Venetoclax

Venetoclax is a targeted medicine used to treat some people with chronic lymphocytic leukaemia (CLL).

Summary

- Venetoclax is a targeted medicine used to treat chronic lymphocytic leukaemia (CLL).
- It comes as film-coated tablets that you take by mouth.
- The number of tablets you need to take and how often should be printed on the named label on your medicine packaging.
- You will have blood tests to check how well your CLL is responding to venetoclax.
- Your haematology team will monitor how your body is coping with treatment.
- Some people get side effects of venetoclax. Some people have mild side effects, whereas others get more severe side effects.
- Some side effects can be serious if they are not treated promptly. Contact your haematology team straight away if:
    - You think you might have an infection
    - Your pee is dark or cloudy
    - You have a seizure (fit)
    - You feel weak, exhausted or confused
    - You have pain or bloating in your tummy, diarrhoea or sickness
    - You have difficulty breathing or shortness of breath
    - Your heart rate is fast or uneven, or your pulse is weak or uneven
- Tell your haematology team if you get any other side effects. They may be able to suggest things to help.

Download our leaflet about venetoclax

What is venetoclax?

Venetoclax is a targeted medicine that helps slow down the progression of CLL. It blocks a protein in CLL cells called BCL-2. This protein stops CLL cells dying when they should. Blocking it makes the cells self-destruct and die.

The brand name for venetoclax is Venclyxto.

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Who might take it?

Venetoclax is suitable for adults. Your haematology team might recommend it for you if:

- You have CLL and have not had treatment before **and**:
  - You have a genetic change in your CLL cells called 17p deletion or TP53 mutation **and**
  - Other treatments are unsuitable for you.
- You have had treatment before, but your CLL didn't respond to it or came back after treatment. This is called refractory or relapsed CLL.

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Before taking venetoclax

Before starting venetoclax, your haematology team will carry out checks to ensure it is suitable for you. These include:

- Blood tests to check your blood cell counts
- Blood tests to check your liver and kidney function, and the levels of salts and minerals in your body
- A CT scan to find out if CLL is affecting your organs, like your spleen

Your team may recommend other tests, depending on your circumstances.

Your haematology team may ask if there is any possibility you might be pregnant. You should not take venetoclax during pregnancy or while trying to get pregnant.

Things to tell your haematology team

Some medicines, supplements and food may interact with venetoclax. Or they may increase your risk of side effects. It is important to tell your haematology team about any medicines or supplements you are taking. This includes prescribed medicines and medicines you have bought yourself without a prescription.

Examples include:

- Herbal medicines such as St John's Wort
- Some blood thinners or medicines used to prevent blood clots, like warfarin
- Some medicines used to treat infections, including some antibiotics, antifungal and antiviral medicines
- Some medicines used to treat a rare sleep problem called narcolepsy
- Some medicines used to treat heart conditions
- Some medicines for high blood pressure, including high blood pressure in your lungs
- Some medicines used to treat epilepsy
- Some medicines used to lower cholesterol
- Some medicines used to prevent or treat stroke, or blood clots in your legs or lungs

Venetoclax tablets contain several ingredients. Tell your haematology team if you have any allergies or sensitivities.

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How to take venetoclax

Venetoclax comes as film-coated tablets that you take by mouth.

- Swallow your venetoclax tablets whole with a glass of water.
- Do not chew, crush, or break your tablets and do not dissolve them in water.
- Try to take your tablets at about the same time each day. Take them with a meal because this helps your body absorb the right amount of venetoclax.
- You should drink plenty of water to help reduce side effects. Especially when you start taking venetoclax and when you increase your dose.
- You need to take medicine to help control your uric acid levels. You'll start this a few days before you begin venetoclax. You carry on taking it until you are on a stable dose of venetoclax, or longer if needed. Your doctor will prescribe it.
- Avoid grapefruit, bitter oranges (Seville oranges) or starfruit (carambola) while taking venetoclax. This includes the fruit, fruit juice, or foods or supplements containing them. These foods affect how much venetoclax your body absorbs.
- Do not take supplements containing St John's Wort while taking venetoclax. This is because it affects how much venetoclax your body absorbs.

