

I want to talk about my pain today!

A simple guide on how to talk about your pain
with a healthcare professional

for adults with bleeding disorders

Living with a bleeding disorder means pain is often a constant companion - whether it is the sudden, sharp warning of an acute bleed, the daily background ache of chronic joint damage, or pain associated with menstrual bleeding. Because pain is entirely subjective and deeply tied to your personal experiences, explaining confidently what you feel to a healthcare provider is the most powerful tool you have to get the right care.

This guide is designed to empower adults with bleeding disorders to take control of their health conversations. By using the practical **TILT Framework** (**Type, Intensity, Location, Time**), preparing for your consultations, and learning how to describe both the physical sensation and the practical impact on your daily life, you can work in partnership with your care team to find targeted, effective solutions. You do not have to adapt to unnecessary suffering or manage your symptoms alone - describing your pain accurately is the first step toward reclaiming your comfort, mobility, and peace of mind.

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Understanding Your Pain Experience

Pain is more than just a physical sensation. It is an essential protective mechanism that signals your body to avoid harm.¹ Because everyone learns to interpret pain through early life experiences, it is entirely subjective - there is no "right" or "wrong" way to feel it.

Feeling confident to discuss how your pain feels to you, including activities or actions that make it feel better or worse, is helpful for your healthcare team to hear. Information about your own experiences of your pain can make it easier for your healthcare team to work with you to find a treatment or intervention that may help.

Remember that pain is influenced not just by your joints or muscles, but also by your emotions, stress, and past experiences.

TILT Framework: Mastering the Language of Pain

The TILT method is designed to help you communicate clearly so your healthcare providers can support you effectively. Using TILT can also help you feel more confident talking about your pain and track changes in your pain over time.

Remember, pain that is clearly described is easier to manage.

What is TILT?

TILT is a simple way to talk about your pain using four questions:

T – Type: What does the pain feel like?

I – Intensity: How strong is the pain?

L – Location: Where is the pain?

T – Time: When does the pain happen?

T – Type: What does it feel like?

Try to describe the sensation. You can use your own words or choose from these examples:

- Burning (like heat or fire)
- Sharp or stabbing
- Dull or heavy
- Tight or squeezing

¹ Liu S, Kelliher L. Physiology of pain - a narrative review on the pain pathway and its application in the pain management. Dig Med Res 2022;5:56.

- Throbbing or pulsing
- Electric-shock-like
- Tingling or pins and needles
- Cramping
- Pulling or stretching
- Numb (like a body part has “fallen asleep”)
- Cold
- Aching
- Pain with swelling, redness, or warmth

There are no wrong words. What matters is what you feel. Describing the sensation of your pain helps clinicians identify potential contributors (physical, stress, or psychological) to your pain experiences.

I – Intensity: How strong is it?

To show how much your pain may interfere with your day-to-day activities, you can consider using a numerical scale to rate your pain intensity. This can be incorporated into broader functional descriptions as explained below:

- Mild (1–3): I notice it, but I can still do my activities.
- Moderate (4–6): It bothers me and slows me down.
- Severe (7–10): It is hard to cope with and stops me from doing things.

L – Location: Where is the pain?

Be specific about the “map” of the pain:

- Fixed vs. Moving: Is it in one spot (like the left knee) or spreading from one area to another (like the back down the leg)? Or do you experience pain in multiple body locations??
- Depth: Does it feel close to the surface where you can touch it (skin/joints) or deep inside?

Pointing to the area can also help.

T – Time: When do I feel the pain?

Tracking the timing helps determine if the pain is chronic or related to a specific injury:

- Frequency: Is it constant, or does it come and go?
- Triggers: Does it happen only at night, in the morning, or specifically after activity and movement?
- Duration: Has it lasted for hours, days, or months?

Understanding Chronic vs. Acute Pain

- Acute Pain: This is usually a "red alert" signal, like the intense, constant pain of an active joint bleed. It tells you that something is happening *right now* that needs treatment.
- Chronic Pain: This is pain that lasts for months or persists long after a bruise or bleed has healed. You can also have chronic pain without an obvious injury. For some, being completely pain-free may not be a realistic goal.
- The Goal: While acute pain requires immediate medical intervention (like factor replacement (in case of a bleed) and/or appropriate pain medications), chronic pain is about management and reduction, so it interferes less with your daily life.

Important! Don't ignore "background" pain. Many people with bleeding disorders adapt to a certain level of daily soreness or morning stiffness caused by microbleeds or synovitis.

Morning Check: If you wake up feeling stiff or "rusty" and it improves as you move, mention this specifically.

Specific Considerations for Women and Girls

Women and girls with bleeding disorders often experience pain that is unique to their anatomy and reproductive health. These sensations should be described with the same clarity and degree of personal impact on your health as a joint bleed.

