

Things to remember

Society

Faemophilia

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- Every child is different. Sports and activities must be enjoyable, accessible and be something they will want to continue with.
- Access to green spaces, pavements and cycle routes make physical activity part of daily life.
- The risk of injury for all sports can be minimised if appropriate precautions and strategies are in place.
- Pain and discomfort in muscles and joints after exercise is normal; however, if you have any concerns contact your child's physiotherapist or nurse.
- If a joint or muscle bleed is suspected in your child, contact your haemophilia team for further advice.
- **P.R.I.C.E or POLICE** (whichever your centre recommends)

P.R.I.C.E. - Protection / Rest, Ice, Compress, Elevate.

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The Little Bleeders Fund provides grants for young people with bleeding disorders and mobile activities. Grants are available to help towards the to help towards the to help towards the duipment, travel,





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- POLICE Protection, Optimal Loading, Ice, Compression, Elevate.
- Be honest with your haemophilia centre about what activities you want to do or how you sustained an injury. This way they can give you the best support to recover and achieve your goals. Please continue to talk to your doctor or specialist nurse if you are worried aboit any medicl issues your child may have.



A-Z guide to sport and physical activity for children with a bleeding disorder The following information is a guide to encourage you and your child with a bleeding disorder to get moving with confidence.

Active: Children aged one to five should be active for at least 3 hours per day. The activities should be varied throughout the week and include some that help strengthen their muscles and bones. These could include playground activities, jumping, climbing, dancing, scooting, swimming, cycling, and messy play. The key is every movement counts.

Babies: All babies need to be given the opportunities to develop their movement skills. No matter what stage, babies will learn best when provided with a variety of different positions and environments to practice their developing skills; for example, supervised tummy time on a mat or using toys to encourage them to move when learning to roll or crawl. Don't let their bleeding disorder stop you from facilitating their normal development.

Choosing sports: When choosing a sport for your child, it's important to consider their interests, physical capabilities and any previous injuries. Ensure that the benefits of playing sports outweigh the potential risks of injury or bleeding. While most sports can be enjoyed safely, seeking personalised advice from your child's haemophilia team before starting any new activity is recommended.

Development: Encourage and support their normal development; children learn and grow through physical exploration and practice, whether learning to stand, walk, run, jump, catch, throw, and hop. It's vital you let your child practice these skills. Developing these physical skills and abilities leads to physical competence which plays a role in protecting from injury.

Exercise: Being strong, healthy, and fit can help reduce the risk of injuries and bleeds. Regular exercise has lots of health benefits, not just building stronger bones and healthier muscles. It encourages healthy growth and development, improves self-esteem, improves posture and balance, lowers stress and encourages a better night's sleep.

Family: Remember that your child will be influenced by your habits. Healthy and active parents will have healthy and active children. Have you considered being physically active together, a family bike ride, a walk together, a spot of yoga or playing games.

Guidelines: Children with a bleeding disorder should be encouraged to meet national guidelines for physical activity participation, just as their peers. Children aged 5-18 should be physically active for at least 60 minutes per day. The correct level of activity is when you are still able to talk but feel a bit breathless. The 60 minutes does not have to be done all at once, you can break it up into smaller more manageable sessions.

High risk: Participating in any activity or sport carries the possibility of injury and bleeds. Certain activities may have a higher risk of serious injury, particularly those affecting the head or neck. The level of risk can be affected by several factors, including age, type of sport, level of intensity, competitiveness, environment, and underlying health conditions. If your child participates in a high-risk sport or activity, your haemophilia centre can advise on reducing risks or considering alternative options.

Injuries: Injuries happen, whether it's a cut or graze, a sporting injury such as a sprain or strain or a muscle or joint bleed. Understanding what you need to do for your child when an injury occurs is important. This could be just 'normal' first aid measures or be more specific advice on who to contact or what medicine is advised by your haemophilia centre.

Joints: The aim is to prevent joint bleeds but if a joint bleed happens it is important that each bleed is managed and followed up appropriately. Seek advice from your haemophilia centre when it first happens, ensure you have guidance on recovery and returning to sports. Keeping your child's joints in good condition when young, will benefit them as adults. Move more: Reducing the time spent sitting is important for physical health. Break up long periods of sitting with movement, stand up and a stretch or a quick game. Think about how much time is spent in front of screens throughout the day. This includes watching TV, time on tablets, game consoles and phones. Reducing screen time is another way of ensuring you move more.

