

Sirolimus Reference Guide

Sirolimus is a medication that allogeneic stem cell transplant patients take after transplant to prevent graft-vs-host disease (GVHD). GVHD is when the cells in your donor's stem cells attack your body's tissue. It can happen in many different systems of the body. GVHD is a common complication after allogeneic stem cell transplant, though it does not affect all patients. Sirolimus is also called Rapamune[®]. Dana-Farber most commonly uses 1 mg and 2 mg tablets of sirolimus, but it may also be prescribed in 0.5 mg tablets or in liquid form.

How to Take Sirolimus & Manage Your Dosing

- Take sirolimus one time each day in the morning.
- Take sirolimus at about the same time each day to help you keep a steady level of sirolimus in your body.
- If you feel nauseous or if you think you might vomit, take your nausea medicine before taking sirolimus.
- Take your sirolimus with or without food, and be consistent.

The dose of sirolimus you take may change frequently. That means the instructions on the pill bottle you receive from the pharmacy will not always match the instructions from your doctor. **Always follow your doctor's instructions.** We will measure your sirolimus level through blood tests during your visits and let you know if the dose needs to change.

- If we don't call you, keep taking the same dose of sirolimus. No call, no change.
- If you need a different sirolimus dose, we will call you and tell you what your new dose is. Be very careful calculating how many tablets are in your new dose. If you want help figuring out how many tablets to take, call your care team (MD or NP/PA).
- If you use a pill box, be sure to change out the sirolimus tablets every time your dose changes.

Sample Dosing

If your dose is 4 mg once per day

$$1 \text{ mg} + 1 \text{ mg} + 1 \text{ mg} = 4 \text{ mg}$$
or
$$2 \text{ mg} + 2 \text{ mg} = 4 \text{ mg}$$

Do's and Don'ts of Taking Sirolimus

Don't

- Don't take sirolimus in the morning before you come to Dana-Farber for blood work.
- · Never stop taking sirolimus without talking to your Dana-Farber care team.
- Don't take any herbal supplements.
- Don't eat or drink anything with grapefruit, grapefruit juice, blood oranges, Sunny Delight, Fresca, or Squirt.
- Don't breastfeed while taking sirolimus.

Do

- Call your care team before you take any new medications, vitamins, minerals, or supplements as sirolimus can interact with other medications.
- Request refills for sirolimus before you run out.
- Talk to your doctor about birth control options while taking sirolimus.
- Keep this medication safe from children in your home.
- Wash your hands after handling the liquid form of sirolimus.

On Days When You Come to Dana-Farber for Blood Work

- Don't take sirolimus in the morning when you come to Dana-Farber for blood work.
 If you take tacrolimus, don't take it either. We will check your sirolimus level when we do blood work at Dana-Farber.
- · Take the rest of your medicines at their normal times.
- Bring your sirolimus with you to Dana-Farber to take after your blood has been drawn.
- If the level of sirolimus in your blood is too high or too low, your dose will be changed starting with the next day's dose.

Possible Side Effects of Sirolimus

Sirolimus has many possible side effects. Some people have more side effects, some have less. Common side effects include:

- · Nausea or vomiting
- Diarrhea or constipation

Call your care team if your side effects are hard to control, won't go away, or if you notice something that worries you.

When to Call Your Care Team

- If you want help calculating your new dose.
- Before you take any new medicine, even if another doctor asks you to take it.
- Before you take any new supplements or any new over-the-counter medicines.
 Sirolimus can interact with other medications and herbal supplements; therefore, it is important to notify your care team of new medications.

Common Questions

What should I do if I vomit after taking sirolimus?

If it has been more than 30 minutes since you took sirolimus and if you don't see any sirolimus tablets in the vomit, don't take any more sirolimus until your next dose.

If it has been less than 30 minutes since you took sirolimus or if you do see sirolimus tablets in the vomit, you need to take that dose again.

What if I forget to take sirolimus?

Take your daily dose as soon as you remember as long as it is on the same day that you were supposed to take the dose. **Never take two doses in the same day.** Be sure to tell your care team if you miss a dose.

The instructions on the bottle are different from my doctor's instructions. What do I do?

The dose of sirolimus you take may change frequently. That means the instructions on the pill bottle you receive from the pharmacy will not always match the instructions from your doctor. Always follow your doctor's instructions.

What if there are different colored tablets in the sirolimus bottle?

Call the pharmacist. Sometimes, a medication looks different when it is made by different manufacturers. Or different doses of the same medication may look different. Call your pharmacist to confirm you have received the correct medication.

What if I can't afford my medicines?

Call your Dana-Farber care team *right away* if you have concerns about paying for your medicines. We will connect you with someone who can help with financial resources.

More Information about Sirolimus

An interactive video, **How to Take Sirolimus**, is on the Stem Cell Transplant Patient Education website: **sctpatiented.dana-farber.org**. Go to **After Allogeneic Transplant** then to **Medication Guidelines**.