



YOUR GUIDE TO

Understanding VOD/SOS associated with your or your loved one's stem-cell transplant

**Learn about the signs and symptoms
of VOD/SOS, and then work with your
transplant team if they occur.**

VOD/SOS=veno-occlusive disease/sinusoidal
obstruction syndrome.



Jazz Pharmaceuticals

What is a stem-cell transplant?

A stem-cell transplant is a medical procedure used to treat different types of diseases, including cancer.

You will receive chemotherapy and/or radiation to prepare your body for the transplant.

There are two types of stem-cell transplants:



Autologous stem-cell transplant

Healthy, blood-forming (hematopoietic) stem cells are collected from the patient and stored.

The patient then receives chemotherapy before the cells are put back in their body.

- This type of transplant is commonly used to treat certain cancers (eg, neuroblastoma, multiple myeloma, non-Hodgkin and Hodgkin lymphoma, and solid tumors) and plasma cell disease (eg, amyloidosis and POEMS syndrome)



Allogeneic stem-cell transplant

Hematopoietic stem cells are collected from another person called a donor. This person can be a full-match donor (eg, a sibling), a half-match donor (known as a haploidentical donor), or an unrelated donor.

- This type of transplant is also commonly used to treat certain cancers and plasma cell diseases, as well as certain genetic diseases and bone marrow failure diseases. You can find more information on the following page



A CLOSER LOOK: _____

Allogeneic transplants have a greater risk of a complication known as VOD/SOS

Since not every transplant recipient will have access to a full-match donor, haploidentical donors have become increasingly more common as they give people more options when it comes to finding a donor.

However, using a non-full-match donor may increase the risk of developing VOD/SOS.

Allogeneic stem-cell transplants are commonly used to treat:

- Certain cancers (eg, acute myeloid leukemia, acute lymphoblastic leukemia, and myelodysplastic syndrome)
- Plasma cell diseases (eg, amyloidosis and POEMS syndrome)
- Genetic diseases (eg, sickle cell disease and thalassemia)
- Bone marrow failure diseases

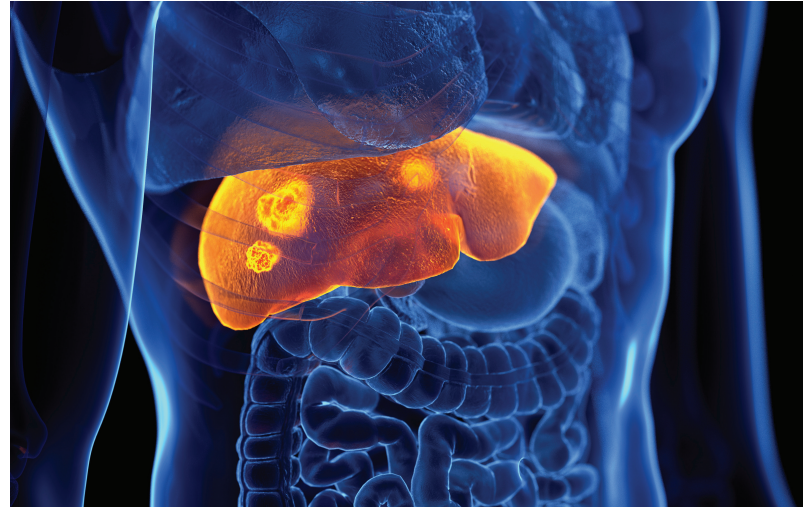
Continue reading this brochure to learn more about VOD/SOS after stem-cell transplant.



What is VOD/SOS?

VOD stands for veno-occlusive disease. It is also sometimes referred to as SOS, or sinusoidal obstruction syndrome.

VOD/SOS is a disease that can damage the small blood vessels of the liver. This damage results in reduced blood flow to and from the liver and impaired liver function. VOD/SOS is a complication of stem-cell transplantation and other risk factors associated with certain chemotherapies given to prepare the body for the transplant.

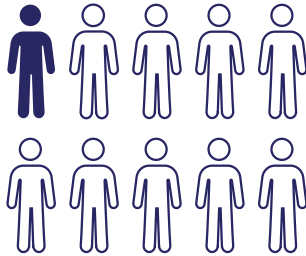


VOD/SOS is a serious condition that can get worse quickly. As you prepare for your transplant, your medical team will do their best to spot and lower the risk of VOD/SOS. By learning the signs, you can help too.