Not all about sports: Being active doesn't have to mean organised sport. It can be active travel such as biking or walking to nursery or school, taking the stairs rather than the lift, or helping with jobs around the house. Engaging in playful activities like hide and seek, treasure hunts, obstacle courses or imaginary adventures in the park are also great ways to stay active.

Overweight: Think about whether you are supporting your child to maintain a healthy weight, through a balance of being physically active and having a healthy, varied and balanced diet. Being overweight can impact on the health and function of joints and muscles.

Physical Education: All children with a bleeding disorder should be included and participate in PE and sports. Ensure the school, teachers and coaches understand your child's bleeding disorder. Think about whether there are any specific considerations, any adaptations to the lessons or things that should be avoided. Good communication between the school, yourself and the haemophilia centre are essential.

Questions: Your haemophilia centre will help you and your child stay physically active while ensuring safety. It's important to ask questions, as they can offer you personalised advice. Don't hesitate to seek help, no matter how many questions you may have.

Recovery: After any injury or bleed, a time of recovery is vital. What to do during the recovery and for how long will vary depending on factors such as your child's age and the site and severity of the bleed. Recovery will be guided by your haemophilia centre; it may include activities to avoid and specific exercises to promote a full recovery. Not following the appropriate recovery guidance could lead to more problems both in the short or long term.

School: Inclusion and participation in physical activity at school, are important for your child physically, socially, and emotionally. This will include play times, PE and after school clubs. To ensure this is done safely, communicate with the school about your child's bleeding disorder, any specific considerations, and what to do in the event of an 'accident'. Allowing your child to participate helps develop the skills and strength they will need to manage their bleeding disorder when older.

Treatment: Whether your child is on 'prophylaxis' or 'on demand' treatment, it is useful to communicate to your haemophilia centre what sports and physical activities they do to ensure their treatment meets their individual needs. Some children on 'prophylaxis' can have their treatment tailored around their sports and physical activity to reduce the risk of a bleed. Some children may need different treatment during and recovering from a bleed. Please discuss this with your haemophilia centre team.

Understanding: It's important that you or anyone who looks after your child knows what to look out for in terms of a possible joint or muscle bleed. Knowing the signs of a joint or muscle bleed in your child is important. Symptoms may include pain, stiffness, swelling, or limited movement. Contact your haemophilia centre immediately if you have any concerns as this can speed up the recovery process.

Vigorous Activity: Activity which gets the heart rate up and makes you slightly breathless (but still able to speak) such as swimming, running, cycling, walking up the stairs, skipping, dancing, scooting or ball sports should be included into

Keep it fun, keep it going: Keeping sports and physical activities fun and enjoyable will help to encourage your child to remain active throughout their childhood. Establishing good physical active habits when young influences good physical activity habits for life, therefore continuing to benefit both their health and joints.

> Lower the risks: Using specific strategies can help reduce injury risk in physical activities and sports. Proper equipment, following rules/supervision, considering surroundings and others' skills, and being prepared are key to lowering the risks.

the weekly routine.

Where you are: It's worth exploring the resources, facilities and opportunities available in your community, such as those provided by schools, swimming pools, leisure centres and local parks. These places may offer activities and opportunities that can encourage children to stay active.

- **EXample:** Talk to your physio or nurse for examples of activities, routines, safety measures and injury management. Connect with others with bleeding disorders, they can give examples they have used while taking part in sports and physical activities. Speak to your nurse about this.
- Yoga: Have you thought about yoga or similar exercise sessions? The skills learned of body awareness, posture, muscle strength, flexibility and mobility are all skills which will have benefits to minimising joint bleeds and injury. It could be practicing stretches or yoga poses at home, following a video class or finding a specific lesson.
- Zzzzzz: Sleep is essential for a child's physical health, mental well-being, growth, and development. It is also necessary for the body to recover after exercise or an injury. Establishing a bedtime routine can support your child's body clock and promote relaxation.