

Sirolimus for the prevention of rejection after a liver transplant

Information for patients

This leaflet contains information about sirolimus, which is a medication that can be used to prevent rejection of the donor liver after a liver transplant. If you have any other questions or concerns, please do not hesitate to speak to the doctors, pharmacists or nurses caring for you.

What is sirolimus?

Sirolimus is a drug used to suppress your body's own immune system and prevent it from rejecting the transplanted liver. The dose will be adjusted depending on the medication levels in your blood.

Sirolimus preparations

There is only one preparation of sirolimus so you do not need to worry about different brands.

Sirolimus is taken once per day in the morning. Swallow the tablets whole with a glass of water, 1 hour before or 2 hours after food.

Dose

The dose will be altered according to how much of the medicine is in your blood. This is checked by a blood test at the clinic.

If your blood tests show you need to have your dose changed (up or down), you will be contacted.

Sirolimus comes in tablet form and is available as different strengths which are 0.5mg, 1mg and 2mg.

The 0.5mg tablet does not release its active ingredient into the bloodstream at the same rate and in the same amounts as the 1mg and 2mg tablets. Therefore, multiples of the 0.5mg tablets should not be used as a substitute for other tablet strengths.

What should I do if I forget to take a dose?

If you remember within 12 hours of when you usually take the dose, take that dose straight away and take your next dose at the usual time. If you remember over 12 hours from when you usually take the dose, forget this dose and take your next dose at the usual time.

Never take a double dose to make up for missed doses.

What if I take too many tablets?

Get help immediately:

- from your specialist team, Monday to Friday, 9am to 5:30pm (details below)
- outside of these hours, please contact NHS 111, an out of hours GP, or attend an emergency department (A&E) if you are very unwell

Should I take sirolimus on the day I have a clinic appointment?

The level of sirolimus in your blood is checked when it is at its lowest. This will be just before you are due to take a dose, so do not take sirolimus before you are due to have a blood test.

On the day that you attend your clinic appointment do not take your morning dose. Bring it with you to take after you have had your blood test. This allows the medicine concentration to be accurately measured.

Side effects of sirolimus

Sirolimus has several side effects but not everyone will experience them.

Listed below are the most common side effects:

- headache
- fatigue
- upset stomach
- diarrhoea or constipation
- high cholesterol
- slow wound healing
- reduced kidney function
- increased risk of infections
- an increase in the risk of certain cancers

You may notice some of these side effects yourself. Tell the doctor or pharmacist if you do as there is often a solution.

Can I stop taking sirolimus at any time?

No. Stopping sirolimus will increase the chance of the new liver being rejected. Do not stop taking sirolimus unless your specialist team tells you to.

If you are concerned about side effects, please contact your specialist team (details below).

How long will I take sirolimus?

You will need to take it lifelong after a transplant unless specifically told otherwise by your specialist team.

Will sirolimus be the only medication I take to prevent rejection after my liver transplant?

No. Unless specifically told by your specialist team you will be on at least one other medication to prevent rejection after your liver transplant.

Monitoring

As mentioned, you will have the sirolimus level in your blood checked to ensure you are on the correct dose.

Your kidney function, liver function, full blood count, cholesterol levels and blood pressure will also be monitored while you are on sirolimus.

Taking other medicines with sirolimus

Some medicines can increase or decrease the sirolimus level in your blood. Always check with your doctor or pharmacist if you are prescribed new medications or if you buy any new medicines over the counter, including herbal and homeopathic medicines.

There are various medicines that you should NOT take while on sirolimus. Some examples include:

- antibiotics called erythromycin and clarithromycin
- non-steroidal anti-inflammatory medicines such as ibuprofen or diclofenac
- some antifungals called fluconazole (unless advised by your specialist liver team).

Always check with a doctor or pharmacist that any new medicine is safe for you to take. If you are in doubt, contact one of the hospital pharmacists.

Fruits to avoid with sirolimus

You should avoid eating grapefruit or Seville orange or drinking grapefruit or Seville orange juice while you are taking sirolimus. They contain a chemical that affects the level of sirolimus in your blood.

Other citrus fruits are safe to eat or drink.

Storage

- Store your sirolimus in a cool, dry place, away from direct sunlight.
- Keep the blister in the outer carton to protect from light.
- Keep your sirolimus out of the sight and reach of children.
- Do not use after the expiry date on the packaging.
- Ask your pharmacist how to dispose of any medicines no longer needed.

Supply

You will receive your sirolimus from hospital when you attend your outpatient appointments.

Ensure that you ask for a supply when you attend. As this is a specialist medicine, the supply cannot come from your local community pharmacy.

You will be supplied with enough medication to last until your next clinic appointment. If for some reason, this does not align, you should email the liver secretaries who can contact the prescriber who reviewed you in clinic and they will be able to arrange a prescription. If this occurs, please ensure you contact the team at least two weeks before you are due to run out of your sirolimus.

Is sirolimus safe in pregnancy?

No. Sirolimus is not recommended in pregnancy due to the potential risk to the unborn child.

Please discuss any family planning with your specialist team and tell them if you are considering having a baby. If you become pregnant while taking sirolimus please inform the specialist team as soon as possible.

Vaccines

Some vaccines contain a live form of the virus. These are called live vaccines. If you are taking sirolimus, you cannot have live vaccines. Please talk to your liver doctor or pharmacist if you are not sure about this.

It is still important to get the following:

- Flu vaccine: recommended
- COVID-19 vaccine: recommended
- Pneumococcal vaccine (Pneumovax®): recommended
- Shingles vaccine (Shingrix®): If recommended ensure that you received the NON-LIVE formulation

Is it safe to be in the sun?

Sirolimus can increase risk of sunburning, and so national advice on sun safety should be followed:

- limit the amount of time you spend in the sunlight and seek shade from 11am to 3pm
- never burn
- wear protective clothing and sunglasses
- use high sun protection factor (at least SPF 30)
- regularly check your skin for changes (for example, new moles or changes to existing moles)
- avoid exposure to additional ultraviolet (UV) light, such as tanning machines

Additional information

If you take sirolimus, you may be more at risk of getting infection.

If you come into skin contact with someone with chickenpox or shingles, or if you develop chickenpox or shingles, you need to contact your doctor immediately.

How can I find out more?

If you would like any more information on sirolimus, or if you need to get in contact with a member of the liver team, please contact the team using the details below (available Monday to Friday, from 9am to 5.30pm).

- Liver Outpatients: kch-tr.liver.outpatients@nhs.net
- Liver Pharmacy Team: kch-tr.liverpharmacy@nhs.net

MyChart

Our MyChart app and website lets you securely access parts of your health record with us, giving you more control over your care. To sign up or for help, call us on 020 3299 4618 or email kings.mychart@nhs.net. Visit www.kch.nhs.uk/mychart to find out more.

Sharing your information

King's College Hospital NHS Foundation Trust has partnered with Guy's and St Thomas' NHS Foundation Trust through the King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas' hospitals. King's College Hospital and Guy's and St Thomas' NHS Foundation Trusts share an electronic patient record system, which means information about your health record can be accessed safely and securely by health and care staff at both Trusts. For more information visit www.kch.nhs.uk.

Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. They can also pass on praise or thanks to our teams.

Tel: 020 3299 4618

Email: kings.pals@nhs.net

If you would like the information in this leaflet in a different language or format, please contact our Interpreting and Accessible Communication Support on 020 3299 4618 or email kings.access@nhs.net