

**CHOOSING JOINT SURGERY
IN HAEMOPHILIA:
LET'S PLAN
YOUR SURGERY
AND BEYOND**



ACT

AGREE OPTIONS WITH YOUR HEALTHCARE TEAM
CHECK YOUR READINESS FOR SURGERY
TAKE THE RECOMMENDED STEPS

References: 1. Escobar MA, et al. Haemophilia 2018;24(5):693-702. 2. 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]. 3. World Federation of Hemophilia. Guidelines for the management of haemophilia. 2nd edition. Available from: <https://www1.wfh.org/publications/files/pdf-1472.pdf>. [Last accessed January 2020]. 4. Valentino LA and Kapoor M. Expert Rev Med Devices 2005;2(6):699-711. 5. National Hemophilia Foundation. Physical Therapy Practice Guidelines for Persons with Bleeding Disorders: Total Knee Replacement. 2015. Available from: <https://www.hemophilia.org/sites/default/files/document/files/238PTTotalKneeReplacement.pdf>. [Last accessed January 2020].

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WHY ARE WE HERE TODAY?

You've made the important decision to go ahead with joint surgery.

Today we will discuss the preparations for before, during and after your surgery. We will help you to:

- Make arrangements including physiotherapy, good nutrition and preparing your home for after surgery
- Address any fears you have, so you feel ready and relaxed on the day of your surgery

Your nurse will be your consistent healthcare partner from pre-surgery and throughout rehabilitation.

Your friend/family member/carer should also be closely involved at every stage, to offer you support.



The box below appears several times in this booklet, showing information for patients with inhibitors.

i Special considerations for patients with congenital haemophilia with inhibitors (CHWI)

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.¹

THE REASONS YOU ARE SUITABLE FOR SURGERY

You have been put forward for surgery for one or more of the following reasons:²

? Pain and loss of function is reducing your ability to care for yourself in daily life, such as washing and dressing

Pain is making it difficult for you to sleep

You have tried different medications but they do not lessen the pain, or a medication that was working no longer works

Other options that you've tried (e.g. rest, splinting, mobility aids) do not reduce your pain

Bleeding into a joint is common, although this is not usually the main reason for surgery

Do you feel that one or more of these things applies to you?

HEALTH PREPARATIONS BEFORE SURGERY

PHYSIOTHERAPY²

Before surgery, your physiotherapist will teach you exercises to strengthen your body. These exercises will be personalised for you and the type of surgery you will be having.

For example, if you are having a hip or knee replacement, some exercises will strengthen your upper body to make it easier to use crutches or a walking frame during recovery.

Your physiotherapist or occupational therapist may also show you how to perform movements such as getting out of bed and showering after your surgery. They will also check whether you will need any extra equipment at home to help you.

Sticking to your physiotherapy plan is crucial to getting the most out of your surgery.

PHYSICAL AND DIETARY PREPARATIONS²

These simple steps may help you to get ready for surgery and recover more quickly.

Before your operation you should:

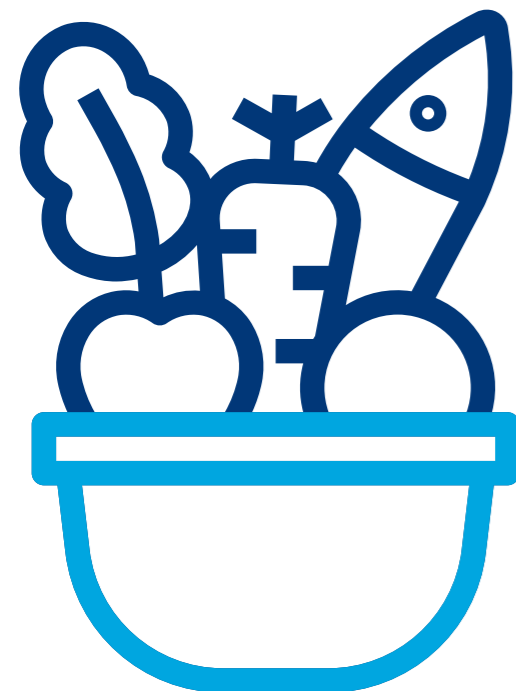
- Make sure any tooth or gum problems are fixed to reduce infection risk
- Eat healthily – but do not diet unless advised. If you are overweight your surgeon may ask you to lose some weight before surgery
- Cut down or quit smoking
- Don't drink alcohol for at least 2 days before surgery – your healthcare team may recommend avoiding alcohol for some time afterwards, too
- Tell your healthcare team if you get any infections the week before surgery – including a cold or fever

? When is your next physiotherapy appointment booked for?

? Do you need to book a dentist appointment?

Are you eating well?

Do you have any other health concerns?



HOME AND WORK PREPARATIONS

HOW COULD YOU PREPARE YOUR HOME FOR YOUR RETURN AFTER SURGERY?²

Here are some ways you could prepare:

- Remove rugs/loose carpets and tidy cables so you do not trip over them
- Rearrange furniture to create room for wheelchairs/walking frames
- Consider installing a raised toilet/ toilet seat and handrails, and putting a chair and grip bars in your bath/ shower
- Set up an area where you can spend most of your recovery, with a bed or armchair, and a table for drink/food/ TV remote/books/telephone/radio, and a bin nearby
- Gather useful items such as a shoehorn, long-handled bath sponge and grabbing tool
- Freeze some healthy meals and buy disposable cutlery and dishes
- Apply for a temporary disabled parking permit

If needed, you may be referred to an occupational therapist, who can help you with these preparations.

