



NF1 Plexiform Neurofibroma **Symptom Guide for Caregivers**

KOSELUGO® (selumetinib) is a prescription medicine that is used to treat children 2 years of age and older with neurofibromatosis type 1 (NF1) who have plexiform neurofibromas that cannot be completely removed by surgery. It is not known if Koselugo is safe and effective in children under 2 years of age.

IMPORTANT SAFETY INFORMATION

Before taking Koselugo, tell your healthcare provider about all of your medical conditions, including if you:

- have heart problems
- have eye problems
- are pregnant or plan to become pregnant. Koselugo can harm your unborn baby
 - Females who could become pregnant and males with female partners who could become pregnant should use effective birth control (contraception) during treatment with Koselugo and for 1 week after your last dose
 - Tell your healthcare provider right away if you become pregnant or think you may be pregnant during treatment with Koselugo
- are breastfeeding or plan to breastfeed. It is not known if Koselugo passes into your breast milk
 - Do not breastfeed during treatment with Koselugo and for 1 week after your last dose
 - Talk to your healthcare provider about the best way to feed your baby during this time

Please read full Important Safety Information on the back cover. Please see full Prescribing Information, including Patient Information, by clicking [here](#) or at Koselugo.com.



Koselugo[®]
(selumetinib)
10 mg & 25 mg capsules

Collaborate with your child's doctor to take an active approach to decision-making about their treatment plan

As a caregiver, it can be tough watching your child struggle. We hope this guide will help educate you and your child about plexiform neurofibromas (plexiform tumors), which are non-malignant tumors.



WHAT ARE PLEXIFORM TUMORS?

30%–50%

Plexiform tumors occur in about 30%–50% of patients with NF1



They can grow from nerves anywhere in the body



Even small tumors can sometimes cause serious symptoms



Not every child will have the same plexiform tumor symptoms

Surgery may be an option, but your child's doctor may not recommend it if the plexiform tumor is too close to critical nerves or near major organs. If that is the case and your child has symptoms, their doctor may consider Koselugo as a treatment option.

If you, yourself, have previously been diagnosed with NF1, your child's experience may be different from yours

IMPORTANT SAFETY INFORMATION (cont'd)

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, or herbal supplements. Especially tell your healthcare provider if you are taking aspirin, blood thinners, or other medicines to treat blood clots. Koselugo contains vitamin E, which may increase your risk of bleeding.

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Signs of symptomatic plexiform tumors

It can be especially difficult for younger children to understand and express their symptoms. Reach out to your NF1 specialist if you notice signs of symptomatic plexiform tumors, such as:

PHYSICAL CHANGES

Have a cluster of small lumps formed under your child's skin?
Have you noticed any skin discoloration?
Have any lumps begun to protrude through the skin?



DIFFICULTY MOVING

Is your child having difficulty moving any part of their body?
Does your child get tired more often?
Can your child sleep comfortably?
Is your child experiencing any tingling or stinging sensations?



PAIN

Is your child no longer doing their usual activities?
Is your child fussier than usual?
Does your child seem bothered or uncomfortable?



OTHER SYMPTOMS

Is your child having **trouble breathing**?
Is your child experiencing **vision changes** or other eye problems?
Is your child having **bowel or bladder problems**?



Remember—if your child experiences a new plexiform tumor symptom, or if a symptom your healthcare team knows about has gotten worse, report it as soon as possible.

IMPORTANT SAFETY INFORMATION (cont'd)

Koselugo may cause serious side effects, including:

Heart problems. Koselugo can lower the amount of blood pumped by your heart, which is common and can also be severe. Your healthcare provider will do tests before and during treatment with Koselugo to check how well your heart is working. Tell your healthcare provider right away if you get any of the following signs or symptoms:

- persistent coughing or wheezing
- shortness of breath
- swelling of your ankles and feet
- tiredness
- increased heart rate

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Together, you and your healthcare providers are a powerful team

Even if your child develops a new plexiform tumor, remember—your healthcare team is always there to guide you. You should feel comfortable reaching out to the team to ask questions. Depending on the location and severity of your child’s plexiform tumors, their healthcare team may include the following experts, who can each provide important information and recommendations about your child’s condition and treatment plan:



GENETICISTS



NURSES



NEUROLOGISTS



ONCOLOGISTS



SURGEONS

In-person visits with doctors have become less frequent for many patients, but plan to routinely stay in contact with your child’s healthcare team.



Keeping an eye out for plexiform tumor symptom changes
can be an important way to help your child during their NF1 journey



IMPORTANT SAFETY INFORMATION (cont’d)

Eye problems. Koselugo can cause eye problems that can lead to blindness. Your healthcare provider will check your vision before and during treatment with Koselugo. Tell your healthcare provider right away if you get any of the following signs or symptoms:

- blurred vision
- loss of vision
- dark spots in your vision (floaters)
- other changes to your vision

Severe diarrhea. Diarrhea is common with Koselugo and can also be severe. Tell your healthcare provider right away the first time that you get diarrhea during treatment with Koselugo. Your healthcare provider may give you medicine to help control your diarrhea and may tell you to drink more fluids.

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INDICATION

What is Koselugo?

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Skin rash. Skin rashes are common with Koselugo and can also be severe. Tell your healthcare provider if you get any of the following signs or symptoms:

- rash that covers a large area of your body
- peeling skin
- blisters

Muscle problems (rhabdomyolysis). Muscle problems are common with Koselugo and can also

be severe. Treatment with Koselugo may increase the level of a muscle enzyme in your blood, which may be a sign of muscle damage. Your healthcare provider should do a blood test to check your muscle enzyme levels before you start taking Koselugo and during treatment. Tell your healthcare provider right away if you get any of the following signs or symptoms:

- muscle aches or pain
- muscle spasms and weakness
- dark, reddish urine

Your healthcare provider may change your dose, temporarily stop, or permanently ask you to stop taking Koselugo if you have any of these side effects.

The most common side effects of Koselugo are:

- vomiting
- stomach pain
- nausea
- dry skin
- feeling of tiredness, weakness, or lacking energy
- muscle and bone pain
- fever
- inflammation of the mouth
- headache
- redness around the fingernails
- itching

These are not all the possible side effects of Koselugo.

Please see full Prescribing Information, including Patient Information, by clicking [here](#) or at [Koselugo.com](https://www.koselugo.com).

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