Heavy and Painful Periods (Dysmenorrhea)²

While many women experience cramps, those with bleeding disorders often face secondary dysmenorrhea, where the pain is more intense and lasts longer due to the volume of blood loss.

- The "Clot" Pain: Passing large blood clots (larger than a 1 euro coin or a grape) can cause the cervix to dilate, resulting in sharp, labour-like cramping.
- Duration: Pain that starts days before your period and continues until the bleeding completely stops is a key clinical indicator to share.
- Quality of Life: Note if the pain is so severe that it prevents you from going to school, work, or social events.

Ovulation Pain

Some women experience sharp, one-sided abdominal pain mid-cycle during ovulation. In women with bleeding disorders, this can sometimes involve a small amount of internal bleeding into the abdominal cavity, which causes a dull ache or significant tenderness.

² To identify a heavy menstrual bleeding please use a simple 7-2-1 rule. Available in different languages [here](#).

Chronic Pelvic Pain

Long-term heavy bleeding can lead to conditions like endometriosis or iron-deficiency anaemia. Chronic anaemia itself can cause persistent headaches, muscle fatigue, and a "heavy" feeling in the limbs.

Always report any pain related to women's health to your healthcare provider! Most pain is manageable, and your quality of life can be improved! Being a woman does not mean suffering in silence every month.

Pain Management in Bleeding Disorders

Bleeding Disorder Treatment "Burden"

Newer treatment options may reduce the overall treatment "burden" of living with a bleeding disorder. Better haemostatic control may also have a positive impact on pain related to living with a bleeding disorder. Medications that require fewer injections to achieve adequate haemostasis may help reduce pain and trauma associated with intravenous access. However, for many people this is not the case, and they may still require daily infusions.

A tip to reduce the pain from venous injection: find the right needle (the right thickness and sharpness) by trying different options.

Note: if you are on demand for factor replacement therapy, and you have pain, but you are not sure whether it is a bleed, infuse yourself within two hours, and then investigate the reason with your clinician.

Analgesic Ladder and Safety

Acute Pain Management

The WHO Analgesic Ladder³ suggests starting with non-opioids and moving to stronger medications as needed. It focuses on individualised care, often using adjuvant medications to achieve freedom from pain.

- Step 1: Mild Pain: Non-opioid analgesics (e.g., paracetamol, aspirin, other NSAIDs) with or without adjuvant medications.
- Step 2: Moderate Pain: Weak opioids (e.g., codeine, tramadol, hydrocodone) plus non-opioids and adjuvant medications.
- Step 3: Severe Pain: Strong opioids (e.g., morphine, fentanyl, oxycodone) plus non-opioids and adjuvants.

³ Ventafridda V, Saita L, Ripamonti C, De Conno F. WHO guidelines for the use of analgesics in cancer pain. *Int J Tissue React.* 1985;7(1):93-6.

Chronic Pain Management

Opioids are strictly not indicated for managing chronic pain in bleeding disorders. Instead, pain management relies on a multidisciplinary team (MDT) approach. Pharmacological options are carefully selected alongside MDT care and may include anti-inflammatories if the pain is classified as secondary chronic pain linked to joint damage (arthropathy).

NSAID Warning

Using anti-inflammatories like aspirin, ibuprofen, or naproxen is often discouraged because they can stop platelets from working, making bleeding risks even higher. If an anti-inflammatory is absolutely necessary, a specific class of prescription NSAIDs known as COX-2 selective inhibitors (such as Celecoxib (Celebrex), Etoricoxib or Parecoxib) is preferred.

 **Crucial Caveat:** "Safer" does not mean entirely risk-free. Even COX-2 inhibitors carry small risks of spontaneous GI bleeding and cardiovascular side effects. For general mild-to-moderate pain that does not involve severe swelling, Acetaminophen (Paracetamol) remains the true first-line choice. **Always seek advice from your haematologist before using any anti-inflammatories.**

Important Note on Pain Relief for Women

NSAIDs are the "gold standard" for period pain only in the general population. Discuss "haematologist-approved" alternatives like tranexamic acid (to reduce flow and thus reduce clot pain) or hormonal options with your specialist.

Preparing for Your Consultation

Reflecting on these clinical questions will help you and your clinician have a more focused and productive discussion.

1. Understanding Your Current Pain

- Describe the pain using the TILT method.
- What pain is bothering me the most today?
- Is my pain worse today than yesterday?
- Am I worried about this pain? Why?
- Am I concerned that it could be a bleed? What makes me think that?
- Is this pain new or different from what I usually experience?

