On the move with haemophilia

Haemophilia is a rare genetic bleeding disorder where the blood does not clot properly because of the lack of an essential blood protein, called *clotting factor*, that helps control clotting and prevent bleeding.

That people with haemophilia bleed to death is a common misconception. They do not bleed any faster than anyone else, but their bleeding continues for longer. Internal bleeding into the joints and muscles can be a serious concern, and so risks of bleeding should be avoided or minimised.

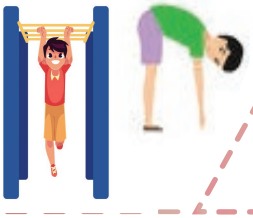
To prevent bleeds, protect joints, and maintain overall health, people with haemophilia can benefit from physical activity, like exercise and sports. The health risks from inactivity can be substantial and long lasting, so young people with haemophilia should be encouraged not only to undertake appropriate physical activity but also to be aware of the risks of inactivity and injury and how to manage bleeding.

Benefits of exercise or sport for people with haemophilia

Helps develop strong and flexible muscles that could help prevent injuries and as a result help prevent bleeds and joint damage

Strengthens bones and helps reduce risk of osteoporosis and fractures

Boosts mental health



Improves balance and coordination

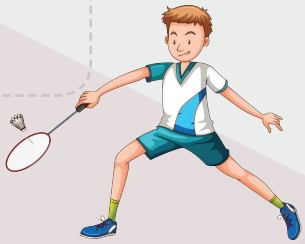
Helps maintain healthy weight and decreases strain on joints

Factors to consider when choosing suitable exercises and sport for the child with haemophilia

Strength

Flexibility

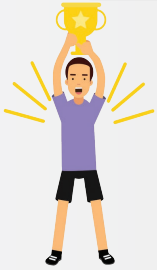
Coordination



Balance

Fitness

Motivation



Before engaging in exercise or sport

Sports or exercises, especially those with a lot of physical contact or collisions, repetitive or extreme movements or involving high speeds or great heights, can have the highest risk of injury for a person with haemophilia, so precautions should be taken to decrease the risk. Here are some of them:

- Involve the haemophilia care team when choosing a sport or activity. Assessment by the doctor and ongoing monitoring by a haemophilia physiotherapist may be needed.
- Use suitable and standard protective equipment and attire (e.g. correctly fitting shoes, bike helmet, padded gloves, leg pads).
- Use additional protective wear such as bracing or taping as recommended by the physiotherapist.

Consider the young person's interests, physical ability and fitness, medical history, and any risks of complications. **Keep in mind that key reasons for young people to participate in sports and exercise include the chance to hang out with friends and to have fun.**

Warming up and cooling down

To help reduce the risk of injury, it is important to do pre-exercise warm-up and then cooling-down exercises.

Warm-up provides a transition from rest to exertion and reduces the risk of injuries.
Cool-down gently works the major muscle groups to actively remove waste products, which can help decrease muscle soreness and stiffness.

Warm-up and cool-down exercises need to be individualised by consulting with a physiotherapist and treatment centre.

Pre-exercise factors replacement

When discussing treatment plans with the young person and their parents or carers, the haemophilia care team will need to take sporting activities into account. The young person with haemophilia should follow the protocol for factor replacement therapy as discussed with their haemophilia care team. This might involve injecting factor replacement concentrate prior to the activity, if needed. The possibility of unplanned exercise or physical activities should also be considered, and it is recommended that factor replacement therapy be readily available to manage any injuries that may arise in these situations.

Preventative treatment, also called *prophylaxis* or *prophy*, is used to minimize the risk of bleeding, pain and damage to the joints and muscles. This is done by injecting doctor-prescribed factor replacement therapy (commercially prepared clotting factor concentrate), usually by the young person or their parent at home.

Recognising a bleeding episode

Joint bleeds

The risk of a bleeding injury to the joints depends on both the individual and the activity. Factors related to the individual include their strength, fitness, body conditioning, previous injuries, and skill level. Factors related to the specific sport or exercise include playing surface, nature of body contact, use of protective equipment, and the player's position on the field or court.