If you miss a dose

If you forget to take venetoclax:

- Take it as soon as you remember, if it's **within 8 hours** of your dose time.
- If it's **longer than 8 hours** by the time you realise you forgot to take it:
    - Skip the missed dose
    - Take your next dose at the usual time the following day
- If you are sick (vomit) after you've taken venetoclax, don't take any more that day. Take your next dose at the usual time the following day.

> **It is important not to take a double dose. If you've taken more venetoclax than you should, talk to your doctor, nurse or pharmacist. Or go to the hospital immediately. Take your medicine and the leaflet from its box with you.**

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Dose

Venetoclax comes as film-coated tablets containing 10mg, 50mg or 100mg of venetoclax. The number of tablets you need to take should be printed on the medicine packaging. If you are not sure, ask your doctor or nurse.

You take venetoclax once a day, starting on a low dose of 20mg. Your doctor usually increases the dose over the next 4 weeks until you reach the full dose of 400mg. You might hear people call this the 'ramping up' stage.

Most people increase their dose like this:

- Week 1: Take two 10mg tablets once a day
- Week 2: Take one 50mg tablet once a day
- Week 3: Take one 100mg tablet once a day
- Week 4: Take two 100mg tablets once a day
- Week 5 onwards: Take four 100mg tablets once a day

For the first 4 weeks of treatment, you will get a new pack of venetoclax each week. They usually come as blister packs with the daily dose you need contained within each blister. This will help you take the right dose each day while your doctor is increasing your dose.

During the first few weeks of treatment, you should take your venetoclax in the morning. This will help with follow-up blood tests while your doctor increases your dose.

When you are taking the full dose, try to take your tablets at the same time every day.

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Where to take venetoclax

You usually go to a hospital day unit for your first dose of venetoclax, and when your dose is increased. This is so you can be monitored closely. Some people may need a short hospital stay.

The rest of the time, you can take venetoclax at home (or wherever you are staying).

> **You can store venetoclax at room temperature. Keep it safe where children cannot see or reach it.**

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How long do you take it for?

> **Do not stop taking venetoclax without discussing it with your haematology team.**

Most people carry on taking venetoclax for as long as it is working. Your haematology team may suggest stopping venetoclax and trying a different treatment if:

- It is not working well
- It stops working
- You are having side effects that are difficult to cope with
- Check-ups show it is affecting other parts of your body, like your kidneys
- You become pregnant

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Monitoring

When you first take venetoclax and after your first dose increase, you'll have blood tests:

- Before you take your tablets
- 6 to 8 hours after taking your tablets (or more often, if your team think you need it)
- Around 24 hours after taking your tablets

After that, you'll be monitored each time you increase your dose. You'll have blood tests before you take your new increased dose. You may have more blood tests after taking the new dose, if your haematology team think you need them.

Your haematology team will check how well venetoclax is working and how well your body is coping with it.

- You'll have blood tests to check your blood cell counts and the levels of salts, minerals and uric acid in your body.
- You'll also have occasional blood tests to check how well your liver and kidneys are working.
- Your doctor or nurse will check for signs and symptoms of infection and serious side effects.
- Your team might recommend other tests, depending on your circumstances.

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Precautions

There are some precautions to be aware of when you are taking venetoclax.

