LET'S TALK ABOUT JOINT SURGERY IN HAEMOPHILIA

The reason for having this meeting is to discuss the possible risks and benefits of joint surgery and talk through any worries you may have.

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

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ELECTIVE ORTHOPAEDIC SURGERY IN HAEMOPHILIA

The purpose of the meeting is to discuss the potential risks and benefits of orthopaedic surgery with the patient and talk through any concerns they may have.

HELP YOUR PATIENTS WITH HAEMOPHILIA TO:

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

The box below appears several times within this flip chart, highlighting considerations for patients with inhibitors.

Special considerations for patients with congenital haemophilia with inhibitors (CHwI)

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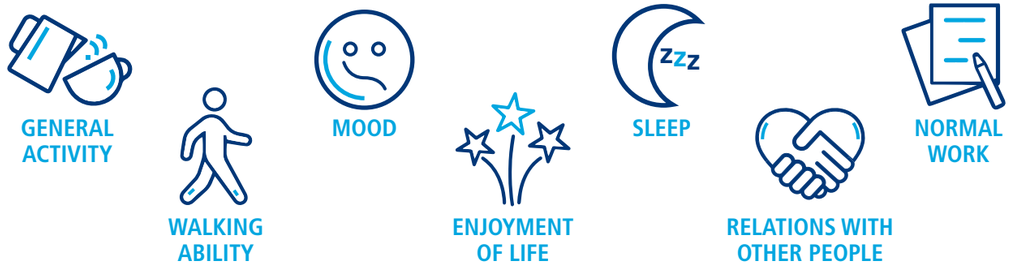
HOW DOES YOUR PAIN AND DISCOMFORT AFFECT YOUR LIFE?[1]

Rate the following factors out of 10.
0: no effect **10:** major effect



ARE YOU READY FOR SURGERY?[2]

Your healthcare team will assess your current health level and may suggest you are ready for surgery if:

- Pain interferes with your everyday life, e.g. work and socialising
- Pain and loss of function is reducing your ability to care for yourself in daily life, such as walking, attending work or school, 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

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.[3]

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THE PATIENT'S CURRENT HEALTH STATUS AND SUITABILITY FOR SURGERY

Here you can establish how the patient's current level of pain and discomfort impact their life, and whether they feel ready for surgery.

- How does your current level of pain and discomfort impact the aspects listed?
- Do you feel ready for surgery?

Patients with CHwI may have more negative impacts to their daily life than those without inhibitors[4]

This is a good opportunity to complete a quality of life (QoL) and pain questionnaire to allow comparison before and after their surgery

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THE BENEFITS AND RISKS OF SURGERY

Possible benefits to you are **reduced pain, improved movement and alignment of the joint and reduction in joint bleeds**, which will **improve your quality of life**.[2]

Potential risks include **bleeding during or after surgery, infection and development of an inhibitor**.[2,6,7]

Many people with haemophilia have gone through surgery before, with positive outcomes.[5,6]

Delaying surgery can result in further joint damage that may be more difficult to treat later on.[3,7]

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THE POTENTIAL BENEFITS AND RISKS OF SURGERY

Share patient experiences from your local centre to provide the patient with further insights into the positive outcomes, which may include:[2]

- Reduced pain and discomfort
- Improved movement
- Reduced bleeding

Give an overview of the potential complications of surgery, including:[2,6,7]

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

In a survey of >100 patients with CHwI having surgery, almost three-quarters (73.1%) reported that the surgery improved or greatly improved their QoL – with the highest ranking benefits being less pain, fewer bleeds, and improved mobility.[8]

Patients with CHwI may have a high expectation of success for their surgery with careful planning.[5,9]

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YOUR HEALTHCARE TEAM

WHAT IS YOUR ROLE?[3]

You will need to communicate with the members of your healthcare team throughout the whole process, as well as involve your friend/family member/carer who will be supporting you.

You will also play an active role in your rehabilitation after your surgery.

