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I'M LUCKY TO BE ALIVE.

LISA, 47
CHILD MINDER,
WEST MERSEA, UK

I was at work and I started to feel pins and needles in my arm and on the left side of my body. My mouth started to droop. I later found out that I was having a mini stroke.

It had all started a few weeks earlier when I began to feel extremely tired and unwell. The whites of my eyes had turned yellow and I had one instance of blood in my urine. The doctor thought it might be anaemia but the blood test results didn't come back in time.

What happened at work was very scary but thankfully my colleagues responded quickly and called an ambulance immediately. I was taken to the accident and emergency (A&E) department of Colchester General Hospital. They thought at first it might be a migraine. I was admitted to A&E and throughout the day my symptoms were getting increasingly worse. I was having blood taken when I began to have a seizure. At this point my memory goes blank.

The next thing I remember is waking up and seeing very bright lights. I was confused and didn't know where I was. I had no memory of being transferred to University College London Hospital (UCLH) by ambulance. I was in the Critical Care Unit.

"The nurses were very kind and patient with me. They had to tell me again and again that I had something called TTP (thrombotic thrombocytopenic purpura) and that it was very serious."

The nurses were very kind and patient with me. They had to tell me again and again that I had something called TTP (thrombotic thrombocytopenic purpura) and that it was very serious. I just could not believe that it was all that bad because I was feeling so much better than I had done for weeks. I had also woken up rather bizarrely with a strong cockney accent. I was finding everything very funny and was constantly making jokes, although in hindsight what was happening to me was not funny at all.

TTP is such a rare condition that it is almost unbelievable to think that I have it. But it happened. I am lucky that the haematologist at Colchester General Hospital knew about this rare condition; if he hadn't reacted so quickly and got me transferred to the specialist centre, I might not be alive today.

I was in Critical Care for a few days, then later was given my own private room with a beautiful view over London. My treatment involved plasma exchange, which is a true miracle machine. For hours at a time I was hooked up through needles in my neck while my plasma was taken out of my body and replaced with other people's plasma. I went through this process again and again, until my platelet count returned to normal. I was at the hospital for two weeks. It's almost like a top hotel, and all the staff are so caring, kind and friendly. My consultant, Dr Marie Scully, and all the staff know you by name. Despite the circumstances of my stay, it is a lovely place to be. You feel as if you are the only person who is ill.

This whole experience has been very traumatic for me and my family. My mum, who is 70 years old, could not get her head around what was happening, which was made worse by the fact it was hard for her to visit me when I was at the hospital in London. My daughter, who is 13 years old, was on holiday in Florida with her father when I became ill. My mum had to wait for my daughter's plane to land before calling her to tell her I was unconscious in Critical Care.

"I was recently at a patient event and met one of the transfusion laboratory staff, and when I told him my name he said: "I know your blood!" He hadn't met me but he knew my story!"

After what happened my daughter didn't want to leave me or let me go anywhere. She was scared that something would happen again. That's the awful thing about it – they can't say whether or not I will have a relapse.

The TTP Network is a patient group set up by patients to support patients and their families. As TTP is so rare, it is great to meet other patients who have been through something similar to you – you form a strong bond straight away. The more people who know about this condition the better. Nobody I knew had heard of this before it happened to me. As patients, we want to know why we got TTP and if we will have a relapse. I attended a recent TTP patient day in London, and it was so lovely to see a lot of staff from the hospital there too; they had given up their free time for us, they really care. Many of us also took part in a sponsored walk for TTP Education & Research during UCLH's 2016 London Bridgathon, which raises money and awareness for the condition. I met one of the transfusion laboratory staff from the hospital, and when I told him my name he said: "I know your blood!" He hadn't met me before but he knew my story!

It's difficult to come to terms with living through a near death experience. I had to take three months off work and it took time to recover physically. Many of the patients I've met have experienced side-effects after TTP, such as depression or extreme tiredness, but I haven't experienced any. I live a perfectly normal life now. I have a very physical job as a childminder for very young children so I'm never sitting down. I suppose I have reacted relatively positively to what happened. I know I'm one of the lucky ones to have survived this. I am a much happier person than I was before this happened. I just feel so grateful to be alive. I believe more than ever that you should live for the now.