- Venetoclax can make you vulnerable to serious infections. You might need to take medicines to prevent infections while taking venetoclax.
- You should avoid eating grapefruit and starfruit (carambola). This includes the fruit, fruit juice, or foods or supplements containing them.
- You should avoid eating bitter oranges (Seville oranges). This includes the fruit, bitter orange juice or food made with bitter oranges, like marmalade.
- Venetoclax might make you very tired or dizzy. This might affect your ability to drive or operate machinery.
- Other medicines might interact with venetoclax and affect how well it works. Your haematology team will tell you whether or how to take other medicines while you're taking it. Or whether you need a different dose of venetoclax than usual.
- You should not have live vaccines when you have CLL or when you are on venetoclax. It is safe to have non-live vaccines. But they might not work as well as they do in other people.



"If your GP prescribes you a new medicine, ask them to check that it's safe to take with venetoclax. Your pharmacist can check for interactions with your other medications, too."

— Helen, living with CLL since 2015

Precautions to prevent tumour lysis syndrome

When you're taking venetoclax, you'll have medicine to help prevent tumour lysis syndrome. Your dose of venetoclax is also increased very gradually to help prevent it.

You need to drink plenty of water too, as this will also help prevent it. Try to aim for 1.5 to 2 litres of fluid every day. Especially:

- For 2 days before starting venetoclax
- The day you start venetoclax
- Every time you increase your dose

You can include non-alcoholic drinks and non-caffeinated drinks in this amount. But not grapefruit, Seville orange or starfruit juice.

If you're struggling to drink enough, your haematology team might give you fluid through a drip before your treatment.



"The weeks when venetoclax is started and ramped up are extra busy. You need to have blood tests at certain times before and after each new venetoclax dose to check you aren't developing tumour lysis syndrome."

— Jane, living with CLL since 2004

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Leukaemia Care Registered Charity Number 1183890. Scotland Registered Charity Number SC049802
Helpline: 08088 010 444

Fertility, pregnancy and breastfeeding

We do not know what effect venetoclax has on fertility or pregnancy. Based on animal studies, it may damage sperm and harm unborn babies.

- If you could get pregnant, it's important to use effective contraception. You should do this while you are taking venetoclax and for at least 30 days after stopping treatment.
- We do not know whether venetoclax affects the way hormonal contraceptives work. So, you need to use a barrier method like condoms, a diaphragm or cap.
- If you're taking venetoclax and think you might be pregnant, tell your haematology team as soon as possible.
- Venetoclax may cause male infertility. If you hope to make someone pregnant in the future, talk to your haematology team before starting treatment. They will talk to you about options to preserve your fertility, such as freezing your sperm.

Breastfeeding

We do not know if venetoclax passes into breastmilk. Or how it might affect breastfed babies or children.

> **You should not breastfeed while you are taking venetoclax.**

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Possible side effects

You may get some side effects while you are taking venetoclax. Some people have very few side effects, whereas others get more serious side effects. They may differ from day to day.

Your haematology team should tell you what side effects to look out for, and who to contact if you need to.

> **If you are worried about any symptoms or side effects, contact your haematology team. You do not have to wait until your next appointment.**

Your haematology team might:

- Prescribe medicines to help manage some side effects
- Suggest things you can do to help you cope with side effects
- Lower your dose of venetoclax if your side effects are serious or difficult to cope with
- Recommend pausing or stopping venetoclax, if needed

You can also report side effects via the MHRA Yellow Card Scheme.

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Side effects you might notice

This is not a full list of all the side effects that can happen. The patient information leaflet in your medicine package has more information. Or you can find the leaflet in the Electronic Medicines Compendium.

Here, we list some of the more common side effects of venetoclax. These affect at least 1 in every 100 people who take venetoclax.

Infections

Contact your team straight away if you think you have an infection. Look out for:

- A high temperature (38°C or higher)
- Shivering, chills or sweating
- Sore throat, sneezing, blocked or runny nose or earache
- Cough, chest pain or shortness of breath
- Burning or stinging when you pee, or peeing more often than usual

Tummy problems

You might get diarrhoea or constipation. You might feel sick or be sick. If you have these side effects, your team can give you medicines to help.

Fatigue

You might experience extreme tiredness or lack of energy.



