



CATEGORY OF PAPER					
Specific action required:		Provides Assurance:	✓	For Information:	✓

Board of Directors' Meeting – 25/10/2018	
<b>Report title:</b>	<b>Patient Story</b>
<b>Purpose of report:</b>	The purpose of the report is to provide the Board with a reflection of our service delivery through a patient experience or staff perspective, with a view to use these experiences to continually improve the services delivered
<b>Key issues:</b> <i>(key points of the paper, how this supports the achievement of the Trust's corporate objectives, overview of risk implications, main risk details on page 2)</i>	<p>This patient story is accompanied by a video. This is the story of the late Aimee Barber, who sadly passed away at the age of 28 due to a blood clot that had travelled to her kidneys. Aimee was diagnosed with Vascular Ehlers-Danlos syndrome at the age of 9.</p> <p>Ehlers-Danlos syndrome (EDS) is a rare condition that affects connective tissue. There are many types of EDS and Vascular Ehlers-Danlos syndrome (VEDS) is often considered to be the most serious. It affects the blood vessels and internal organs, which can cause them to split open and lead to life-threatening bleeding.</p> <p>Following Aimee's death, her mother, Mrs Gail Barber, raised complaints with a number of areas in the NHS, including our service, in regards to the care Aimee had received. In relation to our service Mrs Barber wrote to us in November 2017 raising the following concerns:</p> <ol style="list-style-type: none"> <li>1. What was recorded by the ambulance service regarding the Vascular Ehlers-Danlos Syndrome</li> <li>2. Why we have to explain about this every times an ambulance arrived?</li> <li>3. Was the ambulance equipped to deal with this?</li> <li>4. Why did the crew feel that it was appropriate to make Aimee feel like a time waster?</li> </ol> <p>Mrs Barber's complaint was answered and this subsequently led to a Subject Access Request for records. A local resolution meeting with the Investigating Officer and a Complaints Manager took place so we could try to resolve Mrs Barber's complaint, which included additional issues raised following our initial response and receipt of records.</p> <p>Mrs Barber wanted us to understand what Aimee had endured and the impact on her family. It was clear throughout our discussions and meeting with Mrs Barber that she is passionate about raising the awareness of VEDS throughout the NHS so that other patients' and their families do not have the same experience.</p> <p>As a result of our investigations and meeting action has been taken to raise awareness of VEDS with operational crews and clinicians in our operations center.</p> <p>The investigation into Mrs Barber's complaints found no harm was caused by the clinical care provided by NEAS.</p> <p>The report provides assurances that we listen to concerns raised and take action to share learning and improve the patient experience.</p>
<b>Issue previously considered by:</b>	N/A
<b>Recommended actions:</b>	The Board is asked to review this paper and accompanying video and take assurance that we take all concerns raised seriously and listen to not only the specific complaint but the wider issues faced by patients in some difficult circumstances
<b>Sponsor / approving director:</b>	Director of Quality and Safety
<b>Report author:</b>	Gillian Summers, Complaints Manager, Patient Experience Team
<b>Governance and assurance</b>	

<b>Link to Trust Priorities:</b> <i>(please tick)</i>	Organisational Sustainability	Improving Quality & Safety	Workforce & Investors in People	Clinical Care & Transport	NHS 111 & Clinical Assessment Service	Comms & Engagement
		✓		✓	✓	✓
<b>Link to CQC / KLOE:</b> <i>(please tick)</i>	<b>Caring</b>		<b>Responsive</b>	<b>Effective</b>	<b>Well Led</b>	<b>Safe</b>
	✓		✓	✓	✓	✓
<b>Link to Trust values:</b> <i>(please tick)</i>	<b>Pride</b>	<b>Strive for excellence</b>	<b>Respect</b>	<b>Compassion</b>	<b>Take responsibility &amp; be accountable</b>	<b>Make a difference – day in &amp; day out</b>
	✓	✓	✓	✓	✓	✓
	<i>(Please explain how this paper supports the application of the Trust's values in practice)</i>					
Following the complaints process and meeting with Mrs Barber has ensured the patient's family's voice has been heard. This was a difficult process for Mrs Barber and her family and in engaging fully we showed we continue to take pride in the service we deliver and strive to provide an excellent service. During the process we demonstrated respect and compassion by understanding and listening to Mrs Barber and we have been able to give her the platform to share Aimee's story with the view of improving understanding of Vascular Ehlers-Danlos syndrome and the experience for other patients.						
<b>Any relevant legal / statutory issues?</b> <i>(Such as relevant acts, regulations, national guidelines or constitutional issues to consider)</i>	N/A					
<b>Equality analysis completed</b> <b>If this is not relevant please explain why:</b>	<b>Yes</b>		<b>No</b>		<b>Not Relevant</b>	
					✓	
An equality analysis is a review of a policy, function or significant service change which establishes whether there is a positive or negative impact on particular social groups						
<b>Key considerations</b>	<b>Details</b>					
<b>Confirm whether any risks that have been identified have been recognized on a risk register and provide the reference number:</b>	Not applicable					
<b>Please specify any Financial Implications</b> <b>Please explain whether there are any associated efficiency savings or increased productivity opportunities?</b>	Not applicable					
<b>Are any additional resources required e.g. staff capacity?</b>	Not applicable					
<b>Is there any current or expected impact on patient outcomes/experience/quality?</b>	Improved patient experience and awareness for staff.					

