and one was a competitive horse rider.

I discovered that both boys started prophylaxis at a very young age, initially every other day and then three times a week when they were at primary school. Sometimes they took extra doses, especially when they were exercising, and at the first feeling that they were having a bleed. They had also attended haemophilia summer camps in Germany where they learned about their disease, treatment and self-help. As a young nurse, they helped me realise the importance of teaching young people how to administer prophylaxis independently at home [1].

THE VALUE OF SUMMER CAMPS

The Croatian Haemophilia Society organised its first summer camp for members and their families in 2007, at around the time I first met the twins. The camps have continued every year, except during the pandemic when they went online. I was the first nurse to volunteer to help, and while I taught patients to self-administer their treatment, I also learned so much from them about their daily lives and the problems they encountered.

Going to these summer camps and being able to teach so many young people to look after themselves has been one of the most satisfying parts of my career, and I continue to go to them today. Funded by donations, they're usually four to five days long, and participants can attend educational talks and workshops about different aspects of haemophilia and self-treatment. One of the twin brothers still comes to the venepuncture workshop to talk about how he learned to treat himself, and to show others how he does it. His uncle, who is older and has had haemophilia complications and a knee endoprosthesis, also comes along to talk about his experiences with younger participants. There are plenty of fun activities for the children as well as the lectures, though.

KEEPING ACTIVE FOR THE FUTURE

Luka and Marko still attend our clinic once a year for a check-up – and they still have no damage to their joints. They take such good care of themselves, they have good jobs and families of their own, and they lead the same sort of lives as people who do not have a bleeding disorder. The brothers have been an inspiration for the way I have cared for people with haemophilia in the 20 years since meeting them. In fact, they are still my motivation for encouraging patients to get moving instead of sitting in front of the TV or computer. I explain that taking part in safe, recreational sports will give them healthier joints, give them more self-confidence and enable them to lead a 'normal', healthy life [2]. I have even become a Nordic Walking coach myself, as this is great exercise for people with bleeding disorders!

Getting to know patients such as Luka and Marko over such a long period of time has been very important. Understanding the circumstances of individual patients and their families means that I can organise their care according to their specific needs. For example, if a patient is training for a sport or likes travelling, the haematologist prescribes an extra dose of factor and the nurse educates them on how and

Josipa's recommendations for other health care professionals

- Really get to know your patient – their lifestyle and social circumstances as well as their medical history – so you can provide the best possible care to suit their needs
- Remember to approach each patient as an individual – advice and suggestions that seem good to us may not always seem best from their point of view
- Making small adjustments to a patient's care plan can make a big difference to a patient's life. It's the beauty of the nurse's role that we can make that difference.
- Recognise when patients are skipping doses of medication. They may think they don't need them because they are doing so well – but they need to understand that every dose counts!

when to self-administer. It's worth finding out about a patient's daily routine; if they are sedentary in the morning and more physically active in the afternoon, I advise them to have their extra dose before that activity [3]. Knowing what can be achieved with modern treatments and good care is very motivating and helps me address new challenges.

Haemophilia care has changed so much and our goals are so different compared to 20 years ago. Before, we focused on preventing permanent joint damage and the special needs of those with hepatitis or HIV infection. With the treatments we have access to today, we see far fewer joint bleeds and infection has almost disappeared. We can now focus on enhancing the quality of life of people with haemophilia. Today's patients will live much longer than they would have expected in the past, so we need to do the best we can to ensure those extra years are good years for them.

ACKNOWLEDGEMENTS

The author has advised no interests that might be perceived as posing a conflict or bias.

Informed consent has been obtained from the individuals reported in this paper.

Writing support was provided by Jenny Bryan.

REFERENCES

1. Khair K, Meerabeau L, Gibson F. Self-management and skills acquisition in boys with haemophilia. *Health Expect* 2015; 18(5): 1105-1113. doi: 10.1111/hex.12083.
2. Negrier C, Seuser A, Forsyth S, et al. The benefits of exercise for patients with haemophilia and recommendations for safe and effective physical activity. *Haemophilia* 2013; 19(4): 487-498. doi: 10.1111/hae.12118.
3. Martin AP, Burke T, Ashgar S, et al. Understanding minimum and ideal factor levels for participation in physical activities by people with haemophilia: An expert elicitation exercise. *Haemophilia* 2020; 26(4): 711-717. doi: 10.1111/hae.13985.

HOW TO CITE THIS ARTICLE:
Belev J. Living, Caring, Learning – Early education, active lives and tailored treatment in haemophilia care. *J Haem Pract* 2023; 10(1): 36-38. *https://doi.org/10.2478/jhp-2023-0007*