

# LET'S TALK ABOUT JOINT SURGERY IN HAEMOPHILIA

Deciding whether surgery could be right for you



# ACT

**AGREE** OPTIONS WITH YOUR HEALTHCARE TEAM

**CHECK** YOUR READINESS FOR SURGERY

**TAKE** THE RECOMMENDED STEPS



# SHOULD ELECTIVE ORTHOPAEDIC SURGERY (EOS) BE A CONSIDERATION FOR YOUR PATIENT?

Help them to make an informed decision



# ACT

HELP YOUR PATIENTS WITH HAEMOPHILIA TO:

**AGREE** OPTIONS WITH THEIR HEALTHCARE TEAM

**CHECK** THEIR READINESS FOR SURGERY

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## WHAT CAUSES JOINT PROBLEMS IN HAEMOPHILIA?

- Joint problems are caused by bleeding into the joints<sup>1</sup>
- This causes damage to both the cartilage and the lining of the joint<sup>1</sup>
- Over time there is further damage with worsening pain, reduced mobility and function, and a risk of further bleeds<sup>1,2</sup>
- Surgery can help to reduce pain, improve function and mobility, and reduce joint bleeds for people with joint problems in haemophilia<sup>1</sup>

Joint health can deteriorate over time even with low bleeding rates.<sup>3</sup>

## WHAT ARE THE CAUSES OF HAEMOPHILIC ARTHROPATHY?

- Give an overview of the underlying causes and clinical features of joint damage in haemophilia
- Consider reviewing the patient's scans (radiology/ultrasound/MRI) with them at this point, to illustrate the extent of damage and potential need for surgery

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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 healthcare team. Surgery in patients with haemophilia (with or without inhibitors) should always be done in consultation with a specialised haemophilia treatment centre.<sup>4</sup>



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## WHAT ARE THE AIMS OF SURGERY?

Many people with haemophilia have gone through surgery before, with positive outcomes.<sup>5,6</sup>

The aims of surgery will depend on the type of surgery you are having, the joint affected and how much damage there is. They may include:<sup>1,7,8</sup>



**Reduction of pain and discomfort**  
(generally the most important aims)



**Improvements in mobility and the range of motion of the joint**  
(this depends on the type of surgery and other factors)



**Improvement in function and well-being**

## WHAT ARE THE OBJECTIVES OF EOS IN HAEMOPHILIC ARTHROPATHY?

Highlight the objectives of EOS for the patient:<sup>1,7,8</sup>

- Reduction in pain is generally the most important – This can bring improvements in quality of life
- Improvement in mobility won't be a goal for all patients
- Reduction in joint bleeds is an associated benefit for some patients,<sup>1</sup> but is not usually an indication for surgery

Consider the achievable goals of surgery for this patient. What benefits can they realistically aim to see from their surgery, given the joint affected and the severity of arthropathy?



In a survey of >100 patients with congenital haemophilia with inhibitors (CHwI) having surgery, three-quarters (73.1%) reported that the surgery improved or greatly improved their quality of life.<sup>8</sup> Surgery has proved successful for patients with high-titre inhibitors, with improved quality of life.<sup>9</sup>

However, it is important for patients to be aware that there is less surgical experience for patients with inhibitors compared to those without, and the risk of complications is higher.<sup>8</sup>

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**Improvement in function and well-being**

## POTENTIAL RISKS OF SURGERY

When considering surgery, it is also important to think about potential risks.

- Risks include bleeding during or after surgery, infection and development of an inhibitor<sup>1,5,7</sup>
- Careful preparation and planning by your healthcare team can help to reduce the risks of surgery, such as bleeding or infection<sup>1</sup>
- Planning for surgery is carefully personalised, with bleeding and pain management plans put in place<sup>4</sup>

Your healthcare team will put together bleeding and pain management plans for you at an early stage of your care.<sup>4</sup>



## MANAGING RISKS OF EOS

- Introduce the multidisciplinary team (MDT), including the haematologist, haemophilia nurse, surgeon and physiotherapist, among others
- Outline the role of the MDT in minimising complications and optimising outcomes from surgery
  - For example, maintaining a high level of clotting factor replacement (or bypassing agent for patients with inhibitors) throughout wound healing can help to reduce infection rate<sup>7</sup>
- The MDT can help the patient make a well-informed decision about surgery<sup>6</sup>

Key concerns about surgery expressed by patients with haemophilia include fear of:<sup>8</sup>

- Post-surgical pain
- Lack of improvement in mobility
- Complications such as bleeding

**?** Ask the patient if they have any concerns surrounding surgery. Consider sharing experiences from your local centre.