Early signs of a joint bleed

- Tingling or tight feeling in the joint
- Pain and discomfort with movement
- Affected joint may feel warm to the touch

Later signs of a joint bleed

- Pain at rest
- Swelling
- Tenderness
- Severe loss of motion

Bleeding in the joint can cause severe damage and blood may remain in the joint for up to 14 days, long after the pain has gone. The joint might be permanently damaged if bleeding is repeated. **So, all joint bleeds should be managed and rehabilitated to prevent long-term damage.**

Arthropathy is the term used to refer to joint damage that is like arthritis. It can affect range of motion or mobility, cause chronic pain, and can weaken muscles.

Muscle bleeds

Bleeds can happen in any muscle, and the cause is often easy to recognise, such as a direct blow or a pulling or tearing sensation with exertion or overstretching. Identifying and treating muscle bleeds early helps prevent re-bleeding and permanent muscle damage.

Signs of a muscle bleed

- Aching within the muscle
- Tenderness when muscle is touched
- Pain when muscle is stretched or forced to contract
- Pins and needles or numbness
- Limping if the leg muscle is affected
- Visible swelling

Permanent muscle damage can result from bleeding that is repeated or not properly rehabilitated. If bleeding occurs in deep muscles, nerves and blood vessels can become damaged, which can cause numbness, loss of muscle function, or muscle death. Muscles that develop scarring after healing can adversely affect flexibility. This can lead to further muscle injuries and can place additional strain on surrounding joints.

Any bleeding episode in a person with haemophilia, regardless of severity, can be serious and will need medical advice and treatment. **Some bleeds can be life threatening (e.g. those in the head, spine, neck, throat, chest, or stomach). Seek medical assistance immediately.**

Recovering from a bleeding episode

A person with haemophilia should take adequate time needed to fully recover from a bleeding episode. Often the amount of time to recover from a joint or muscle bleed episode is longer for a person with haemophilia compared to the recovery time for sports injuries that may occur in a person without haemophilia.
Factor replacement therapy should be given as soon as possible after the injury or at the first sign of discomfort. Following the P.R.I.C.E.R. method to help reduce pain and swelling is also recommended.

P.R.I.C.E.R. treatment of joint and muscle bleeds

P.R.I.C.E.R. stands for protection and product, rest, ice, compression, elevation, and rehabilitation. This method reduces the risk of swelling and pain of joint and muscles.

	**Protect and Product** • To prevent further damage • Stop the activity and avoid weight bearing • Self-administer clotting factor concentrate to control bleeding
	**Rest** • Rest the affected arm or leg • Use a splint, sling, or crutches if necessary
	**Ice** • Apply ice or cold packs for 15-20 minutes every 2 hours • Wrap ice in a towel to prevent burning
	**Compression** • Apply compression using a wrap or bandage
	**Elevation** • Elevate the affected limb • Assessment by haemophilia care member or healthcare professional
	**Rehabilitate** • For every bleed • Minimises risk of permanent damage

Remember that a person with haemophilia does not bleed any faster than anyone else, but rather their bleeding continues for longer. **Any bleed should be reported to the haemophilia care team.**

Rehabilitation

The ultimate goals of rehabilitation are:

- preventing re-bleeds
- healing joints and muscles
- controlling pain, and
- getting the young person back to physical activity.

Returning to physical activity after a bleeding episode does not follow standard timelines. **Each bleed and person is unique.** The haemophilia care team or Haemophilia Treatment Centre will be able to give individualised advice that will help with this.

To lower chances of a re-bleed, the young person with haemophilia should resume activities gradually and under the guidance of their care team, including their physiotherapist. **With the young person's or family's consent, communication between the physiotherapist and teacher or coach should also be encouraged so that the correct rehabilitation message is relayed.**

Rehabilitation by a physiotherapist is the gold standard of care after every bleed before resuming exercise or sport. The physiotherapist uses various tools and techniques, including muscle strengthening, range of movement exercises, monitoring, use of crutches, slings, splints, or wheelchairs, and education.

Resources

If you need more information or support, contact your local Haemophilia Treatment Centre:

- Australia – *https://www.haemophilia.org.au/support-services/treatment-services*
- New Zealand – *http://www.haemophilia.org.nz/assets/Docs/Haemophilia-Treatment-Centres-NZ.pdf*

Or visit the haemophilia foundations of Australia and New Zealand:

- Haemophilia Foundation Australia – *https://www.haemophilia.org.au/*
- Haemophilia Foundation of New Zealand, Inc. *http://www.haemophilia.org.nz/*

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