YOUR MULTI-DISCIPLINARY TEAM

HAEMATOLOGIST
- Treatment and monitoring plan
- Prevent bleeding during surgery and post-surgery rehabilitation

SURGICAL NURSE
- Preparing the patient for surgery
- Surgical support

PHYSIOTHERAPIST
- Assess suitability for surgery
- Pre- and post-surgery rehabilitation

SURGEON
- Check suitability for surgery and discuss realistic outcomes
- Perform the surgery
- Discuss rehabilitation

An overview of the multi-disciplinary team[3]

ANAESTHETIST
- Pain management plan
- Treatment management plan
- Maintain anaesthesia and haemostasis during surgery

HAEMOPHILIA NURSE
- The patient's consistent partner from pre-operative planning, day of surgery and throughout rehabilitation
- Communication of treatment plan
- Ensuring administration of clotting factor

OCCUPATIONAL THERAPIST
- Enables patients to achieve their optimal independence level and to facilitate a safe discharge home

AND OTHERS...
- Perhaps a dentist, psychologist, pharmacist, social worker and/or special coagulation laboratory may also need to be involved

Talk through the roles of the different team members.

EXPLAIN YOUR ROLE AS THE HTC NURSE:[3]

- Importantly – you will collaborate with the patient to create an agreed plan
- Coordinate different team members
- Liaise with the surgical team to ensure patient needs are understood
- Set goals for when surgery is completed
- Ensure haemostatic plan is carried out – including monitoring during surgery
- Help to create a pain management plan
- Assess the patient's risk of infection
- Monitor rehabilitation, through regular meetings with the patient/caregiver

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PLANNING BEFORE SURGERY

Personalised preparation can help make sure your surgery is a success – by making sure you are ready mentally and physically.[10,11]

Your healthcare team will carefully plan your surgery, and support you before, during and afterwards.

THIS PLANNING INCLUDES:[3,12]

- Physical assessment by a physiotherapist and surgeon
- Tests, such as blood tests, to assess your eligibility for surgery
- The development of a surgery treatment plan (including monitoring and control of bleeding) and a pain management plan
- Discussion about access to a vein – an important part of your care
- Assessment of any other conditions you may have
- 'Pre-habilitation', including physiotherapy and exercises to strengthen your body
- A dental check to assess teeth and gums

THE PRE-SURGICAL PERIOD

Advise that the planning process includes several tests.

LABORATORY TESTING:[3]

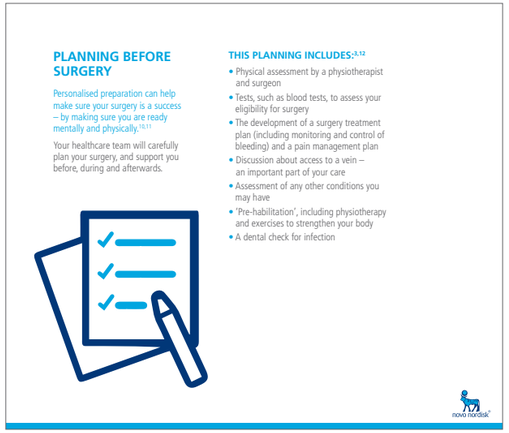
- Routine pre-surgical bloods and inhibitor screening
- If positive for HIV, CD4 levels are obtained and requirement for perioperative antibiotic prophylaxis assessed
- If the patient has hepatitis C, liver function should be assessed before surgery

ASSESSMENT OF THE PATIENT'S COMORBIDITIES:[3]

- E.g. older patients in whom the rate of viral disease or comorbidities (such as cardiovascular disease or cancer) may be greater than younger patients

ASSESSMENT OF CONCOMITANT MEDICATION:[3]

- Assess potential impact of medication on coagulation, and whether it should be continued during the hospital stay



Surgery in patients with inhibitors should only be undertaken by an MDT experienced in this area, at a specialised haemophilia treatment centre.[3]

You may wish to use local surgical information booklets obtained from your orthopaedic department