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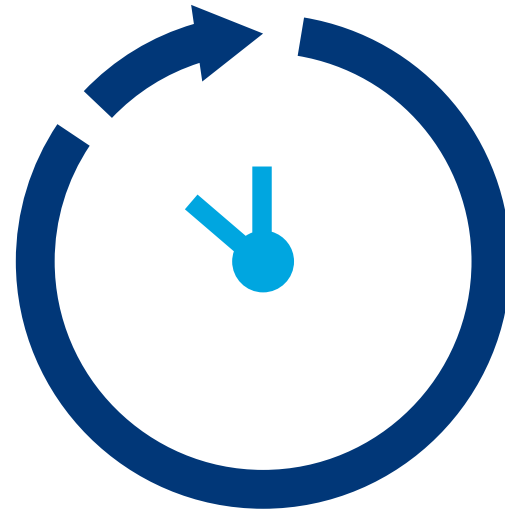
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## CONSIDERATIONS BEFORE SURGERY

- Before surgery you will have a physical assessment, blood tests, urine tests and chest X-ray<sup>7</sup>
- Your haemophilia treatment centre will also carry out coagulation/inhibitor testing<sup>7</sup>
- Your healthcare team will carefully plan your surgery, including development of surgical and pain management plans, and support you throughout the process<sup>4</sup>
- Physiotherapy exercises before surgery ('pre-habilitation') may help you to prepare physically by strengthening muscles, and achieve good results from your surgery<sup>1,4</sup>
- As well as being physically ready for surgery, it is also important that you feel ready, and have considered factors such as recuperation and time off from work<sup>1</sup>
- Your occupational therapist can help consider any home adjustments you may need following surgery<sup>1</sup>



## THE PRE-OPERATIVE PERIOD

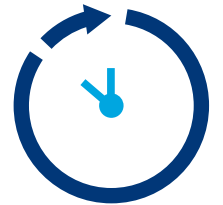
- Reassure the patient that careful preparation and planning before surgery will be done by the MDT to optimise outcomes and minimise risk



Patients with CHwI require additional attention, with agreement on the quantity/mode of bypassing agents administered and need for adjunctive therapy such as anti-fibrinolytics.<sup>4</sup>

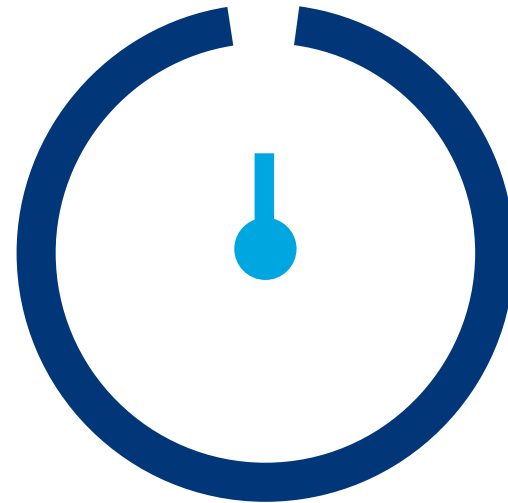
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## CONSIDERATIONS DURING SURGERY

- The length of surgery varies depending on the type of surgery you have; it may take several hours<sup>1</sup>
- Your healthcare team will work together to prevent bleeds and address any unexpected bleeding<sup>4</sup>
- Afterwards you will be moved to the recovery room before moving to a regular room<sup>1</sup>

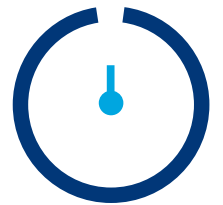


## THE INTRA-OPERATIVE PERIOD

- Give a brief overview of the type of surgery that might be considered for this patient, the expected duration of the procedure/anaesthesia
- Reassure the patient that the surgeon and haematologist will monitor and control haemostasis throughout surgery, while remaining prepared for any unexpected bleeding

