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Ministry of Health

Hemophilia

Overview:

- Hemophilia is a rare genetic bleeding disorder in which the blood doesn't clot normally because it lacks sufficient blood-clotting proteins (clotting factors).
- Hemophilia is caused by a mutation or a change in one of the genes that provide instructions for forming blood-clotting proteins.
- Although the different types of hemophilia have very similar signs and symptoms, they are caused by mutations in different genes.
- There is no way to cure hemophilia, but there are ways to reduce the risk of bleeding complications.
- It is important to seek medical consultation and genetic counseling to prevent passing on this genetic disorder to your child.

Definition:

Hemophilia is a rare genetic bleeding disorder that is caused by a deficiency or lack of blood-clotting proteins (clotting factors). This disorder mainly affects males. Hemophiliacs don't have as many clotting factors as there should be in their blood, so this means that they bleed for a longer time than usual after an injury. It can also lead to organ and tissue damage. The severity of the condition is determined by the amount of clotting factors present in the patient's blood; the less clotting factors a patient has the more severe the condition.

Types:

- Hemophilia A (classic hemophilia): It occurs when clotting factor VIII is either absent or not present in sufficient amounts, and it is the most common type.
- Hemophilia B: It occurs when clotting factor IX is either absent or not present in sufficient amounts.

- Hemophilia C: It occurs when clotting factor XI is either absent or not present in sufficient amounts.
- Acquired hemophilia: It is an autoimmune disorder that is not caused by inherited genetic mutations. This condition is characterized by abnormal bleeding in the skin, muscles or other tissues, and it usually starts during puberty. The exact cause is still unknown.

  Hemophilia A and B are the most common types of hemophilia in the Arab world.

Other names:

Inherited bleeding disorder.

Causes:

When bleeding occurs due to injury, the body normally responds by ordering blood cells to clump together and form a blood clot to stop the bleeding. Closing the damaged blood vessels prevents excessive blood loss. People with hemophilia don't have as many clotting factors as there should be in their blood. This means that they bleed for a longer time than usual after an injury.

Risk factors:

- Genetics.
- Gender; It affects males more than females.
- Pregnancy.
- Cancer
- Autoimmune diseases (such as: multiple sclerosis).

Symptoms:

Symptoms of hemophilia vary from mild to severe, depending on the patient's level of clotting factors. The main symptom of hemophilia is uncontrollable bleeding; hemophiliacs may also experience:

- Pain, swelling or burning sensation in the joints.

- Unexplained bruises due to internal bleeding. When blood gets trapped in an injured area, it may form a solid swelling of clotted blood (hematoma).
- Bleeding gums especially after tooth loss.
- Bleeding after circumcision.
- Bleeding after vaccinations.
- Bleeding in the head of an infant after delivery.
- Blood in the urine or stool.
- Frequent nosebleeds.

When to see a doctor:

It is important to seek medical attention in the following cases:

- Easy bruising.
- Uncontrollable bleeding.
- Pain and swelling in the joints (joint bleeds).

Complications:

- Internal bleeding.
- Adverse reaction to blood clotting medications.
- Joint damage.

Diagnosis:

Hemophilia is diagnosed with blood tests to determine if clotting factors are missing or at low levels. There are three ways to determine whether a person has hemophilia, including:

- Family history.
- Laboratory tests: A complete blood count (CBC) test to measure the coagulation rate, and determine the type of hemophilia and the severity of the disorder.

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Treatment:

There is no way to cure hemophilia, but there are treatments that can reduce the risk of bleeding complications especially bleeding in the brain or joints; these treatments include:

- Genetically modified recombinant clotting factors for the prevention and treatment of prolonged bleeding; these medications are administered through intravenous tubing, usually by an injection into a person's vein or below the skin.
- Preventive treatment: Certain medications are used to prevent or reduce the frequency of bleeding episodes.

Prevention:

The best way to prevent hemophilia is through genetic counseling before pregnancy to prevent passing on this genetic disorder to your child, especially if the disease runs in the family.

Guidelines for patients suffering from hemophilia:

- The best way to avoid joint bleeds is by knowing, preemptively, when bleeding is likely to occur, and take the clotting factor in due time before the joint is affected.
- Treating joint bleeds must be supervised by a medical team, so that they can provide the patient with the clotting factor as soon as possible.
- Engage in regular physical activity, after consulting your doctor and determining the appropriate type of exercise for your condition.
- Maintain a healthy weight to protect your joints.
- Avoid taking nonsteroidal anti-inflammatory drugs (NSAIDs)(such as: Aspirin); as some may disrupt your blood's ability to form clots.
- Maintain oral and dental health to prevent excessive bleeding due to tooth extraction.
- Be sure to consult your doctor before undergoing any surgery, to ensure that all the necessary precautions are taken.

- Make sure to protect your children from any equipment or tools found at home or elsewhere to prevent injuries and bleeding as much as possible.
- Limit play-time injuries by making your child wear a helmet, and protective knee and elbow pads.
- Make sure that your home is free of furniture with sharp edges, and always remember to keep sharp objects out of children's reach.
- Be sure to use the safety belts and straps in highchairs, car seats, and strollers to protect your child from falls.
- Parents also should learn how to examine their child and recognize signs of bleeding.
- Ensure that your child wears a medical ID bracelet that indicates their condition.
- Children are allowed to engage in physical activity as it helps keep their muscles flexible, and strengthens their joints. Children and adults who have hemophilia should be physically active, but there may be some limits.
- Avoid contact sports and other activities that are likely to lead to injuries and bleeding. (Examples of these activities include: football, hockey, and wrestling).
- Inform your child’s school and teachers about their condition, and make sure that their physical activity trainers are informed as well if your child is allowed to participate in contact sports.

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Frequently Asked Questions:

- **Are aspirin and anticoagulant drugs safe for people with hemophilia?**
  People with hemophilia should not take aspirin or other NSAIDs.
- **Are there other drugs that can aggravate bleeding?**
  There are many drugs that can increase bleeding severity (such as: aspirin, ibuprofen, and diclofenac), in addition to certain antidepressants (such as: fluoxetine), as well as anticoagulants and blood thinners (such as clopidogrel and warfarin). This shows that hemophilia patients should always consult a doctor before taking any medications.
  Is it possible to determine whether the fetus has hemophilia during pregnancy?
  Yes, it's possible.

Misconceptions:

- **All mothers with hemophilia pass on the disease to their children.**
  Fact: The chance of passing on the disease to the child is 50%.
- **Physiotherapy can increase the symptoms of hemophilia.**
  Fact: Physiotherapy can relieve hemophilia symptoms, and improve joint recovery.
- **Hemophilia patients should avoid physical exercise**.
  Fact: on the contrary, engaging in physical exercise strengthens the muscles, and protects the patient from bleeding or damaging their joints. However, it is very important to exercise with caution and choose non-aggressive sports, such as: swimming and walking.

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