<p><b>Specify whether appropriate clinical and/or stakeholder engagement has been undertaken:</b>  <i>(stakeholders could include staff, other Trust departments, providers, CCGs, patients, carers or the general public)</i></p>	<p>Patient story to be shared via Comms Team for publication in The Summary or PULSE</p>			
<p><b>Are there any aspects of this paper which need to be communicated to our stakeholders (internal or external)?</b>  <i>(Please tick – if 'yes' then please complete all boxes. Please briefly specify the key points for communication and ensure the Comms team are informed via <a href="mailto:publicrelations@neas.nhs.uk">mailto:publicrelations@neas.nhs.uk</a>)</i></p>	<b>Yes</b>	<b>No</b>	<b>Positive</b>	<b>Negative</b>
	✓		✓	
	<b>Proactive</b>	<b>Reactive</b>	<b>Internal</b>	<b>External</b>
	✓		✓	

**Board Meeting  
Patient Story  
25<sup>th</sup> October 2018**



Aimee Barber 1988 - 2017

This is Aimee's story (as told by Mrs Barber abridged.).

Mrs Barber begins by sharing the story of the journey Aimee went through, including the initial diagnosis and complications which arose: *"Aimee was born in 1988; she was a well and a beautiful child. She enjoyed life and did everything any other children did. Aimee had 2 older brothers. Aimee loved life, did everything; went on holidays, went to school, she smiled all the time, laughed all the time. When Aimee was 9 she was not very well and was sick, I thought it was a virus or bug. Later that night she vomited in bed and called a Doctor who opened the surgery. Aimee had blood in her vomit. Aimee walked into surgery at midnight and when the Doctor examined Aimee and saw the blood we were told to take her to hospital straight away. The Doctor phoned ahead and everybody was waiting, Doctors and Nurses outside the hospital waiting for Aimee; they took her in and resuscitated her for 5 hours and eventually operated. Aimee's large bowel had perforated; a spontaneous perforation. Aimee was taken to Intensive Care and was on a ventilator for a week."*

After having a colonoscopy it was decided Aimee would have a reversal some 5 months later and Mrs Barber describes the issues Aimee continued to have; *"The operation went well but over the next 7 or 8 days Aimee deteriorated. Only I noticed she was deteriorating. On the eighth day I took Aimee home for a break but the pain on ride home was horrendous, so after an hour I took her back. By the time I had taken her back she had peritonitis and septicaemia; she was critical and they had to operate again. Aimee had an ileostomy and from then on she had a lot of infections. They did not know why this 9 year old child would present with a spontaneous perforation of the large bowel; with no infection, no bruising around it. Weeks after, the paediatrician was at a meeting at another hospital and asked around in general if anybody would know why this child would present with this and someone said had you looked Ehlers-Danlos Syndrome up. The Doctor later said, after looking this up, it was like a light bulb had been switched on. Aimee was referred to a hospital in Cardiff, Wales and had some tests there; blood tests and skin biopsies and it was proved Aimee has Vascular Ehlers-Danlos syndrome, which life was threatening.*

*"As a parent you start to look up this and I researched and investigated all the information. Aimee was going through a lot of pain and hated the stoma. She used to say she didn't mind the illness she just hated the stoma, but she had some good friends through school and that was the main thing, being able to be open about it with friends that knew what was going on. I put a big bubble around her and let her go out, to make her feel a normal child but I took all the worry. She had a good teenage life, went out; she laughed all the time, smiled all the time, she loved her friends. She met her boyfriend when she was young and they got their own house, she was house proud, had a horse and six dogs. She was not in as much pain then but was in and out of hospital for different things. When she was 21 Aimee's bowel burst again, her small bowel; they found a small hole. She was operated on again and went into intensive care. This time she was on an adult ward. I would stop in with her all the time, more because I felt like I was the one that knew. I could tell Aimee had an infection just by looking in her eyes; she would have a little bit of red in her eyes. She was sent out of hospital sometimes with an infection then her stomach would open the very next day because of infection; this was all down to the Ehlers-Danlos Syndrome because it is a connective tissue disorder; it's rare."*

