Talking about your joint health

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Before your appointment...

- Think about what you want to get out of each appointment at least a few days beforehand.
 Identify 3 priorities you would like to discuss e.g. joint pain, joint bleeds and exercising
- Make sure your Haemtrack record is up to date this helps your haemophilia team assess how well your treatment is working
- Think about how your joint health affects your daily life school or college, work, hobbies, social life, travel
- Write down your questions and concerns. It may help to note these down as you think of them, in a pocket notebook or on your phone
- Put them in a rough order of what is most important you may not be able to get through everything in one go
- Think about bringing a close friend or family member with you for support
- Talk to your friend or relative beforehand about what you want to get out of the meeting

Questions about general joint health:

- How many joint bleeds have you had in the past (month / 3-months / since your last appointment) Have these been spontaneous or because of injury?
- Are you as active as you'd like to be, or have you been limited by joint pain or damage?
- Are there any activities you avoid for fear of having a bleed?

Questions about improving your joint health:

- What more can be done to keep my joints as healthy as possible? What can I do? What can be done for me?
- How often should my joint health be measured?
- How can my treatment be changed to allow me to...?
- Is there any treatment that can protect me so that I can play sports / cycle etc...?
- I already have some joint damage what are the best ways for me to exercise and stay as fit as nossible?
- What can be done to protect my joints from further damage? What can I do? What can you do?

Questions about preventing bleeds:

- I'm getting joint bleeds when I ... What can I do to reduce my risk?
- I'm getting spontaneous joint bleeds. How can my treatment be altered to reduce the risk of these?
- What can I do to lower the risk of joint bleeds or swelling?
- Are there particular joints that are more at risk of bleeds than others?
- I'm getting bleeds in one particular joint why is this and what can be done about it?
 What can I do? What can you do?
- Why am I getting bruising / swelling / bleeds when I'm so careful about taking my treatment?
- Is my current treatment enough for my level of activity?
- I want to be more active but my bleeds are preventing it what can be done to help?
 What can I do? What can you do?

If you have joint pain:

- Keep a record of when and where you have pain. Include whether anything makes it better or worse – you can complete a pain score chart. There is an example below.
- Think about how your pain is affecting your daily life school, college, work, hobbies, social life, travel, sleep
- Think about how to describe your pain for example, is it: aching, stabbing, sharp, shooting, burning, nagging
- Think about whether your pain is chronic (lasting >3 months) vs acute (more temporary)

Questions about joint pain:

- Why am I having pain in my joints? What does this mean?
- What exactly do you think is causing my pain?
- How can my condition be managed to protect my joints and reduce the risk of pain increasing in the future? What can I do? What can you do?
- What treatment is available to prevent me from having chronic pain in my joints in the future?
- How can I manage my joint pain? What can you do to help?





At the appointment...

- Come prepared to take notes or ask your companion to do this for you. It's hard to remember everything that's said. If you want to record the meeting on your phone, do ask if everyone there agrees to this before pressing record!
- Start by saying how important it is for you to manage your own condition. Help your healthcare professional understand what's most important in your daily life, for example, being active, travelling, school or work. Try to be honest about your concerns
- Outline your main issues first and say you'd like to go through each in turn
- Aim to phrase 'open' questions. These are ones that can't be answered with 'yes' or 'no'. So, rather than "Do you think my treatment is going well?" say "How do you think we could best improve my treatment so that I can ...?"
- Don't be afraid to say if you feel you're not being heard: "I'm not sure you've understood how concerned I am about...
- Ask for an explanation of anything you don't understand, particularly medical jargon [hyperlink to glossary]. If you're not sure, try repeating back what you think they've said: "So you mean...." Then they can clarify if necessary
- Make sure you leave with a set of agreed actions: "So I'll...and you'll..." If possible, get an agreed timeframe for what will happen when

After the appointment...

- Follow up with your treatment centre if agreed actions don't happen according to plan
- Don't give up! If you think a change to your treatment will improve your day to day life or protect your future health, be persistent
- Do continue to keep your Haemtrack records up to date. They will help with all your future discussions with your healthcare team



Pain score chart

Please place a mark on each scale below to describe your pain and how it affects you.

How intense is your pain?



How distressing is your pain?



How much does your pain interfere with your daily life?



Example that can be used with young children



Glossary

Acute – short term • Arthropathy – damage to a joint or joint disease • Arthroscopy – putting a scope inside a joint through a small cut (incision), either to diagnose a problem or give treatment • Aspiration – sucking out, for example, using a syringe to remove blood from inside a joint • Atrophy – wasting or shrinking, usually of a muscle because of lack of use • Aura – feeling in a joint that means you are about to have a bleed • Cartilage – smooth, shiny material that covers the ends of the bones inside a joint • Chronic – long term • Complementary therapy – used alongside medical treatment, usually to help with symptoms or improve quality of life, for example massage or aromatherapy • Extended half-life (EHL) factor – replacement factor that lasts longer in the bloodstream, meaning you can have injections less often • Fibrosis – thickening and stiffening of body tissues • Haemtrack – record of all your haemophilla treatment and any bleeds. Used to monitor the success of your treatment • Inhibitors – proteins called antibodies that develop in your blood and fight against your factor replacement • Intra-articular – inside a joint, for example an intra-articular injection• Microbleeds – very small bleeds that don't cause any symptoms but can still cause damage inside a joint over time • Misalignment – not lined up, not in the right position • On-demand treatment – factor replacement that you only have when you have a bleed • Personalised treatment – a treatment plant that is put together specifically for you • Prophylaxis (prophylactic treatment) – treatment with factor replacement that you have regularly to prevent bleeds • Radiosynovectomy (radioactive synovectomy) – a radioactive injection into a joint, it shrinks the joint lining to prevent repeated bleeds or pain in a joint • "PRICE" – Protection, Rest, Ice. Compression and Elevation: Now to treat a joint bleed • Spontaneous bleeds – bleeds that happen for no obvious reason • Synovectomy – surgery to remove an inflamed a hadractive injection find a joint little of sport tailing of piretent respect to the constraint and in the plant of the plant trial plant

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Working in collaboration to support the Haemophilia Community