? Do you have any concerns about getting your home ready?

HAVE YOU EXPLAINED YOUR UPCOMING SURGERY TO YOUR EMPLOYER OR PLACE OF EDUCATION?²

- They will need to be informed of your surgery and time off afterwards
- If your job is not physically demanding, you may be able to return within 6 weeks. If it is demanding, you may need at least 3 months off
- You may need to make some temporary changes to your place of work or study
- You will need to catch up on missed lessons/exams if still in education
- You can discuss recovery times with your surgeon and physiotherapy team

Your nurse can help you access some work and education downloadable pieces, which explain to your employer or education institution how they can help you.

? Do you need a social worker to help you with your finances?

Does your employer/ education institution need information to help support you after your surgery?

i If you have inhibitors, your recovery period may be longer due to your rehabilitation and treatment plan²

MEDICAL PREPARATIONS BEFORE SURGERY

Checking the medications you are already taking²

- Your healthcare team will check whether you should continue taking any existing medications

Planning access to a vein^{3,4}

- Access to a vein (e.g. for a drip) is important to give you clotting factor during and after surgery
- The choice of method varies between patients
- If you cannot take your medication at home, your healthcare team will need to make other arrangements, for example community care or transport to hospital

? Sometimes a blood transfusion is needed. Do you give consent to this if needed?

LEADING UP TO YOUR SURGERY

Physical examination – a few weeks before surgery²

- You will get a complete physical examination to check that you do not have any conditions that will affect your surgery

Routine tests – a week before surgery²

- Blood tests (including checking for inhibitors)
- Electrocardiogram (ECG) to check heart rate and rhythm
- Chest X-ray
- Urine testing
- Temperature and blood pressure
- Level of virus in patients with HIV/Hepatitis C

Testing may be carried out in different hospital departments, with clotting/inhibitor testing done within the haemophilia treatment centre.

Orthopaedic (bone) examination – shortly before surgery²

- The results from other examinations are forwarded on to your surgeon
- The surgeon will then examine your operation site, review your results, and address any concerns you may have

Pain medication²

- You will get a pain relief plan personalised to your needs
- Your pain control will be closely monitored during and after surgery

Anaesthesiologist meeting²

- You will meet your anaesthetist to discuss the anaesthesia that will be used

Your nurse will provide support and information throughout the whole process and help plan your discharge.

? Do you have the dates in your diary for your meetings?

i If you have mild haemophilia A or are receiving intensive factor replacement for the first time, you will be monitored for inhibitors throughout surgery, during rehabilitation and screened during your routine follow-up³

i If you have inhibitors, your care will be managed by a healthcare team experienced in this area, at a specialised haemophilia treatment centre¹

REHABILITATION AFTER YOUR SURGERY

Good care and assistance at home is important to help you recover quickly:²

- You may need someone to stay with you for at least a few days after you return home from surgery
- They may need to help you follow instructions for your care after surgery, and monitor your recovery
- They may also need to help you with daily tasks such as cooking, washing, cleaning and childcare

Although your pain will be managed, you should take care not to strain yourself during recovery.

If you live alone or have additional care needs, and do not have someone to stay with you when you leave hospital, you may need to go to a rehabilitation centre or request home care.

? Do you have someone lined up to help you out for the first few days/weeks?



ASSESSING YOUR READINESS FOR SURGERY

Here is a useful checklist to assess your readiness for surgery.

It ensures that you have considered various preparations to facilitate good outcomes and a smooth recovery period.

Please complete this sheet and bring it back to your haemophilia treatment centre. Your healthcare team can then help you with any needs and queries you may have before surgery.

Current overall eligibility and movement ability²

- Are you taking care of your health in preparation for surgery? For example, no teeth/gum infections, healthy diet, no smoking, low alcohol intake
- How do you feel about your current joint movement?

Other health and social preparations²

- Any concerns around your physiotherapy exercises?
- Are you confident about whether you can continue taking existing medications?
- Do you have someone to help you at home after surgery?
- Any other health or social concerns?

Home preparations²

- Do you feel confident about the preparations you need to make at home?

Work/education preparations²

- Do you feel confident about the preparations you need to make with your employer/place of education?

Overall readiness for surgery²

- Any other concerns we haven't covered?

PAIN MANAGEMENT PLAN

You will experience some pain and discomfort after surgery, but these will be managed with medication.

Please complete this sheet with your physiotherapist to help to clarify your goals after surgery.

Pain relief options^{3,5}

- Your pain will be managed with help from the anaesthesiologist
- Aspirin and other “non-steroidal anti-inflammatory drugs” (such as ibuprofen) should not be used for pain management after an operation, as they affect blood clotting
- At first, a type of painkiller called “opioid” medication may be given through a vein. Later, opioid medications may be given by mouth
- When pain is decreasing, a milder painkiller may be used
- Cooling devices can also be used for pain relief and to manage swelling

Your pain and movement goals after surgery

Weeks after surgery	My pain goals	My movement goals
0 (straight after surgery)		e.g. To walk five steps with my frame on day 1
1	e.g. My pain is fully removed by medication	
2		
3		
4	e.g. Pain does not impact my life at all	