"Some people have nausea as a side effect and find that taking venetoclax at bedtime helps, after the ramping up stage ends. It reduces side effects, as

they sleep through them. Once I was on 400mg a day, with the agreement of my consultant, I changed to taking my tablets at bedtime."

— Jane, living with CLL since 2004

Sepsis

Venetoclax may lead to a severe response to an infection called sepsis. This affects less than 2 in every 100 people taking venetoclax. So, more than 98 in every 100 people do **not** get it.

Sepsis is serious and needs prompt treatment.

> **Contact your doctor straight away if you develop any of the following symptoms of sepsis:**
>
> - **Confusion, slurred speech or not making sense**
> - **Blue, grey or pale, blotchy skin, lips or tongue (on black or brown skin look**
> - **on the palms of the hands or soles of the feet)**
> - **A meningitis-like rash, which does not fade when you roll a glass over it**
> - **Breathing difficulties, such as breathlessness or rapid breathing**

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Side effects your team might notice

There might be some side effects that your haematology team find during regular checks and blood tests. These include:

- Low levels of white blood cells, which can make you more vulnerable to infection:
- Low levels of neutrophils (neutropenia)
- Low levels of lymphocytes (lymphopenia)
- Low levels of red blood cells (anaemia)
- Changes to the level of salts in your blood, which may be a sign of tumour lysis syndrome:
    - High levels of potassium and phosphate

    - Low levels of calcium
    - High levels of uric acid

- Changes in your kidney function

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Serious side effects to know about

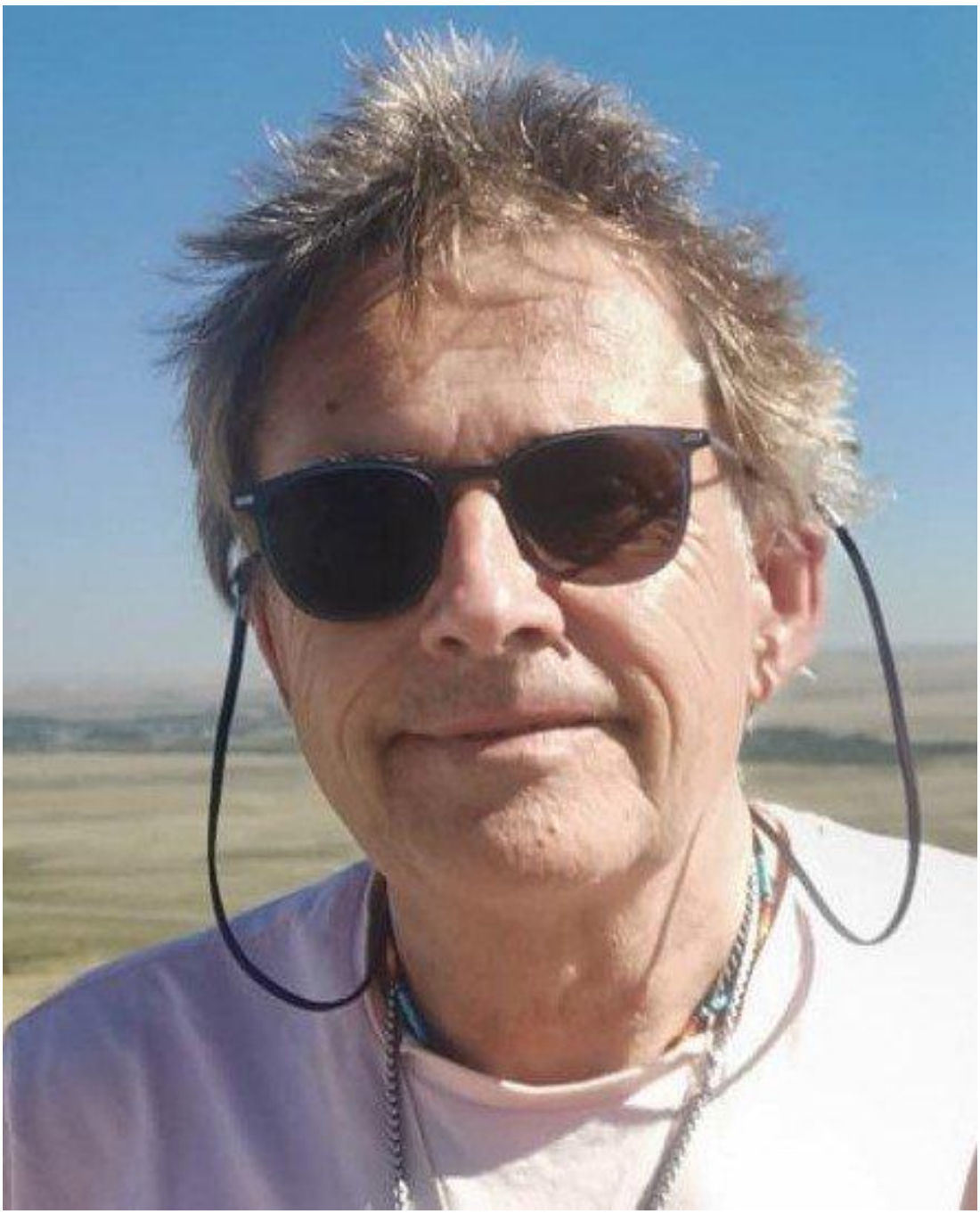
Venetoclax is very good at killing cancer cells. It can cause many cancer cells to break down all at once. When this happens, the dying cells release a lot of chemicals into your blood. This can cause a serious condition called tumour lysis syndrome.

