

# CHOOSING JOINT SURGERY IN HAEMOPHILIA: WHAT COULD IT MEAN FOR ME?



## IN THIS BOOKLET YOU WILL FIND:

- Information on how surgery could help you
- Information on how clots, bleeds and pain are managed
- A timeline of the surgical journey
- QR codes to download information leaflets for your workplace or place of education to inform them about the surgery and recovery process

# ACT

AGREE OPTIONS WITH YOUR HEALTHCARE TEAM

CHECK YOUR READINESS FOR SURGERY

TAKE THE RECOMMENDED STEPS

# WHAT ARE THE POTENTIAL BENEFITS AND RISKS OF SURGERY?



## BENEFITS OF SURGERY MAY INCLUDE:<sup>1</sup>

- Pain relief
- Improved quality of life
- Improved movement and use of a damaged joint (depending on the type of surgery)
- Improved alignment of a damaged joint
- Fewer joint bleeds



## RISKS OF SURGERY MAY INCLUDE:<sup>1</sup>

- Bleeding during or after surgery
- Infection
- Development of an inhibitor



## PAIN MANAGEMENT<sup>2</sup>

- Your haematologist and surgical team will review your pain management plan with you, to ensure that pain is controlled after surgery and beyond
- Information on pain medication following your discharge from hospital will be provided by your nurse



## PREVENTING AND MANAGING POTENTIAL BLEEDS AND CLOTS<sup>2</sup>

- Your healthcare team will put together a personalised management plan after checking the results of your blood tests
- The plan will apply to the time before, during and after your surgery
- Details of your factor replacement therapy will be decided, and a backup plan put in place in case of bleeding
- If you have inhibitors, you will be closely monitored to ensure treatment with a bypassing agent is given at the right time
- Measures to prevent clots include wearing compression stockings – your healthcare team will advise you



## YOU CAN FEEL CONFIDENT ABOUT HAVING JOINT SURGERY

- Many people with haemophilia have had surgery before, with good outcomes<sup>3,4</sup>
- Personalised physiotherapy after surgery will support your recovery<sup>1,5</sup>

This material is for educational and informative purposes only. It should not replace any advice or information provided by your haemophilia specialist and/or other healthcare professionals.

Surgery in patients with haemophilia (with or without inhibitors) can carry specific risks that should be carefully assessed and discussed with your haemophilia specialist and multidisciplinary care team. Surgery in patients with haemophilia (with or without inhibitors) should always be done in consultation with a specialised haemophilia treatment centre.<sup>2</sup>



# WHAT WILL MY HEALTHCARE TEAM LOOK LIKE?



# INFORMING YOUR EMPLOYER/ EDUCATION INSTITUTION ABOUT YOUR SURGERY

- Your healthcare team will guide you on how much time you need for rehabilitation after surgery<sup>2</sup>
- You will need to rest and perform your exercises during this time to achieve your planned outcomes<sup>1,6</sup>
- Your haemophilia nurse will be able to help you with getting a doctor's certificate to show your employer/education institution

If you have a smart phone, scan the relevant QR code below to access downloadable sheets to help in your discussions with your employer/education institution. You can print off the sheets by visiting the web addresses on a computer, or from your phone.

## SCAN QR CODE FOR DISCUSSION SHEETS

Employer QR:



Education Institution QR:



It is important that you keep to your rehabilitation programme to achieve the best outcomes – in particular, ensuring you administer your prescribed treatment on time, following your physiotherapy plan and attending follow-up appointments.<sup>1,6</sup>

Staying active and continuing with the exercises outlined by your physiotherapist will help you strengthen the muscles around your joint and improve movement.<sup>1</sup>

It is also important to remember to eat healthily and take your pain medications as prescribed.<sup>1</sup>

# WHAT COULD MY SURGICAL JOURNEY LOOK LIKE?

## BEFORE SURGERY<sup>2</sup>

- Your surgeon will help you decide if surgery is right for you, and plan your surgery
- You will meet your healthcare team to set specific goals tailored to your individual needs and find out what you can expect from surgery, and address any worries that you may have
- Your assessments before the operation will include lab tests and a physical examination
- You will work with your physiotherapist, surgeon, haematologist and occupational therapist to determine the best approach to physical rehabilitation, including exercises
- Your team will develop your personalised plans for bleeding control, anaesthesia, pain management and venous access<sup>2,7</sup>
- **Your surgery date will be scheduled**

## DURING SURGERY<sup>2</sup>

- Your surgical and haemophilia teams will monitor your surgery to prevent bleeding and unnecessary clotting
- How long your surgery will take depends on the type of surgery you are having
- **After surgery is performed, rehabilitation will begin**

## AFTER SURGERY<sup>2</sup>

- If you do not have inhibitors you will receive coagulation factor, and if you have inhibitors you will receive a bypassing agent – following your haematologist's plan
  - Doses will be adjusted over time, depending on factor levels and your body's response
- Your pain management plan will be followed
- You will carry out your rehabilitation exercises with your physiotherapist and at home – and you will be advised on which activities you should participate in, and which to avoid
  - If you have inhibitors, physical rehabilitation may take a little more time than in those without inhibitors, to ensure bleeding is controlled at your operation site<sup>1</sup>
- You may need to use a walking aid and/or compression stockings at first, and will need assistance at home for at least a few days<sup>1</sup>
- The length of your hospital stay will depend on your operation and recovery

**References:** **1.** Canadian Hemophilia Society. Challenges, Choices, Decisions. A Guide on Orthopedic Surgery for People with Hemophilia. Available from: <https://www.hemophilia.ca/files/Challenges-Choices-Decisions%20Hemophilia.pdf>. [Last accessed January 2020]. **2.** Escobar MA, et al. Haemophilia 2018;24(5):693–702. **3.** Giangrande PLF, et al. Orphanet Journal of Rare Diseases 2018;13(66):1–6. **4.** Rodríguez-Merchán EC. EFORT Open Rev 2019;4:165–173:1–9. **5.** Orthoinfo. Total knee replacement exercise guide. Available from: <https://orthoinfo.aaos.org/en/recovery/total-knee-replacement-exercise-guide/>. [Last accessed January 2020]. **6.** Stephensen D. Haemophilia 2005;11 (Suppl 1):26–29. **7.** Valentino LA and Kapoor M. Expert Rev Med Devices 2005;2(6):699–711.

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