

Patient information

Bleeding disorder of unknown cause (BDUC)

Haematology Liverpool

What is a Bleeding Disorder of Unknown Cause (BDUC)?

Some people have symptoms of a bleeding disorder, but all available tests come back as normal. If you have a strong history of bleeding symptoms, then we will likely diagnose you with a bleeding disorder of unknown cause (BDUC).

In the future through scientific developments, we may be able to diagnose other bleeding disorders. We currently offer genetic testing, to see if there are any changes in genes associated with bleeding disorders related to blood clotting, although finding any genetic abnormalities linked to bleeding problems is rare.

People with BDUC generally only need treatment if you have troublesome bleeding, or to prevent excessive bleeding at high-risk times such as:

- Surgery.
- Invasive medical procedures.
- Dental work.
- Childbirth.

How do we diagnose a BDUC?

During your initial consultation/ testing phase of your care, we carry out all the relevant tests available to us with an aim to determine if we can identify a known cause for your bleeding symptoms. We also carry out a Bleeding assessment tool questionnaire (BAT) to quantify the severity of symptoms, and to help us determine if we feel you have a bleeding disorder.

Normal range for the BAT (Bleeding Assessment Tool) questionnaire is less than four in adult males, less than six in adult females and less than three in children.

If you have an elevated BAT score, that demonstrates a bleeding tendency in keeping with symptoms typical of a bleeding disorder, we then will use our clinical judgment and provide a diagnosis of BDUC.

This diagnosis will not negatively impact your day to day living and will only be of concern if you are actively bleeding, sustain an injury or need surgery. As you now have this diagnosis, you will be registered under our care on the National/Local database with a bleeding disorder and receive an alert card to carry around with you.

This Alert card can be shown to any clinician should you sustain injury, and they will be able to liaise with experts within our team for advice. Should you require treatment for injury or surgery, you now have a team of expert doctors and nurses to ensure you receive the most effective treatment and care.

How do you get BDUC?

It is unknown if your bleeding disorder is inherited or acquired, as we have not determined the root cause. When Genetics samples are taken, if you opted for the laboratory to store your DNA, if new genetic mutations are discovered then it maybe that we are able to provide a more specific diagnosis in the future.

What are the symptoms of BDUC?

Common symptoms:

- In women and girls, heavy and prolonged bleeding during menstruation (known as menorrhagia).
- Nose bleeds.
- Bleeding from gums.
- Easy bruising.
- Bleeding after surgery.
- Bleeding after trauma or injury.
- Heavy bleeding from a cut.

Rare symptoms:

- Blood in your urine (known as haematuria).
- Bleeding in your stomach or intestines (blood in stools (poo) or black tarry stools).
- Bleeding into your muscle.
- Bleeding into your joints (known as hemarthrosis).
- Bleeding into your brain.

What are the treatment options for BDUC?

Tranexamic Acid

This works by stopping the early breakdown of a clot that has been made after injury to your blood vessel. Fibrin is a protein that gives the blood clot stability. Tranexamic Acid stops the substances that destroy the fibrin within the clot.

It is particularly useful for mouth bleeding and therefore a very good preventative treatment when you are having a dental procedure.

This treatment is usually given orally as tablets. It can also be given by an intravenous (IV) drip if you are in hospital and can be made into a mouthwash.

Tranexamic Acid is not used when there is blood in your urine, as small clots can occur which can then block your urinary tract and cause you pain.

Common side effects are:

- Nausea (feeling sick) and vomiting.
- Diarrhoea.
- Joint or muscle pain.
- Muscle cramps.
- Headache or migraine.
- Runny or stuffy nose.
- Stomach or abdominal pain.

Other side effects may include skin rash and changes to your colour vision.

Solvent detergent Fresh Frozen Plasma (SD-FFP, Octaplas)

Fresh Frozen Plasma (FFP) is a sterile, frozen solution of pooled human plasma (blood) from several donors, that has lots of clotting factors in it.

As FFP is made from donated blood, there is an extremely small risk that you may get a blood-borne virus. There are ways in which these risks are minimised by the drug company. The first is that donors are carefully screened to make sure they do not carry these viruses. Secondly, testing for signs of viruses at each donation. And finally, the FFP has been treated with a solvent detergent process to inactivate or remove any possible viruses.

FFP is always given in hospital, either in an outpatient unit or on a ward. It is given to you after thawing, through a cannula (a small tube into a vein in your arm) directly into your vein over a period of one to two hours.

The possible side effects are:

- Breathlessness.
- Dizziness.
- Chest discomfort.
- Skin itchiness and rashes.
- Headache.
- Tingling feelings.

You will be closely monitored while you are given FFP. If you do have any side effects tell the nursing team straight away.

Desmopressin (DDAVP)

DDAVP stimulates release of your own clotting factors (factor VIII (eight) and VWF von Willebrand Factor) from storage sites in the body into the blood. Levels of clotting factors are increased by three to six times your baseline level for 12-24 hours. If necessary, you may have a repeat dose after 12 hours. In some people repeated infusions may not be as effective because the body doesn't have the chance to rebuild its stores. The dose is calculated according to body weight.

It cannot be used if you have certain medical conditions and does not work for everyone. We may perform a DDAVP trial prior to any emergencies or surgical interventions to see if this medicine is suitable for you.

Platelet transfusion

Platelets come from people who donate their blood via the NHSBT (NHS Blood and Transplant).

All blood donors are carefully screened to make sure they do not carry any viruses (such as Hepatitis and HIV) and tested for these before use, so the risk of you getting a virus from a transfusion are minimised.

The platelet transfusion is given to you as a drip through a cannula (a small tube into a vein in your arm). This usually takes 15 to 30 minutes and can be done in an outpatient unit or on a ward.

If a platelet transfusion is necessary, it would usually be given just before your procedure or if there were any bleeding problems.

Once transfused, the transfused platelets have an immediate effect.

How will I feel after my platelet transfusion?

Most people having a platelet transfusion do not feel anything unusual. You will be monitored either in the outpatient clinic or ward before, during, and just for a short time after your platelet transfusion.

If you feel unwell at any time you should tell your healthcare professional straight away. Some people may develop a temperature, chills, a rash, or breathing difficulties. These reactions are usually mild and can be easily treated with paracetamol, an antihistamine, or simply slowing down the transfusion.

Severe reactions are extremely rare, but if they do happen staff are trained to recognise, and treat them.

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further information

If you have any queries or questions, please contact the Bleeding disorders team on 0151 706 3397

Text phone number: 18001 0151 706 3397

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