WE HAVE SEEN PEOPLE COME IN WITH TTP AND DIE VERY YOUNG, VERY QUICKLY.

DR MARIE SCULLY,
UNIVERSITY COLLEGE LONDON HOSPITAL

Thrombotic thrombocytopenic purpura (TTP) is an ultra-rare, life threatening blood disorder that can present at any time in life, usually affecting women aged 30–40. This autoimmune condition causes blood clots to form in small vessels throughout the body and can cause organ damage, e.g. in the brain, heart or kidneys.

TTP can occur very suddenly and people affected often turn up at the accident and emergency department, 10% of them presenting in a coma. We have seen people come in with TTP and die very young, very quickly. Once you've seen that, you don't forget.

A delay in diagnosis can have a massive impact on a patient's risk of dying. Once TTP is identified the patient is given plasma exchange with octaplas®, which acts like a cleansing process removing their plasma and antibodies and replacing it. Plasma exchange is carried out until their platelet count goes up; that's when you see a prompt clinical improvement. Before plasma exchange was introduced, there was a 90% mortality rate. Today there is a 90% survival rate. Our priority is to get our patients to survive the acute stage.

Patients often face chronic issues resulting from a frightening near-death experience. They can become anxious and fall into a black hole, resulting in clinical depression. There is a high chance – 30–50% – that a patient will relapse. These people have young families, jobs and partners. Their lives have been seriously disrupted and they live with the fear that it will happen again. TTP is a complete game changer.

University College London Hospital is a centre of excellence for the management of TTP and our objectives are to get quicker diagnosis for patients, improve treatment, and enhance life after TTP, for example by finding ways to predict who will relapse.

With TTP things can go wrong very quickly. We act fast and treat patients as we would want to be treated. We all live by that philosophy. We wouldn't be human otherwise.

ONE IN TEN PATIENTS COMING INTO HOSPITAL WILL REQUIRE A BLOOD TRANSFUSION.

DR JEANNIE CALLUM
DIRECTOR OF TRANSFUSION MEDICINE AND TISSUE BANKS, SUNNYBROOK HEALTH SCIENCES CENTRE, TORONTO, CANADA

One in ten patients coming into hospital will require a blood transfusion. Our centre specialises in the transfusion support of trauma patients, haematology and oncology patients, cardiovascular surgery patients and newborns. We have the largest trauma centre in Canada. When trauma patients come in with massive bleeding, they undergo complex testing so we can find out which coagulation factors are missing. If you give a haemorrhaging patient too little blood they will continue to bleed; however, if you give them too much they will go into fluid overload. The most common complication in transfusion which leads to morbidity or death is transfusion-related circulatory overload (TACO). This happens in patients, usually over 60–70 years old, with heart problems or chronic anaemia. TACO causes heart failure and we see that in 1–3% of transfusion cases.

We were one of the first hospitals in Canada to drive the use of octaplex®, a prothrombin complex concentrate (PCC) which contains clotting factors II, VII, IX and X. When you are on warfarin anticoagulation therapy, your blood is essentially poisoned so that these clotting factors are low. The goal with warfarin is that you don't develop blood clots. If you have a bleed, however, you need an antidote to warfarin. PCCs are used to reverse the effects of oral anticoagulation therapy when bleeding occurs. Before we introduced the use of octaplex® we used fresh frozen plasma (FFP). PCC has been shown to reduce the risk of transfusion reactions, especially TACO, and speed up warfarin reversal time. All our physicians know that we should use PCC instead of FFP; however, on our last audit in 2013 for the Province of Ontario, 10% of our plasma use was still for warfarin reversal despite the availability of a safer alternative. We have now implemented an interceptive process in which, when an order comes in for plasma, the technologists verify if it is an appropriate indication for plasma or for warfarin reversal and, if so, get the physician to change the order to PCCs.

