



York and Scarborough  
Teaching Hospitals  
NHS Foundation Trust

# Venetoclax

Given on its own, in combination with ibrutinib, intravenous obinutuzumab or intravenous rituximab for the treatment of Chronic Lymphocytic Leukaemia (CLL)

Information for patients, relatives and carers

① For more information, please contact:

**Cancer Services**

**York Hospital**

Wigginton Road, York, YO31 8HE

Monday to Friday 08:30 to 17:00: 01904 726516

Out of hours (ward 31): 01904 726031

**Scarborough Hospital**

Woodlands Drive, Scarborough, YO12 6QL

Telephone: 01723 342447

# Introduction

As discussed with your haematology consultant, you will be starting on a treatment for Chronic Lymphocytic Leukaemia (CLL).

The suggested treatment is venetoclax tablets taken on their own or in combination with a tablet called ibrutinib or with another medicine given intravenously (into your vein via drip). This can be either obinutuzumab or rituximab. Your consultant or nurse will give you more information about these medicines if they are prescribed.

This leaflet will provide more information on the medicine called venetoclax.

## How does this medicine treat my disease?

CLL is a type of cancer affecting white blood cells called lymphocytes. In CLL, lymphocytes multiply and grow very quickly in the bone marrow, spilling into your blood. As a consequence, you will have too many lymphocytes and not enough healthy platelets, white and red blood cells in the blood.

These lymphocytes (or lymphoma cells) produce too much of a protein called BCL-2.

Too much BCL-2 makes lymphoma cells survive longer, instead of dying off at a normal rate. This leads to a reduced number of red blood cells, white blood cells and platelets.

Venetoclax works by blocking the BCL-2 proteins. This helps your body to kill and lower the number of cancer cells. It also slows down the progress of the disease.

## **How do I take venetoclax?**

Venetoclax is an oral medicine which comes as a 10mg, 50mg and 100mg tablets.

You will begin treatment on the lowest dose of venetoclax. Your doctor will gradually increase the dose each week over five weeks as below:

20mg once a day for week one

50mg once a day for week two

100mg once a day for week three

200mg once a day for week four

400mg once a day from week five onwards.

Your dose is increased slowly over five weeks to reduce the risk of you developing tumour lysis syndrome (see page 6-7).

The dose you are given is also dependent on the blood test results. It is not unusual for there to be a delay in increasing the dose because of the test results.

You should not drink **grapefruit juice**, eat **grapefruit**, **Seville oranges** (often used in marmalades), or **starfruit** while you are taking venetoclax. These foods may increase the amount of venetoclax in your blood, because they contain natural compounds that can reduce normal body's ability to remove venetoclax from your system.

Your consultant will be able to tell you about expected treatment duration with venetoclax. Treatment can be stopped if you develop significant side effects or decide not to continue with it.

## **Common side effects**

**Infection:** Venetoclax can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is sometimes called neutropenia.

If your temperature is above 37.5°C, or you are unwell you must ring for advice on 01904 726516 (8.30am-5.00pm Monday - Friday) or ward 31 on 01904 726031 at all other times.

It is important to have a thermometer at home to check your temperature. If it is above 37.5°C, or you are unwell with any other signs of infection ring for advice. Signs of infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea needing to pass urine more often than normal or discomfort when passing urine.

**Bruising or bleeding:** Venetoclax can reduce the production of platelets which help the blood to clot. Tell your doctor if you have unexplained bruising or bleeding, such as nosebleeds, bloodspots or rashes on the skin and bleeding gums.

**Anaemia (low number of red blood cells):** While having this treatment you may become anaemic. Taking venetoclax may make you feel tired and breathless. Let your doctor or nurse know if these symptoms are becoming a problem.

**Gastrointestinal disturbance:** You may experience constipation, diarrhoea, nausea or an increase or decrease in weight. Please report any of these symptoms to your nurse or doctor. It is important to drink plenty of fluid and maintain a balanced diet.

**Oedema:** Venetoclax may cause water retention in the feet and ankles. If this happens to you, please let us know.

**Lethargy:** Venetoclax may make you feel tired, short of breath or lacking in energy. It can be frustrating but if you do feel tired, take rest when necessary.

**Electrolyte imbalance:** Venetoclax may cause some of the electrolytes in your blood such as potassium and phosphate to increase. You may be prescribed some medication to correct this. Please let your doctor know if you are suffering from palpitations or muscle weakness, which are the symptoms of electrolyte imbalance.

## **What is tumour lysis syndrome (TLS)?**

Tumour lysis syndrome (TLS) is a serious side effect which may occur with chemotherapy treatment.

