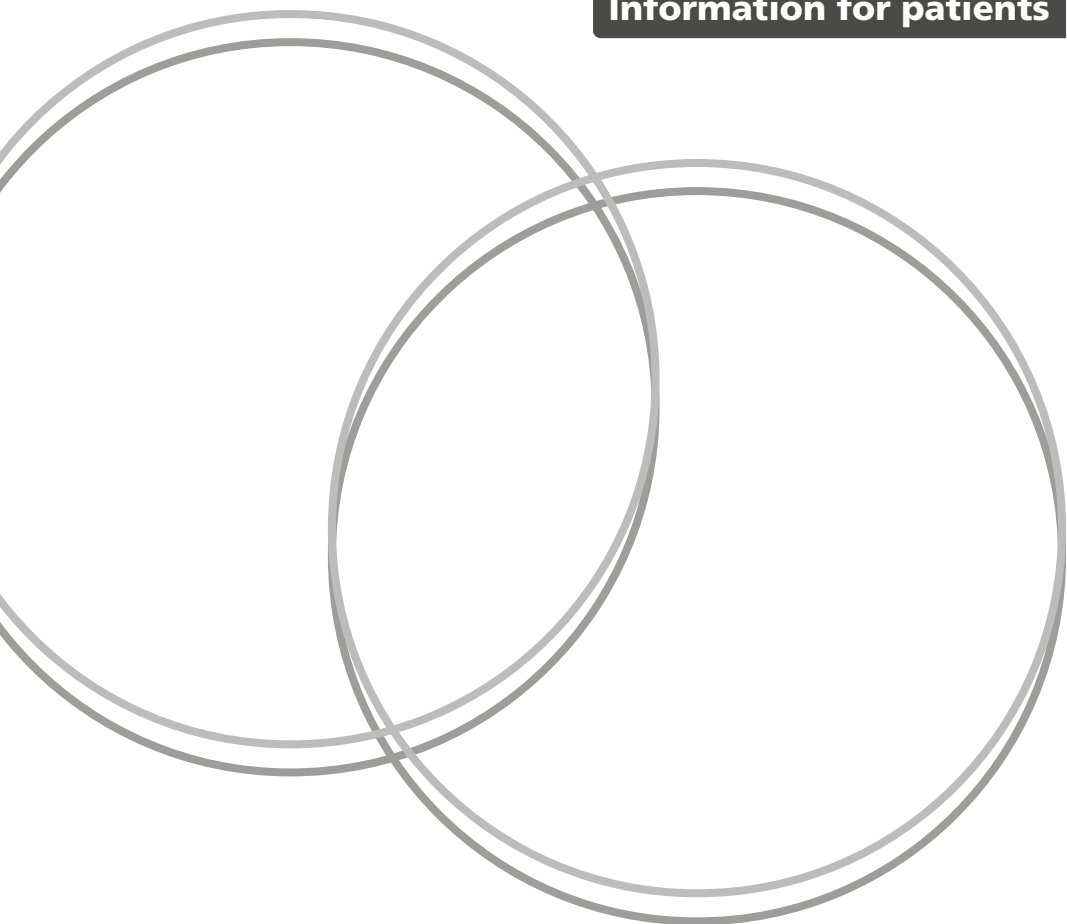


COVID-19 Vaccine-induced Immune Thrombocytopenia and Thrombosis (VITT) and VITT Like Syndromes

Information for patients



What is VITT?

Vaccine-induced immune thrombocytopenia and thrombosis (VITT) is a rare and serious immune condition that leads to blood clotting and low platelets.

It was first described in 2021 as an adverse effect of the Astra Zeneca and Janssen COVID-19 vaccinations. It has subsequently been found to occur rarely after other vaccines, adenovirus and other infections, and even without a triggering event.

Thrombosis:

Clots in the blood vessels blocking the flow of blood.

Thrombocytopenia:

Low platelets (small particles in the blood important for normal blood clotting).

VITT episodes are serious and life-threatening. In this condition, blood clots can form in the blood vessels in different parts of the body including the brain, liver, gut, heart, legs, lungs and kidneys. VITT is considered a medical emergency and people can die from VITT despite best available treatments.

Who gets VITT?

VITT affects women and men equally. It can affect people of all ages. Most people with VITT have not had blood clots before, and do not have other conditions that make them more at risk of blood clots.

There is no evidence that people who have had low platelets for any reason are at increased risk of developing VITT. There is no evidence that people with a haematology disorder are at increased risk of VITT. Currently we can't tell who might develop this condition.

What causes VITT?

People with VITT have unique proteins called antibodies that react to another protein called platelet factor 4 (PF4). The antibodies cause abnormal activation of the platelets and the blood clotting system, leading to clots (thrombosis) forming in the blood vessels. Because the platelets are used up making clots, the platelet count becomes very low (thrombocytopenia).

How is VITT diagnosed?

People with VITT experience many different symptoms. Symptoms start 5 or more days after the initial stimulus (such as the Astra-Zeneca COVID-19 vaccine) and often occur at unusual places in the body.

Unusually severe and persistent headaches are common. They may be worse when lying down or bending forward. The headache may occur with changes in vision, feeling or being sick.

People can also have fits (seizures), weakness on one side of the body or a drop in level of consciousness.

Other symptoms can include:

- persistent abdominal (tummy) pain
- blood in the stools
- chest pain, shortness of breath
- leg swelling.

VITT is diagnosed with blood tests. VITT is confirmed by finding antibodies to PF4 (anti-PF4 Abs) in the blood. Blood tests show low numbers of platelets (thrombocytopenia). Test results also indicate excessive activation of the blood clotting system. This includes very high levels of 'D-dimers' – proteins that happen when blood clots are breaking down – and low fibrinogen – a substance that helps clot formation.