We are currently investigating whether giving fibrinogen concentrate to patients who are bleeding will improve outcomes. Fibrinogen is the first clotting factor and plays a core role in stopping bleeding – it helps your platelets function and is critical to clot formation. In cases of trauma, reduced fibrinogen on arrival increases risk of death. We are trying to determine if the use of fibrinogen concentrates will improve outcomes in severely bleeding trauma patients. We are also investigating if using fibrinogen concentrates after cardiac surgery will result in patients needing fewer red cell transfusions. Fibrinogen concentrate is virally inactivated, unlike cryoprecipitate, and because it is lyophilised rather than frozen it can be used more quickly compared with cryoprecipitate.

I believe that "perfect is the enemy of good". You will never change anything if you get tied up in every minute detail. You have to keep moving forward. Patients should feel confident because there is a massive team of transfusion medicine scientists, technologists, physicians and pharmaceutical partners dedicated to improving bleed management, working very hard every day. There is huge collegiality in this field between different centres and countries. There are thousands of people around the world who are dedicated to driving safety for donors and patients, and passionately working on innovative solutions and improving blood transfusions.

BEHIND EVERY TEST TUBE IS A PATIENT.

KENNETH AMENYAH
TRANSFUSION LABORATORY MANAGER
VIAPATH BLOOD TRANSFUSION LABORATORY, KING'S COLLEGE HOSPITAL, LONDON, UK

It is estimated that 70% of all decisions regarding a patient's diagnosis and treatment are based on laboratory services. Biomedical scientists carry out a wide range of laboratory and scientific tests to support the diagnosis and treatment of diseases. I have the overall scientific and technical responsibility for managing our team of biomedical scientists and scientific assistant technical officers, monitoring the quality of work processes and supporting staff in training, learning and development needs.

In the Blood Transfusion Laboratory (BTL) we carry out blood grouping tests, antibody screening and specialist tests to identify antibodies to enhance the provision of safe and compatible transfusion to patients. In our laboratory we process on average 300 samples each day. We discuss patients with complex or special requirements with clinicians before deciding on the most appropriate blood and blood products for the patient. Indeed, one can refer to what goes on in the BTL as being the 'live wire' of the hospital. Although we do not have direct contact with patients, we never forget that behind every test tube is a patient.

Transfusion refers to the administration of donated blood products such as red blood cells, platelets or plasma. Blood transfusion is indicated in the treatment of various conditions when blood loss has occurred or the body fails to produce enough blood or blood components to meet the body's needs, e.g. bleeding disorders and blood loss due to surgery and traumas. Blood transfusion therapy can be life-saving.

In BTL we store pre-thawed group AB octaplas®LG for trauma patients and ensure timely allocation of this product for bleeding/haemorrhaging patients. We also use octaplas®LG to support patients on therapeutic plasma exchange.

The transfusion of blood components is an important procedure that should only be undertaken when the clinical benefits to the patient outweigh the potential risks. Strict procedures must be followed to ensure that the correct blood component is given and any adverse reactions are dealt with promptly and effectively.

In recent years, many measures have been implemented to increase blood component safety and the safety of the clinical transfusion process. Haemovigilance programmes report the main risks to patients from transfusion. Appropriate use of blood products is a goal worth aiming for.

The success of treating a patient is determined by good clinical judgement, timely intervention and effective communication between the laboratory and the clinical area. It always gives me great pleasure when staff receive good training to fulfil their role within BTL and ultimately enhance patient care.

BLOOD IS ESSENTIAL FOR THE WELLBEING OF EVERYONE.

DR TAREK OWIDAH
CONSULTANT HAEMATOLOGIST
KING FAISAL SPECIALIST HOSPITAL AND RESEARCH CENTRE, RIYADH, SAUDI ARABIA

In Saudi Arabia our greatest issue is the availability of sufficient blood donors to meet the increasing demand for blood products. Unfortunately there is no central blood banking system so each hospital must be self-sufficient and manage its own blood supply through blood donations. I am campaigning for a central blood system in Saudi Arabia. One of my major goals is to see more blood products made available to patients who need them. We set up a charity for haemophilia patients, through which we are helping to raise awareness and campaign for funds and availability of factor replacement products. Challenges make life more interesting.

When a patient needs plasma, they have their ABO blood group validated. The request will go to the blood bank, which will recommend the best product for treatment based on the patient's blood group and the quantity needed. We use fresh frozen plasma (FFP), and for patients with rare blood groups we use octaplas®. The plasma is taken out of the freezer and thawed to body temperature: 37° Celsius.