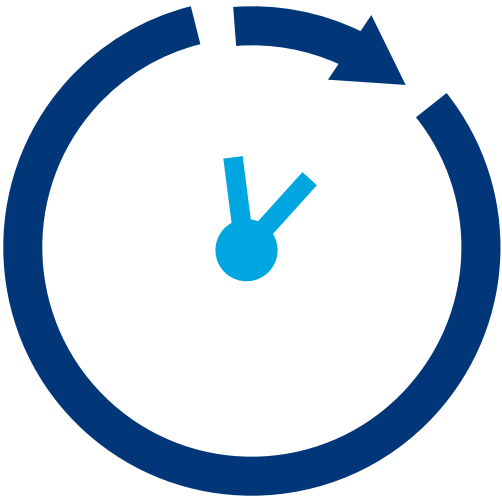
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# CONSIDERATIONS AFTER SURGERY

- Your healthcare team will monitor you closely after surgery<sup>1</sup>
- Your pain will be managed with the plan agreed before your surgery<sup>1,4</sup>
- Post-surgery rehabilitation, including an extended period of physiotherapy, is very important to ensure good recovery after surgery<sup>4,10</sup>
- The amount of time that you spend in hospital and the recovery time will depend on the type of procedure you have, and will vary from person to person<sup>1</sup>
- Care and assistance will be important after discharge from hospital, and transfer to a rehabilitation centre is often advised for a period of time<sup>1</sup>



# THE POST-OPERATIVE PERIOD

Highlight the importance of physiotherapy after surgery to ensure optimal outcomes.

Encourage patients to tell their MDT if they find that their pain is not fully controlled. Poorly managed pain can lead to a negative cycle of muscle spasm, loss of normal function, and ongoing pain.



Note that the patient will likely need assistance at home, at least for the first few days following discharge.

### CONSIDERATIONS AFTER SURGERY

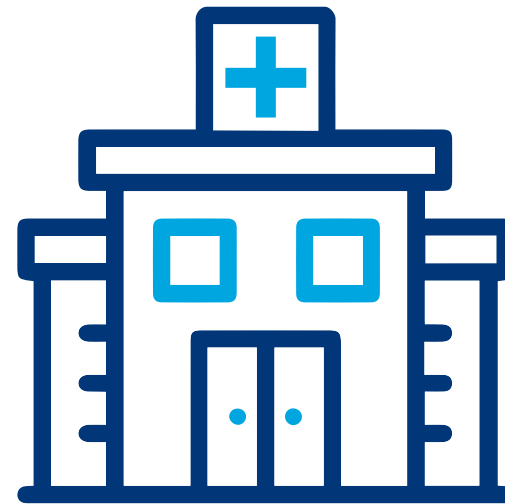
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**i** Surgery for patients with inhibitors (CHwI) is associated with a higher rate of complications. Hospital stay tends to be longer for these patients, to optimise bleeding control.<sup>1</sup>



## SUMMARY OF KEY POINTS

- Many people with haemophilia have gone through surgery before, with positive outcomes<sup>5,6</sup>
- Aims of surgery include reduction of pain and discomfort and improvement in function and mobility<sup>1,7</sup>
- Your healthcare team can help to reduce potential risks such as bleeding and infection<sup>1</sup>
- Your healthcare team will carefully plan your surgery, including development of personalised surgical and pain management plans<sup>4</sup>
- They will support you throughout, from initial discussions about surgery through to post-surgery rehabilitation and recovery<sup>4</sup>



## SUMMARY OF KEY POINTS

Provide an overview of the key points discussed including:

- Objectives of surgery (reduction of pain and discomfort, improvements in mobility and function)<sup>1,7</sup> – managing expectation is also important
- Potential complications (bleeding, infection)<sup>1</sup>
- MDT involvement to help the patient to understand whether surgery is right for them and whether they are ready<sup>4</sup>

Take this opportunity to see whether the patient has any concerns that they would like to discuss.



This is a good opportunity to provide the patient with a copy of the EOS Patient Journey Tool

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**References:** **1.** Canadian Hemophilia Society. 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.** Rizzo AR et al. Clin Cases Miner Bone Metab 2017;14:197–199. **3.** Kuijlaars IAR et al. Haemophilia 2017;23:934–940. **4.** Escobar MA et al. Haemophilia 2018;24:693–702. **5.** Rodríguez-Merchán EFORT Open Rev 2019;4:165–173. **6.** Giangrande PLF et al. Orphanet Journal of Rare Diseases 2018;13:66. **7.** Solimeno LP et al. J Clin Med 2017;6:107. **8.** DeKoven M et al. J Med Econ 2012;15:305–312. **9.** Rodríguez-Merchan EC et al. Haemophilia 2007;13:613–619. **10.** De Kleijn P et al. Haemophilia 2006;12:108–112.

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