TTP & ME

My experience of apheresis plasma exchange treatment for Thrombotic Thrombocytopenic Purpura

Jo Rendall
Diagnosis, symptoms & treatment

- I was diagnosed with TTP on 1 May 2017 at Huddersfield Royal Infirmary.
- I was 42 years old.
- I had been admitted to hospital with jaundice, extreme fatigue and fever the previous night after seeing an out of hours GP.
- My platelet levels had dropped to around 7 as tiny clots formed due the reduction in the Adamts13 enzyme caused by acquired TTP.
- Treatment began immediately with plasma exchange of octaplas via a venal line in my neck, initially at my bedside in HRI and then at the Therapeutic Aspheresis Unit in Leeds.
- I was transferred to the Freeman Hospital, Newcastle Upon Tyne a few days later and continued treatment there on the haematology and renal wards.
- During my time in hospital I was also treated with several blood transfusions, prednisolone, aspirin, rituximab (IV) and mycophenolate mofetil.
Plasma exchange

- During my time in hospital I received 30 plasma exchange treatments over consecutive days.
- The dose was increased to six litres at the Freeman Hospital to try to combat my fluctuating platelet levels which remained below normal levels.
- I had three temporary venal lines inserted, two in the neck and one in the groin, under local anaesthetic.
- A nurse needed to be present throughout the PEX treatment and my blood pressure was closely monitored.
- Treatment usually took over 4 hours.
- I had a full blood count each day.
- I did not suffer any adverse reactions to the plasma exchange treatment apart from minor aches and pains, coldness in the limbs, the need to rest following treatment sessions and some anxiety.
- My main fears about the treatment: suffering an allergic reaction to donated plasma; deep vein thrombosis; what would happen if the PEX did not work.
“Hi all, just wanted to let you know that I was admitted to Huddersfield Royal Infirmary on Sunday feeling unwell and with jaundice. On Monday I was diagnosed with a blood clotting condition called TTP and went to the haematology ward. I had never heard of it and was pretty scared but the consultant assured me that it is very treatable and most sufferers make a recovery in hospital and then have the condition controlled with outpatient monitoring and treatment as necessary. Treatment is being attached to machine to have your blood plasma replaced to reboot the immune system. Currently 4 hours per day but should go down. Travelling to Leeds this morning for that. So far seem to be responding well. Likely to be transferred to Newcastle by the weekend.”

Facebook 3 May 2017
“Just waiting for nurses to hook me up to a drip with a new drug that will hopefully know this TTP thing on the head and get me back home…”

Facebook 8 May 2017

“Looks like I’m going to be here into next week. Platelets are up but fluctuating. At least I have some now though…better than when I was admitted…”

Facebook 11 May 2017

“Had six litres of plasma for the past three days rather than the usual 4.5 litres…hope its working”

Facebook 16 May 2017
“I am the longest serving resident of the women’s bay on the ward now. No discharge date yet but I continue to feel well and the treatment is progressing. I have run out of space for all the cards I have received…keep your fingers crossed”

Facebook 27 May 2017

“Pleased to tell you that I was discharged from hospital this afternoon and am now back home with Graeme after nearly six weeks in hospital…my platelets are back in the normal range. I will be back in hospital next week as an outpatient for checks and continuing with medication for a while but it is lovely to be back home.”

Facebook 9 June 2017
Discharge

• My last PEX treatment was on 3 June 2017.
• I had been given a “day off” to see how I responded.
• By 5 June 2017 my platelet levels had risen and were back in the normal range.
• No more plasma exchange treatment was necessary.
• The venal line was removed.
• It was explained to me that the high dose of PEX had probably resulted in healthy platelets being removed as the same time as the inhibitor. Stopping PEX meant that my platelets could return to a normal level.
• I was discharged from the Freeman on 9 June 2017.
• Initially I was seen at the haematology department at the Royal Victoria Hospital (RVI) in Newcastle on a weekly basis and continued with MMF and aspirin. Steroid doses were gradually tapered off and I took a weekly alendronic acid tablet for a while to counteract bone deterioration from steroid use.
• I remained on sick leave from work until the end of July 2017 and then returned on a phased return.
• By October 2017 I had stopped taking all medication for TTP except aspirin, which was also stopped earlier this year.
A year on…

• I have remained in remission and go for check ups and a full blood count every two months at the RVI.
• The FBC currently includes a test of my Adamts13 levels with the intention of predicting a possible relapse and giving treatment before symptoms happen, should a relapse occur.
• I am in good health, continue to have high platelet levels and suffered no lasting damage from my illness.
• I know that a relapse is possible and that I may need further treatment in the future but at the moment I am enjoying getting on with my life, which has very much returned to normal.
• I feel lucky that my TTP was diagnosed early and treatment with PEX was available and began promptly. As a result I made a full recovery from my TTP episode.
• I am grateful to the wonderful NHS staff who looked after me in HRI, Leeds and Newcastle; all the donors out there; and especially to everyone who is working hard to ensure aspheresis treatment remains as safe as possible for patients like me.

THANK YOU!