How is VITT treated?

VITT requires urgent treatment. People treated for VITT will have the following treatments as an inpatient and will remain in hospital until it is safe for them to go home.

- Infusions containing healthy antibodies (intravenous antibodies – known as Ivlg) are given into the vein. These antibodies are from pooled donations from blood donors. The antibodies interfere with the anti-PF4 Abs.
- Drugs to ‘thin the blood’ called anticoagulants are given to treat the clots and prevent new clots.
- Steroids or other treatments such as rituximab may be given to stop the abnormal antibody activity.
- Clots in the brain, legs or heart may need surgical removal.
- Sometimes a procedure called plasma exchange is needed. Plasma is the fluid part of the blood which contains antibodies, nutrients and clotting factors. Plasma exchange treats VITT by removing the anti-PF4 Abs. The plasma that is removed is replaced with plasma from donors.

What is Intravenous Immunoglobulin (Ivlg)?

Liquid immunoglobulin has antibodies in it which will interfere with the PF4 antibodies and cut-down their effect. It is part of the blood’s plasma and when people donate blood, this part can be separated out. It is taken from donors who are screened to make sure they are healthy. The plasma is then tested for serious infections like hepatitis and HIV. The plasma is purified before it’s used for IVIg therapy. During the therapy, prepared immunoglobulin is infused into your veins. A health care provider uses a needle to get into your vein. Then the medicine can flow from a bag through a tube into your arm. This takes about 2 to 4 hours.

What happens during plasma exchange?

People are usually awake in bed during the procedure. Blood is taken out of a large vein either from a person's arm or from a special line which the doctors will have arranged to be put in. The blood is fed into a machine and spun very quickly so that the different parts of blood get separated into layers. The separated blood cells are returned with the replacement plasma. The person's own plasma will travel into a collection bag and be discarded. Each plasma exchange can take 2 to 3 hours and will be performed by a specially trained Apheresis Nurse Practitioner. Please feel free to ask them any questions.

What are the main side effects of plasma exchange?

During plasma exchange an anticoagulant (blood thinner) is used to stop blood from clotting whilst in the machine. It may cause low calcium levels, leading to tingling in your hands or face. This can be easily treated by the nurses giving you calcium in the vein or with calcium tablets which you chew. People can sometimes also get reactions to the replacement donated plasma even though we use the safest products possible. We can treat most reactions easily with medications.

Anticoagulation (blood thinners)

Non-heparin anticoagulants are used, some are given as a continual infusion (such as argatroban), some by injection into the fat under the skin (such as fondaparinux) and some are given in tablet form (e.g. apixaban, rivaroxaban and dabigatran). Low molecular weight heparin may also be used once the diagnosis of VITT is certain. This is given by subcutaneous injection. When you leave hospital you will be given a tablet blood thinner and should not stop taking this until your doctor knows that the VITT has gone.

Steroids

Many people are prescribed steroids such as methylprednisolone, dexamethasone or prednisolone to treat VITT. These drugs work by dampening down your immune response and reducing the PF4 antibody levels in your blood. When you go home from hospital you may need to take a reducing dose.

Side-effects of steroids

Steroids do not usually cause problems if they are given for a short period of time. People often feel hungrier when taking steroids and may put on weight. If you are worried about possible side effects, please discuss your treatment with your doctor before making any changes to your medication. Steroids should not be stopped suddenly without medical supervision.

Rituximab

Rituximab is a drug that is helpful in many conditions to stop the immune process. Rituximab is given as an infusion through a drip (a small tube into a vein in your arm) for 2 to 4 hours once every 3 to 4 days for four doses.

Most people who are treated with rituximab for have no side effects. The most common problem is a reaction to the infusion (such as a fast heart rate or breathlessness), but you will be monitored closely while it is given.

Before receiving rituximab, you must also be screened for hepatitis B (a viral infection), as rituximab can make this infection more serious.

Going home after VITT

You will be discharged home when your platelet count is normal and you have no new blood clots.

You will need to be closely monitored and stay in contact with the hospital team. For the first 1 to 2 weeks you will be asked regularly how you are to check if any symptoms are coming back. You will need a blood test to check your platelet count every 2 to 3 days during this period. You will have weekly appointments in clinic.

You will feel very tired, even though you are recovering. Gradually ease into your old routine and accept offers of help from friends and family. Consider going back to work part-time if possible. We are able to provide certificates and letters for your employer. Your GP will be informed of your condition and any treatments that you have received.

Everyone is different, but patients can sometimes feel overwhelmed by their experience in hospital. If you feel that you would benefit from support for your mental health as well as your physical condition, you must ask your hospital team or GP.

**Do ask questions about your treatment.
See 'How to contact us' on the next page).**

How to contact us

Please discuss any areas of concern with your doctor in clinic.

For patients who have been recently discharged from the ward, the haemostasis team are available 24 hours a day 7 days a week for advice. Their contact details are as follows:

9am to 5pm, Monday to Friday: 01865 225 316.

Out of hours /weekends

03003 047 777 and ask for the haematology specialist registrar on call.

For non-urgent questions, please contact

orh-tr.clinicalhaematology@nhs.net

or phone: 01865 235 185

If you think your VITT symptoms are returning, please call either the haemostasis team (as above) or Haematology Triage at the Churchill Hospital urgently on 01865 572 192 and we will arrange for you to have a blood test.

Further information

This information, and further medical information about VITT, is also available on the British Society for Haematology website:

www.b-s-h.org.uk/about-us/news/covid-19-updates

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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