Tumour lysis syndrome affects around 2 in every 100 people taking venetoclax. So, around 98 in every 100 people do **not** get it.

Tumour lysis syndrome can make you very unwell while your body tries to cope with changes to your body salts and levels of uric acid:

- Your kidneys may work less well
- Your heartbeat may become irregular
- You may have seizures (fits)

It can happen to anyone taking venetoclax to treat CLL. But it's more likely to happen if you have lots of CLL cells in your body. It's also more likely if you have other health problems like kidney disease or a swollen spleen. This is because it's harder for your body to cope with all the chemicals from the dead CLL cells.



"If you have to go to A&E, tell the staff you have blood cancer and the treatment you're on. Your team might give you a Patient Alert Card to keep with you. In a medical emergency, these cards let people know what medicine you're taking and help keep you safe. "

— Steve, living with CLL since 2011

Contact your haematology team immediately if you develop any of the following symptoms of tumour lysis syndrome:

- **Fever or chills**
- **Diarrhoea, feeling sick or being sick**
- **Muscle or joint pain**
- **Cloudy or dark-coloured pee**
- **Feeling weak, exhausted or confused**
- **Irregular heartbeat or shortness of breath**
- **Pain or bloating in your tummy**
- **Seizures (fits)**

The Electronic Medicines Compendium has a Venetoclax Patient Alert Card.

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If venetoclax doesn't work

If venetoclax is not working well for you, your doctor will discuss your options with you. They might suggest changing your dose, pausing or stopping treatment.

They will talk to you about other treatment options that might be suitable for you.

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Need support?

You are not alone. We're here for you whether you have a diagnosis yourself or know someone who has. If you'd like advice, support, or a listening ear, call our freephone helpline on 08088 010 444 or send a WhatsApp message to 07500 068 065.

Helpline and WhatsApp →

Help us improve our information

We aim to provide information that's reliable, up-to-date, and covers what matters to you. Please complete our short survey to help us improve our information and make sure it meets your needs.

Complete our short survey →

About our information

This information is aimed at people in the UK. We do our best to make sure it is accurate and up to date but it should not replace advice from your health professional. Find out more about our information.

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