TYPES OF SURGERY

There are different types of surgery, depending on the joint affected, how badly it is damaged, and your level of pain.[2]

LENGTH OF HOSPITAL STAY[2]

- Before your surgery you will be admitted into hospital where you will meet the anaesthesiologist, surgeon and nursing staff to discuss any concerns
- Surgery may take several hours, then you will be kept in the recovery room before moving into a hospital room
- The surgeon and haematologist will monitor your progress daily, and nurses will be on hand

- Your pain will be managed at every step. Pain medicine after your surgery will initially be administered intravenously through a drip, and then by mouth[2]
- Your healthcare team are experienced in surgery, and will work together to prevent bleeds, minimise your pain and prevent infection[3]

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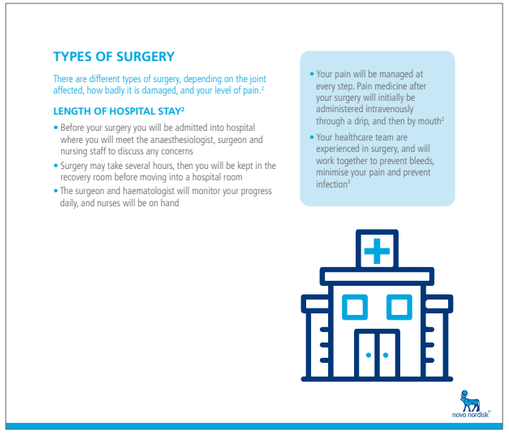
THE SURGICAL PROCEDURE

Explain the intended surgery being proposed, and also consider the potential use of surgical leaflets explaining the surgery.

The most commonly used surgical procedures to correct joint damage are:[2]

- Arthroscopy
- Joint debridement
- Cheilectomy
- Synovectomy
- Arthrodesis
- Arthroplasty
- Osteotomy
- Resection
- Pseudotumour management
- Revision joint therapy



As pain is an important reason for patients to be nervous of surgery, you could reiterate how pain will be managed at every stage – before, during and after surgery

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BLEEDING CONTROL BEFORE, DURING AND AFTER SURGERY

Your bleeding risk will be managed before, during and after surgery by your healthcare team:[3,12,13]

- Your team will prepare a detailed treatment plan and share it with you
- They will ensure that treatment is always available at the right place and right time
- You will be closely monitored to prevent/control bleeds, including blood tests to assess your treatment
- Your nursing team will ensure that good access to a vein is maintained
- There will always be healthcare staff and equipment on hand

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HAEMOSTASIS PRE/INTRA/ POSTOPERATIVELY

Discuss with the patient what their treatment plan may look like – to reassure them that adequate equipment and medication will be available where and when they need it.

Reassure the patient that their care will be maintained consistently – even out of hours. When the day team go home they will hand over to night staff and on-call staff, to ensure seamless care around the clock.

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REHABILITATION AND PAIN MANAGEMENT

WHAT TO EXPECT AFTER YOUR SURGERY:[2]

- The amount of time you spend in hospital will depend on your operation and recovery
- You will need to stay in hospital until you can carry out basic tasks without help
- You may require additional help for several days after leaving

YOUR REHABILITATION

- Rehabilitation will begin soon after your surgery, with careful attention to bleeding and pain management[3]
  - A pain management plan will be in place[2]
  - Physiotherapy before and after your surgery is important to achieving your best outcome[14]

It is important that you are committed to your rehabilitation programme – in particular, following your physiotherapy plan and attending follow-up appointments.[2,11]

> "I was confident with the treatment. The pain was gone. Not 100%, but the time will come when it will go. I can bend my knee. I can walk on the stairs – unlike before."
>
> *Patient with severe haemophilia A with inhibitors, UK*

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REHABILITATION AND PAIN MANAGEMENT

Here you can discuss rehabilitation and pain management with your patient, to reassure them that their pain will subside after a short time, and that recovery happens quickly – with the help of rehabilitation exercises.