Venetoclax breaks down cancer cells. If this happens rapidly, it can cause the cells to release uric acid into the blood. Too much uric acid can lead to kidney failure and imbalances in your blood, particularly your phosphate, potassium and calcium levels.

## **What can be done to reduce your risk of TLS?**

**Drink fluids:** Before you start taking venetoclax and whilst you are slowly increasing its dose, you should drink lots of fluid, at least one and a half to two litres a day. If you are not able to drink this amount you may be given some fluid via a drip into your vein.

During your treatment, you must drink lots of fluid to help your body flush out the broken-down cells and the chemicals they produce.

**Medications to help prevent TLS:** You will be prescribed a medicine called allopurinol which decreases the levels of uric acid in the blood. It is usually prescribed before you start treatment with venetoclax and continued until you reach the 400mg dose. Please ensure you take this each day as prescribed.

**Hospital stay:** If your doctor decides that you have a high risk of TLS, you will be admitted to York Hospital. You will be given an injection, called rasburicase, to reduce the effects of TLS and your bloods will be checked and reviewed every four hours during the day.

You will be discharged when your doctor decides that it is safe for you to continue taking venetoclax tablets at home.

# Blood monitoring

During the first five weeks when you are taking venetoclax, you will need to have frequent blood tests at the hospital. The usual outpatient blood test schedule is in the following table.

When you need to have blood test?	Venetoclax dose				
	20mg	50mg	100mg	200mg	400mg
The day before starting venetoclax and day before <b>each new dose</b> increase	✓	✓	✓	✓	✓
<b>Six hours after taking the venetoclax tablet</b> You will be asked to wait for results in hospital or stay within 30 minutes of the hospital	✓	✓	*	*	*
<b>8am on the second day of new dose</b> You will be asked to wait for results in hospital before you can take your next venetoclax tablet	✓	✓	✓	✓	✓



✓ - blood test is necessary.

\* - blood test might be needed if your blood results continue to show signs of TLS. Your nurse will advise you on the day if this is needed.

If the morning blood test on the second day is okay, the nurse will give you enough tablets to last until your next blood test and explain when they should be taken.

## **Leaving hospital**

When you are at home you should continue to take your venetoclax tablets at the same time each day. Your haematology consultant will ask you to come to the hospital for regular blood tests. It is important to still drink lots of fluid.

After you reach venetoclax 400mg dose, blood tests will be less frequent, and you might be able to have them done at your GP practice or in York Community stadium. You will also be able to go back to your usual amount of fluids.

If you forget to take the tablets, you should take the missed dose as soon as possible on the same day. If a full day has gone by, let your doctor or nurse specialist know.

## **Other things to remember**

- Wash your hands after taking your tablets.
- Keep them in the original package and at room temperature, away from heat and direct sunlight.
- Keep them safe and out of sight and reach of children.
- Read the label to check strength and how many tablets to take.
- If you are sick or vomit just after taking the tablets, contact the hospital. Do not take another dose.
- If your treatment is stopped, return any unused tablets to the pharmacist for safe disposal.

## **References and further information**

Department of Health: [www.dh.gov.uk](http://www.dh.gov.uk)

NHS Website: [www.nhs.uk](http://www.nhs.uk)

Abbvie Starting Treatment with Venclyxto Leaflet (2021)  
Macmillan website (2022)

Cancer Research UK (2022)

If you would like more or accessible information please contact the Haematology nurses on 01904 7265815

## **Tell us what you think of this leaflet**

We hope that you found this leaflet helpful. If you would like to tell us what you think, please contact:

Haematology Nurse, York Hospital, Wigginton Road,  
York, YO31 8HE, telephone 01904 726516.

## **Teaching, training and research**

Our Trust is committed to teaching, training and research to support the development of health and healthcare in our community. Healthcare students may observe consultations for this purpose. You can opt out if you do not want students to observe. We may also ask you if you would like to be involved in our research.

## **Patient Advice and Liaison Service (PALS)**

PALS offers impartial advice and assistance to patients, their relatives, friends and carers. We can listen to feedback (positive or negative), answer questions and help resolve any concerns about Trust services.

PALS can be contacted on 01904 726262, or email [yhs-tr.patientexperienceteam@nhs.net](mailto:yhs-tr.patientexperienceteam@nhs.net).

An answer phone is available out of hours.

# Leaflets in alternative languages or formats

If you would like this information in a different format, including braille or easy read, or translated into a different language, please speak to a member of staff in the ward or department providing your care.

Patient Information Leaflets can be accessed via the Trust's Patient Information Leaflet website:

[www.yorkhospitals.nhs.uk/your-visit/patient-information-leaflets/](http://www.yorkhospitals.nhs.uk/your-visit/patient-information-leaflets/)

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