The most common reasons for plasma transfusions are surgical procedures. Surgeons give prophylactic infusions of plasma to prevent bleeding during surgery. Surgeons are concerned about bleeding during cavity, abdominal, intracranial and orthopaedic procedures. The surgeons tend to be proactive to avoid bleeding, especially during organ transplants. The second most common group of patients with long-term use of plasma are those with rare bleeding deficiencies, such as factor X or II. These patients are prone to bleeding especially with trauma, injury, excessive exercise and surgery. They require regular plasma infusions to increase their coagulation factor levels.

We use a large volume of plasma for the treatment of patients with thrombotic thrombocytopenic purpura (TTP). In our registry we have 100 TTP patients. TTP is a rare, life-threatening condition associated with severe ADAMTS13 enzyme deficiency. It is often associated with renal failure and neurologic manifestations. TTP requires plasma exchange and we usually use FFP; however, when the blood group is rare we use octaplas®. These patients receive large volumes of plasma; for acute patients they can have plasma exchange for anything from five days up to one month depending on their response. We had an interesting TTP case when a young lady in delivery had pre-eclampsia. She had TTP and needed daily plasma exchange for two months. She was AB blood group which is very rare, meaning it was difficult to have sufficient donors to collect enough plasma for her. She was put on 13–15 units of octaplas® daily for two months. For the past year she has been receiving routine supplementation of octaplas®.

Blood products are involved in so many disciplines of medical practice. It is a dynamic and fast-growing area of medicine. The advances in knowledge that have been made during my 18 years of practice have been tremendous. It is a fascinating field and very important because blood is essential for the wellbeing of everyone.

IN HAEMOVIGILANCE OUR GOAL IS TO ENSURE MAXIMUM SAFETY IN ALL ASPECTS OF TRANSFUSION.

BRENDAN BRANIGAN
HAEMOVIGILANCE OFFICER,
BEAUMONT HOSPITAL, DUBLIN, IRELAND

I am a nurse. I worked for over nine years in operating theatres as an anaesthetic/recovery room nurse. I also worked on children's wards, in Intensive Care and as a volunteer in a foreign conflict zone. While abroad, I was often involved in incidents with mass casualties. Today my role includes providing education to doctors and nurses on guidelines in blood transfusion. I am particularly interested in teaching how to manage patients who require massive transfusions due to trauma or other causes. I have been in my current role for 10 years.

Blood transfusion is a complex, fast-changing field of healthcare and that's why education is important to ensure that doctors and nurses have up-to-date knowledge. According to the World Health Organization (WHO), "Haemovigilance is required to identify and prevent occurrence or recurrence of transfusion related unwanted events, to increase the safety, efficacy and efficiency of blood transfusion, covering all activities of the transfusion chain from donor to recipient." The haemovigilance system includes monitoring, identification, reporting, investigation and analysis of adverse events, near-misses and reactions related to transfusion and manufacturing.

In haemovigilance our goal is to ensure maximum safety in all aspects of transfusion. We ensure that nurses and doctors understand the latest guidelines and the measures to avoid risks. Today, plasma is processed to the highest standards available, so we can be confident that patients are protected from being infected with viruses from blood products. However, blood transfusion has some inherent challenges simply from the fact that a patient is getting transfused with a biological substance that comes from another human. Part of my role is to investigate suspected transfusion reactions, which fortunately are rare and usually mild in nature.

Some patients really have no idea of the benefit they have gained through the science of blood transfusion. They may be completely oblivious to it. They might be informed by their doctor or nurse: "We had to give you ten pints of blood" – if only they knew it was much more complicated than that!

A few years ago, while kayaking in Stockholm, I was surprised to see the 'Octapharma' sign over a building, and this chance encounter led to a fascinating visit to one of Octapharma's production facilities. I learned a lot about plasma fractionation there, as well as the interesting history of plasma production in Stockholm.

I have many international contacts in the field of transfusion. We help each other and share knowledge and experience. Blood transfusion is a fascinating field of healthcare, and I really enjoy teaching and bringing new ideas to my hospital which benefit patients.