- Patients can expect some pain and discomfort in the first few weeks after surgery[2]
- Pain may be worse at first, then subside within a few days[2]
- Pre- and post-operative rehabilitation may help increase range of motion, recover muscle strength and reduce pain[3,14]
- They are likely to make the most progress in the first 2–3 weeks following surgery, with continuing improvement possible for 6 months and more[2]

PAIN RELIEF OPTIONS

Some important points are below.

- Initially, IV morphine or other narcotic analgesics can be given, followed by an oral opioid such as tramadol, codeine, hydrocodone, and others[13,15]
- When pain is decreasing, paracetamol/acetaminophen may be used[13,15]
- Cooling devices can also be used for pain relief and to manage swelling[15]

i Patients may be in hospital longer if they have inhibitors, as they may need monitoring for bleeding for a longer time after surgery.[2]

In patients with inhibitors, physical rehabilitation is often delayed by a few days to ensure bleeding is controlled.[3]

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YOUR EXPECTATIONS OF SURGERY

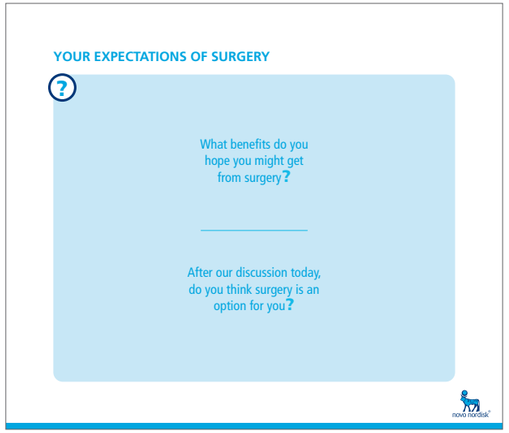
What benefits do you hope you might get from surgery?

After our discussion today, do you think surgery is an option for you?

EXPECTATIONS OF SURGERY

Below are some suggestions for discussion topics before the end of the meeting.

- What are your expectations from surgery?
- How do you feel about surgery?
- Do you still have concerns that can be discussed now, or do you need time to digest?
- Do you need any follow-up information that I have not provided here?
- Joints can deteriorate further without surgery, and surgery is more effective if carried out earlier
- Shall we set some goals for you for our next meeting? For example:
  - I will speak to another patient who has had surgery to hear their experience and help me decide if I am ready
  - I will discuss surgery with my partner and/or family, to help alleviate my fears



DOES ANYTHING CONCERN YOU ABOUT HAVING SURGERY?

"Surgery brings a risk of bleeding"

"I have to miss education/work"

"I fear the unknown as I am managing my pain and discomfort now"

"I might not be able to exercise for a long time after surgery"

"I worry that rehabilitation after surgery would take a very long time"

"I fear having a clot during surgery and being in lots of pain afterwards"

Do any of the above quotes resonate with you?
Do you have any additional concerns that are not covered here?

Quotes are fictitious, included for illustrative purposes only.

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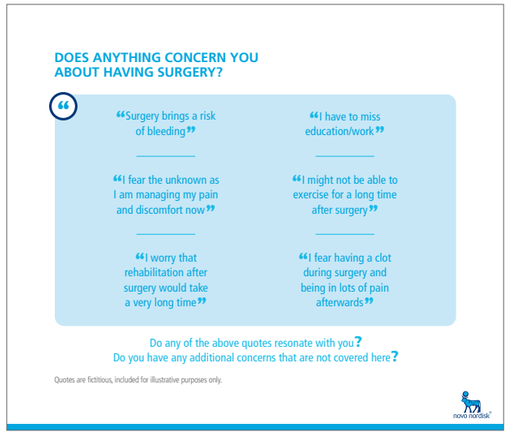
ADDRESSING KEY CONCERNS

Here is an opportunity for the patient to pause and discuss any specific worries about surgery.

- Can they relate to any of the quotes shown?
- What is their main worry?



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Date of preparation: February 2020 HQ19BRO00002

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