

Venetoclax

Given with azacitidine or cytarabine for the treatment of Acute Myeloid Leukaemia (AML)

Information for patients, relatives and carers

() For more information, please telephone the hospital where you are receiving treatment:

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

Contents

Page

Introduction	3
How does this medicine work to treat my disease?.	4
Why do I need to be admitted to hospital?	5
What we do to reduce your risk of Tumour Lysis Syndrome (TLS)	6
How do I take the venetoclax?	7
Leaving hospital	8
Side Effects	8
References and further information	10
Tell us what you think of this leaflet	11
Teaching, training and research	11
Patient Advice and Liaison Service (PALS)	11
Leaflets in alternative languages or formats	12

Introduction

As discussed with your haematology consultant you will be starting a treatment for Acute Myeloid Leukaemia (AML).

Your doctor will give you venetoclax in combination with another medicine (either azacitidine or low-dose cytarabine).

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

How does this medicine work to treat my disease?

AML is a type of cancer affecting white blood cells called myeloid cells. In AML, myeloid blood cells multiply and grow very quickly in the bone marrow, spilling into the blood so that there are too many of them and not enough red blood cells in the blood.

These myeloid cells produce too much of a protein called BCL-2.

Too much BCL-2 makes myeloid 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 kill and lower the number of cancer cells. It also slows down the worsening of the disease.

Why do I need to be admitted to hospital?

You will be admitted to hospital for at least five days for the first doses of treatment. This will enable us to monitor your bloods carefully for tumour lysis syndrome (TLS) whilst you take the medication.

Tumour lysis syndrome (TLS) can occur when cells break down very quickly. Venetoclax allows the cells to break down, and if this is rapid 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 bloods particularly your phosphate, potassium and calcium levels.

What we do to reduce your risk of Tumour Lysis Syndrome (TLS)

Blood monitoring: When you are in hospital, we will keep taking your bloods and monitoring the results. Your bloods will be taken every morning between 6am and 8am before you have venetoclax. They will be reviewed by a doctor, and if all is well, you will be given your venetoclax about 11am. Your bloods will then be taken again six hours after this dose.

Drink Fluids: Before you are admitted to hospital and whilst you are in hospital you should drink **lots** of fluid, at least 1.5 to 2 litres a day. If you are not able to drink this amount you may be given some fluids into your vein through a drip.

It is important to drink lots of fluid to help your body to 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. Please ensure you are taking this each day.

If the doctor identifies you as being at a higher risk of tumour lysis syndrome, you may be given a medication called rasburicase, this is an intravenous medication given into your vein via a drip.

How do I take the venetoclax?

Venetoclax is an oral medicine which comes as a 100mg capsule.

You will begin treatment with Venetoclax on a lower dose. Your doctor will gradually increase the dose each day for the first three days as below:

The dose of venetoclax you will take is:

100mg on day one 200mg on day two 300mg on day three 100mg on day four until day 28

The reason the dose reduces to 100mg on day four is because you will start taking a drug called posaconazole. Posaconazole is an anti-fungal drug which will help protect you from fungal infections. This tablet makes the venetoclax more effective so the dose drops to 100mg.

The dose you are given is also dependent on the bloods taken each day, it isn't unusual for there to be a delay in increasing the dose.

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.

Leaving hospital

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

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

Other things to remember about your tablets:

- 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 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.

Side Effects

Infection: This treatment 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.

It is important to have a thermometer at home, if your temperature is above 37.5°C, or you are unwell with any other signs of infection which may 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.

If your temperature is above 37.5°C, or you are unwell you must ring for advice on 01904 726516 (York) or 01723 342447 (Scarborough) between 08:30 and 17:00, Monday to Friday, or ward 31 on 01904 726031 at all other times.

Bruising or bleeding: This treatment 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. This may make you feel tired and breathless. Let your doctor or nurse know if these symptoms are a problem. You may need a blood transfusion. **Gastrointestinal disturbance:** You may experience constipation, diarrhoea, nausea, 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: This treatment may cause water retention in the feet. If this happens to you, please let us know.

Lethargy: This treatment 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: This treatment may cause some of the electrolytes in your blood such as potassium and phosphate to rise. You may be prescribed some medication to correct this. Please let your doctor know if you are suffering from palpitations or muscle weakness.

References and further information

Department of Health: www.dh.gov.uk

NHS Website: 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 725815.

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: Alex Campbell, Clinical Educator, Ward 31, York Hospital, The York Hospital, Wigginton Road, York, YO31 8HE or telephone 01904 726031.

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.

An answer phone is available out of hours.

Leaflets in alternative languages or formats

Please telephone or email if you require this information 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-informationleaflets/

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