2. Pain and Activity

- Does the pain appear during or after activity?
- If I repeat the same activity, is the pain better or worse the next day?
- Has this pain stopped me from doing something important (walking, working, exercising, sleeping)?

- When was the last time this pain felt easier? What was different then?
- What do my "good days" look like?
- What happens on my "bad days"?

3. Pain and Bruising

- When I have a bruise, what am I most worried about: the intensity, the duration, loss of mobility, or the risk of a bleed?
- How long does it usually take me to recover?

4. Tolerance and Expectations

- What does "manageable pain" mean to me?
- Do I expect to be completely pain-free, or would improvement be enough?
- How does pain affect my mood, sleep, or confidence in moving?

5. Management History

- What has helped me in the past (rest, movement, cold/heat, relaxation)?
- What does not help or makes it worse?
- What would I like to improve most right now?

Chronic Pain Consultation Questions

Just because you have lived with chronic pain for years doesn't mean it isn't important clinical information.

- Does my pain feel like it has become "part of the background" of my day?
- Am I avoiding certain movements or social activities because I am *afraid* of the pain starting, rather than the pain itself?
- How does my chronic pain change my mood or my ability to focus at work/school?
- On a "bad day," what is the one thing I wish I could do that the pain currently prevents?

Consultation Questions for Women and Girls

- Use TILT to talk about the following: how many days before the period does the pain start, does it affect only the central area, or does it extend into the back and down the legs, does it affect bowel function or the urinary tract, and does anything relieve it? (hot water bottle, bath, etc.)
- "Product" Count: Do I soak through a pad or tampon every 1–2 hours on my heaviest days? Or do I need more than 20/day?
- Clotting: Am I passing clots larger than a 1-euro coin? Is the pain sharper when I pass them?
- Ovulation: Do I feel a sharp pain in my lower abdomen midway through my cycle?
- Anaemia Symptoms: Do I feel a "heavy" fatigue or have frequent headaches that correlate with my cycle?

- Medication Safety: Am I taking any over-the-counter pain relief (like ibuprofen) that might actually be making my bleeding worse?

When to Call the Clinic Immediately: Recognising "Red Flags"

While chronic pain can be managed over time, certain types of pain signal an acute emergency - such as a new bleed - that requires immediate action. Contact your haematologist or go to the emergency room if you experience:

- Sudden-Onset Intensity: A rapid increase in pain that feels "different" from your usual daily soreness or chronic stiffness.
- "Bubbling" Sensation: An unusual feeling of warmth, tingling, or "bubbling" inside a joint, which is often the first sign of an active bleed.
- Loss of Mobility: A sudden inability to move a limb, put weight on a joint, or a noticeable decrease in your usual range of motion.
- Severe Sensory Changes: Intense "electric-shock" sensations, sudden sharp pain, new-onset numbness or tingling.
- Physical Changes: New or rapidly increasing swelling, redness, or skin that feels hot to the touch over a joint or muscle.

Clinical Tip: If you are unsure whether the pain is a bleed, it is always safer to treat it as one and contact your clinician immediately. Clearly described "Red Flag" symptoms help your team provide treatment faster.

Expert and Patient Insights

- Trust your body: You know your body best. If something feels off, there is a reason for that, no matter what others tell you. Even small things need to be reported, especially when you have a rare condition. Small things can actually be big things. Don't suffer in silence. Some patients report having a panicking feeling, which they recognise as a signal of a serious bleed taking place. Your mind and body are connected better than you can imagine.
- Describing Severity: When speaking to a doctor unfamiliar with joint bleeds, it is often difficult for them to gauge the severity. Compare a severe joint bleed to an intense toothache to help them grasp the level of pain.
- Focus on "Function" over "Feeling": clinicians can often treat a functional loss more effectively than a pain number alone. While you will always be asked to evaluate your pain on a scale from 0 to 10, as part of the protocol, don't focus exclusively on numbers. Describe your functionality loss, too. Examples: "Because of this pain, I cannot walk normally for two weeks," or "I cannot sleep through the night because of the throbbing".
- Holistic Care: Treat pain holistically. Consider physiotherapy, exercise, and mental health alongside medication.
- Mental Strategies: Just as you use medication for physical pain, you can use mental strategies to help "suppress" or cope with the mental burden of chronic pain. One of our patients said, *"You have to distract yourself; it's what gives you a higher pain tolerance."*

When you find a way to distract your mind, you aren't constantly thinking about the pain or focusing on the joint and the bruise that hurts."

- Connection: Having someone who understands what your pain is like can be hugely valuable.

Pain is not only biological - it is also psychological and social. Talking openly about your fears, expectations and daily challenges helps your physiotherapist understand the full picture.

The goal is not only to treat a joint, nerve, or muscle, but to help you move with more confidence, less fear, and a better quality of life.

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