A CLOSER LOOK:

How often VOD/SOS occurs _____



VOD/SOS may occur in

**~1 out of 10 people who receive
a stem-cell transplant**



VOD/SOS occurs in

2 times as many children as adults

What are the risk factors for developing VOD/SOS?

Data shows that VOD/SOS is more likely to develop in people who have received an allogeneic stem-cell transplant (vs autologous). This is likely because the conditioning regimens given to prepare the body for the procedure are more intensive.

The following risk factors put people at a 10-20 times greater risk of developing VOD/SOS:



Prior exposure to the following cancer treatments:

gemtuzumab (jem-too-zoo-mab) **and inotuzumab** (in-oh-too-zoo-mab)



Having high levels of an enzyme in your liver called bilirubin (billy-rubin)



Prior exposure to a birth control medication called norethindrone (nor-eth-in-drone)

Other risk factors that may trigger VOD/SOS

The following put people at a 3-10 times greater risk:



Patient and disease-related factors:

- Age (age <2 or older age)
- Getting sepsis after a stem-cell transplant



Liver-related factors:

- A history of liver disease
- Iron overload (high ferritin levels)
- Having high levels of liver enzymes called aspartate transaminase (AST) and alanine transaminase (ALT)



Transplant-related factors:

- Receiving high-intensity chemotherapy
- Taking medications like sirolimus, tacrolimus, methotrexate, or cyclosporin-A, which are used to prevent certain transplant-related side effects
- Receiving a treatment for aplastic anemia called antithymocyte globulin (ATG)

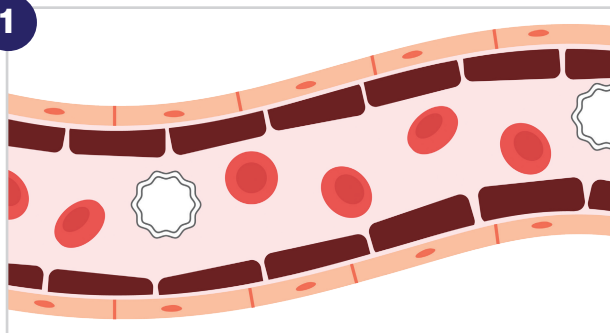


VOD/SOS begins in the liver

When a person is given conditioning regimens to prepare their body for transplant, toxins from these treatments can sometimes build up and damage blood vessels that lead to and from the liver.

This toxic buildup triggers a chain of events that cause the symptoms of VOD/SOS.

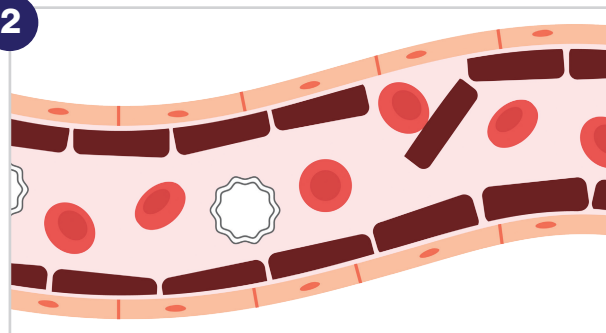
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Before VOD/SOS, the blood vessels leading to and from the liver are healthy.

Healthy endothelial cells form a smooth barrier between blood cells and liver cells.

2



VOD/SOS begins because conditioning regimens have damaged those blood vessels.

Over time, this can cause more harm—for example, damaged endothelial cells can detach from each other, creating gaps where blood cells and/or debris can get trapped.



Red blood cells



White blood cells



Endothelial cells
(en-doe-thee-lee-uhl)

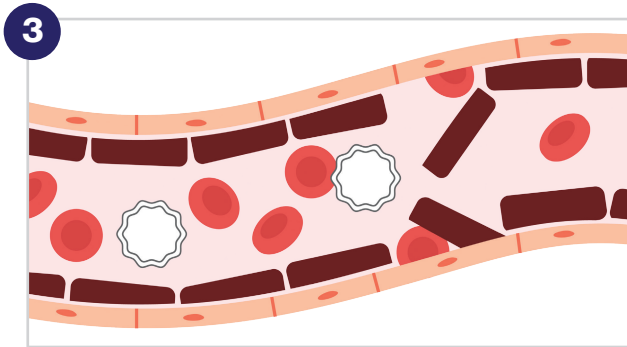


Liver cells



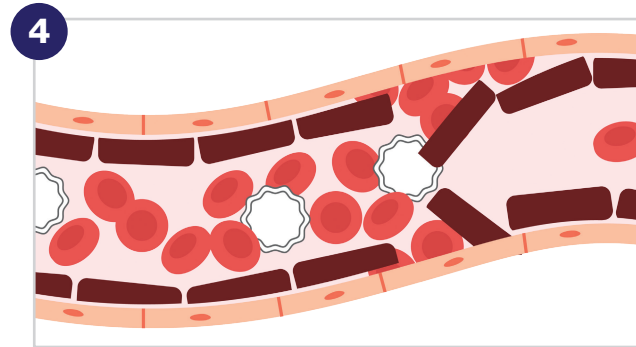
VOD/SOS can progress quickly

As VOD/SOS becomes worse, blood vessels of the liver can become more and more damaged.



