

# COVID-19 vaccine immune thrombosis and thrombocytopenia

## VITT

### Information for patients

#### What is VITT?

Vaccine induced thrombosis and thrombocytopenia is a very rare immune condition, that leads to blood clotting and low platelets.

**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 to a similar extent and can affect people of all ages however many of the cases described so far have occurred in people below 50 years of age although this probably represents the people currently being vaccinated. Most people with VITT have not had blood clots or risks factors for thrombosis.

Currently we have not identified any risk factors for developing this condition.

#### What causes VITT?

Patients with VITT have a unique antibodies to platelet factor 4 (PF4). The antibodies cause activation of the platelets and the blood clotting system, leading to clots (thrombosis) forming in the blood vessels, and a low platelet count as the platelets are used up in the process.

#### How is VITT diagnosed?

People with VITT experience many different symptoms:

Symptoms start 5 or more days after Astra- Zeneca COVID-19 vaccine and often occur at unusual sites in the body.

Headaches are common and unusually severe and persistent, and may be worse on lying down or bending forward. The headache may occur with changes in vision, feeling or being sick. Fits (seizures) can occur, or weakness on one side of the body or a drop in consciousness.

Other symptoms can include:

- Persistent abdominal (tummy) pain
- blood in the stools
- Chest pain, shortness of breath
- Leg swelling

Blood tests show low numbers of platelets (thrombocytopenia) and indicators of activation of the blood clotting system, such as very high D-dimers (much higher than expected for standard blood clots) and low fibrinogen. VITT is confirmed by finding antibodies to PF4 in the blood.

## **How is VITT treated?**

- Intravenous immunoglobulin concentrate (purified from multiple blood donations) is given as an infusion in the vein to interfere with antibodies to PF4.
- Blood thinners are given to treat the clots and prevent new clots.
- Steroids or other treatments such as rituximab may be given to stop the immune process.
- 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. 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 AIDS. 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). 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.

### ***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 3-4 days for four doses.

Most people who are treated with rituximab for TTP 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 1-2 weeks you will be asked regularly how you are and check if any symptoms are coming back. You will need a blood test to check your platelet count every 2-3 days during this period.

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.

## How to contact us

Please discuss any areas of concern with your doctor in clinic. For non-urgent questions, please contact .....If you think your VITT symptoms are returning, please call .....and we will arrange for you to have a blood test.