

Symptom Management

Bleeding

Bleeding refers to blood coming out of the blood vessels. It may be oozing, trickling or flowing. Bleeding can be something that happens inside the body. There may be bleeding with no obvious sign of blood. It may, however, be a flow of blood that you can see.

The risk of bleeding increases when the child:

- * has a condition that affects any of the organs that play a part in making the blood cells – spleen, liver, bone marrow. Bleeding is more likely when the blood cannot clot quickly (low platelets or other clotting elements);
- * has a disease that affects the blood vessels so that they become more fragile and break easily;
- * is not able to take in the vitamins and other things that are needed to produce healthy blood cells.

Watch for these signs of bleeding

- * blood that suddenly appears e.g., gums or nose;
- * bleeding that goes on too long after a cut, poke or scrape;
- * bruising or red spots that just appear on the skin (called petechiae);
- * very dark, loose stools;
- * vomit that looks bloody or like “coffee grinds”;
- * reddish brown urine;
- * red or brown mucus coughed up;
- * heavier than normal menstrual flow;
- * severe headache or other sharp pain;
- * changed level of response or drowsiness;
- * fatigue and/or weakness;
- * shortness of breath;
- * dizziness;
- * faster than usual heart rate;
- * swelling;
- * broken blood vessels in the eyes.

Some children and adults find blood frightening. It is important to do something about both the bleeding and the feelings.

Preventing bleeding

- * **Check with your doctor before giving drugs**
Ibuprofen and aspirin make it harder for the blood to clot.
Do not give your child any medications containing aspirin.

- * **Protect the skin**
Keep skin clean and moist. Wash/bathe regularly. Use only an electric razor to prevent nicks while shaving. Keep the finger and toe nails trimmed (not too short).

- * **Prevent constipation**
There are large veins in the rectum (hemorrhoids). They can break when straining during bowel movements. See the “Constipation” handout for more tips.

- * **Avoid putting anything into the rectum**
Don’t take a rectal temperature, give a suppository or enema, or do a rectal examination unless your doctor or nurse tells you that there is no alternative.

- * **Do not give needles unless essential**
If your child must have an injection, press hard on the site for 5-10 minutes after the poke.

- * **Protect the gums – they bleed easily**
Always check with your doctor before dental work. Give soft food. Use a soft toothbrush, “toothettes”, or even sponges for cleaning the gums. Do not floss teeth.

- * **Avoid activities where there is a high risk of injury**
Protect younger, active children against bumps and scrapes with a padded helmet and padded side rails on the bed.
Discourage sports with a high risk of injury.

- * **Take special care to prevent nosebleeds**
Nosebleeds often start with nose picking, a hard blow or harsh sneeze. Dry mucous can scratch the lining of the nose and cause a nosebleed. You can prevent this by keeping the nostrils moist with nasal ointment (available at the pharmacy) or petroleum jelly.

Aspirin is listed on labels as acetylsalicylic acid.

Managing bleeding

* Apply pressure when possible

If there is a cut or breakdown of the skin, cover the wound with a clean bandage and press down on the area for 4 minutes. This gives the blood time to clot. (Don't lift the cloth and peek.) Sometimes using an **ice pack** will help. Fill a freezer bag with ice.

* Manage nosebleeds

Nosebleeds may start for no reason at all.

- ◆ If a nosebleed does start, squeeze above the nostrils.
- ◆ After 10 minutes, if the bleeding does not stop or slow down
 - try squeezing while someone holds an icepack on the back of the child's neck.
- ◆ After another 5 minutes, if the bleeding still does not stop
 - call your doctor or nurse. Your child's nose may need to be packed with medicated gauze.

* Reassure and calm your child

Be a calm, reassuring presence. Hold your child's hand or hold her in your arms. Use a confident and soothing voice. Sometimes music helps relax and distract.

* Have a plan to manage bleeding

With the doctor or nurse, review what actions you should take if your child starts to bleed. Write these actions down and have them handy.

* Treat the underlying cause

In some children bleeding is a part of the dying process. Treatment that contributes very little to comfort may be a poor choice for your child. (Refer to the handout "Making hard decisions about care.")

Talk with your doctor and nurse about whether there are benefits in treating the cause of the bleeding during this phase of your child's life. Depending on the cause, the doctor may suggest vitamin K, platelet or plasma transfusion.

Do not put ice or icepacks directly on the skin. Wrap in a towel. Apply for 10 minutes.

Parent voice:

Transfusions were the hardest thing to give up on. They had been our lifeline for so long. But, honestly, I couldn't close my ears anymore to his plea to 'just stay at home now'. I had to respect his wishes.... At the hard decision points it helped me so much to go back to what I had said earlier about quality of life.

Getting professional help when appropriate

Call your doctor or nurse during the day if you see:

- * any of the signs/symptoms listed above

If you have not already decided on a plan, call your doctor or nurse as soon as you can if:

- * you cannot stop the bleeding after two attempts to apply pressure;
- * he has a new pain (including headache) that is not going away with your regular plan;
- * she becomes unresponsive, or, you cannot wake her
- * breathing is a problem;
- * you are frightened and need to talk to someone right away.

When you call, give your child's name, age, and diagnosis. Be ready with this information:

1. When did the bleeding or other signs start? Where?
2. How much blood has there been?
3. When and what treatments/medications/blood work has your child had?
4. Has this happened before? What did the doctor do then?

End note

As your child's condition gets worse, and he comes closer to the end of his life, you may come to realize that the "tried and true" ways of managing bleeding aren't working very well anymore. Some children will have some oozing or minor bleeding in their last hours. A few will have a **major bleed** and this will be the way they die. Sometimes the bleeding is internal and you cannot see it. But blood may come out of any opening in the body (e.g., mouth, nose or ears). Because seeing a lot of blood may be frightening, it will help if you are prepared.

A child who dies from a major bleed seems to fade away.