As VOD/SOS progresses, the blood vessels narrow.

This allows more and more blood cells to become trapped between the endothelial cells and liver cells. The narrowing of the blood vessels also leads to decreased overall blood flow.



In some cases, the blood vessels can become completely blocked.

Damaged endothelial cells can cause blood cells to form a blood clot, which can prevent blood flow through the narrowed blood vessels. This can lead to liver cell death and reduced blood flow throughout the liver.

Once VOD/SOS has progressed to this point, other organs, like the kidneys and the lungs, may also be affected.

What symptoms should I look out for?

VOD/SOS is marked by a range of symptoms, which most often occur in the first 21 days following stem-cell transplant; however, they can occur later. **You can play an active role in identifying the symptoms and discussing them with your transplant team.**

These symptoms include:

Rapid and persistent weight gain

Rapid and persistent weight gain can be a key sign of VOD/SOS. This happens when the body retains too much water.



Abdominal pain

As fluid builds up in the liver, it will start to swell. This enlarged liver is called hepatomegaly (heh-pah-toe-meh-guh-lee) and **it tends to cause pain and tenderness on the right side of the body, below the ribcage.**



Abdominal swelling

As pressure starts to build in the veins leading to the liver, it causes fluid to leak out into the abdomen. This is known as ascites (as-eye-tees), and it can lead to abdominal swelling.



Difficulty breathing

VOD/SOS can also cause fluid to build up in the lungs, which makes it difficult to breathe.



Swollen arms/legs/feet

As VOD/SOS progresses, it can cause the kidneys to not work effectively. Decreased kidney function can cause swelling throughout the body.



Additional symptoms

Decreased liver function can also cause skin yellowing, known as jaundice (jon-dis), and decreased kidney function can lead to decreased urination.



A CLOSER LOOK: Identifying the symptoms you can't see _____

Your transplant team will be looking at trends over time. Take note of whether you or your loved one requires a platelet transfusion and/or dialysis.



Also note lab results, especially whether any of the following are elevated:

Bilirubin (billy-rubin)

Creatinine (kree-a-tuh-neen)

Serum transaminase (trans-am-en-aze) and **alkaline** (al-kuh-line) **phosphatase** (phos-fuh-tase)

If you notice two or more of these symptoms, let the transplant team know. They can appear as early as a few days after the transplant or even after you leave the hospital.

Be vigilant. Early detection may be your best defense against VOD/SOS.

If VOD/SOS is suspected, your transplant team may perform additional tests

If you suspect that you or your loved one may have VOD/SOS, the most important thing to do is let the transplant team know right away.

You may also want to take notes of which symptoms you've noticed and when you started noticing them so that you can share this information with the transplant team. You can use the space on the next page to take notes. **However, signs and symptoms alone may not be enough for your doctor to confirm a VOD/SOS diagnosis.**

Once you have reported your symptoms to the transplant team, your doctor may want to further assess if you have VOD/SOS:

Blood tests to monitor kidney and liver function

Ultrasound

Imaging (X-ray or CT/CAT scan)

A liver biopsy (in rare cases)

Once a diagnosis is made, treatment may begin. There is a treatment that may be effective for VOD/SOS, and the transplant team may want to get you started on it right away.

While VOD/SOS can be serious, if found quickly, it can be treated

Use this page to keep track of your symptoms, and if you notice two or more, let the transplant team know.

Remember, the most common symptoms include:

- Abdominal pain
- Abdominal swelling
- Swollen arms/legs/feet
- Difficulty breathing
- Weight gain
- Skin yellowing
- Decreased urination
- More frequent platelet transfusions

Notes:

Don't ignore the signs of VOD/SOS

Early detection and early treatment may lead to better outcomes.

VOD/SOS can quickly become serious, so work with your transplant team if you notice any symptoms.

The earlier VOD/SOS is found and treated, the more likely you or your loved one are to make a full recovery.



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