Mrs Barber also tells us how Aimee continued to have complications as she got older and the pain associated with this; *“Then she started to get a lot of pain, she went to see a gynaecologist and had seen a cardiologist from 16 and they decided the best thing with her having VEDS was for her to have a cardiologist to look after her aorta; she had an echo cardiogram every year. It could have gone wrong at any time; that was part of her illness that Aimee’s aorta could dissect. She started to get a lot of pain, she had cysts on her ovaries, she also had a hernia but no one would operate on Aimee unless it was life threatening, so she was in a lot of pain. She started to go to A&E more and more, sometimes 3 times a week. Sometimes she needed an ambulance, she should have had an emergency ambulance every time because that’s what the medical professionals who deal with EDS say. Aimee went through her life and not many people had heard of Ehlers-Danlos Syndrome and Aimee had the Vascular type and Aimee’s was life threatening, it’s the only one out of all the types that is life threatening. It’s very hard to get the finances and get people to believe and get the training.”*

Sadly Aimee’s pain meant she often needed strong pain relief. As Aimee has been in pain from a young age she managed high levels of pain differently to others. This, and a limited awareness of the condition meant that some health professionals judged Aimee as a ‘morphine seeker’.

*“Aimee’s cardiologist did say to her that if she did have an aortic aneurysm he might not be able to save her life. We took that on the chin. She loved her house, making her own decisions. She had a lot of pain in all her body, it was getting worse, different kinds of pain relief; some worked. She started to take Oromorph; [different people giving different advice about how much to take]. One morning thought she may have overdosed and that gave her a mental thing about it and could not take it after that. We found that, when she was poorly and in all this pain, the only thing that would really make the pain go away was intravenous morphine, or intravenous tramadol or intravenous paracetamol and anti-sickness as well and that would help her with all the pain but nobody really took any noticed and in the midst of all this one time Aimee was judged as a morphine chaser.*

*“I would say 98% of ambulance crews were absolutely amazing with her, but a couple, you could tell by their faces sometimes, they never said it but I think they thought Aimee was a morphine chaser as well. That was so upsetting because anybody that knows Aimee and knows how strong and what a zest for life she had, she wouldn’t take morphine, she would not want any tablets that would make her sleep the next day. Sometimes when she was younger and in terrible pain the nurses and Doctor would come in and asked what her pain score was, she would say 9, 10 or more but she would have her leg over the side of the bed in A&E and she would say I’m not going to writhe on the floor for anybody, I’m not going to scream or writhe on the floor. When she went for appointments she would always have her make up on, she like her nails done and she loved new clothes”.*

Mrs Barber ends by sharing with us who Aimee was and why she wants her story to be heard: *“That was who she was; full of fun, full of life and I would play war with her but still let her have a life and I am happy for that. I know her friends were happy and they talk about how good a life she had. She had a good family, two beautiful brothers, good friends, she was Aimee Barber.*

*“I am sharing Aimee’s story to raise awareness of Vascular Ehlers-Danlos Syndrome, I am sharing this story for Aimee Barber, who was very much loved.”*

**Action plan:**

Mrs Barber made her complaint and very kindly shared Aimee’s story with the aim of improving awareness of Ehlers-Danlos Syndrome, in particular Vascular Ehlers-Danlos Syndrome and for clinicians to be mindful of how patients who have suffered pain from childhood manage the presentation of pain. At the request of the Investigating Officer, Mrs Barber provided information regarding the condition to share with operational staff.

Action	Owner	Timescale
Effective Communication In and Out of the Emergency Operations Centre and accurate recording of info to be discussed during 1:1's with all Dispatch staff.	EOC	Complete-July 2018
NHS information regarding Ehlers-Danlos Syndrome has been placed on The Lamp for access by Emergency Operations Centre Clinicians and this is being highlighted during the Clinicians monthly 1:1s so the Clinicians can familiarise themselves with the condition.	EOC	November 2018

A Patient Care Update with information regarding the condition has been issued for Operational staff	<b>Emergency Care</b>	<b>Complete-</b> September 2018
Share Aimee's story with all staff through The Summary / Pulse to raise awareness.	<b>Patient Experience</b>	November 2018

**Document Information**

<b>Author Name:</b>	Gillian Summers
<b>Author Title:</b>	Complaints Manager, Patient Experience Team

<b>Sponsor Name:</b>	Joanne Baxter
<b>Sponsor Title:</b>	Director of Clinical Care and Patient Safety