

## **Eve and her Mum (Paula) - their story:**

### **Doctor who wouldn't listen or accept that a 12-year-old girl really was seriously ill**

#### **12-year-old Eve had recurring ear infections; became very unwell**

During 2010, twelve-year-old Eve had recurring episodes of ear infection. A few days before Christmas that year, her mother, Paula, brought her to Accident & Emergency at Hospital A. The doctor she saw diagnosed an ear infection and prescribed antibiotics. Over Christmas, Eve was very nauseous and experiencing dizziness. On New Years Eve, she was very unwell. She was unable to dress herself or do anything, and had double vision, so Paula took her back to A&E in the same hospital. This was mid-morning, when A&E was very quiet with only 4-5 patients.

#### **Doctor in A&E wouldn't listen; dismissed Eve's symptoms as 'attention seeking'**

Unfortunately, they had a very unsatisfactory and distressing experience with the doctor (registrar) there. Initially he even refused to see them at all. Paula and Eve were in a curtained-off cubicle and could hear the doctor talking to the nurse outside. Aloud, and in front of everybody else, he was saying things like *'she was already seen, I don't want to see her, why should I see her ....she has been diagnosed with an ear infection, hasn't even finished the antibiotics, why should I be doing this'*.

They heard the nurse trying to cajole him, again in front of everybody, *'ah, do it for my sake, do it as a favour to me.....she has a little bit of double vision'*. Eventually, as a favour to the nurse, he came in to see them, but his attitude seemed to be that he couldn't be bothered, had made his mind up before he saw them and that they were wasting his time. He looked in Eve's ear and said there was still infection there and to finish the antibiotics. Paula asked about the nausea and double vision, and felt it should be obvious that Eve was quite ill as she had to help her from the chair to the bed. But the doctor dismissed this, saying, *'I think a little bit too much television... looking at her phone, and I also think getting a lot of attention from her mum'*.

Although Paula believed that the doctor was negligent in his manner and diagnosis, she did not say anything at the time for fear of antagonising him and the ramifications this might have for Eve's care. But it was awful *'to have a doctor saying no, I'm just not dealing with it ...I don't know whether it was because it was New Year's Eve or his last day in ENT at that hospital, I don't know...he just decided he wasn't going to deal with her...you know...'* On the way home Eve was crying and very upset, saying she was not looking for attention, even though Paula tried to reassure her that she knew she wasn't.

#### **Horrific few days with nowhere to go for help**

As it was New Year's, Paula then had to wait until January 2 to get an appointment for Eve with her GP. On the night she brought Eve home, Paula slept next to her, on the floor in her bedroom...*'I was so scared, so scared...because I thought maybe she had a tumour ...and you feel completely isolated, totally on your own, just kind of pushed away...no one to go to...At the time I didn't think of going to Hospital B [other hospital] because of the [experience at] Hospital A, you know, no one's going to listen to me...it was absolutely horrific, it really was ...We also knew that Hospital B did not have an ENT speciality so didn't think they could help us'*.

### **GP appalled; referred them to another hospital....**

The GP was appalled when she saw Eve and heard their experiences with the doctor at Hospital A. Paula *'felt like a paranoid Mum'* but the GP said *'no, you know your daughter, keep going...'* She said they would just have to skip that hospital (even though it had the ENT speciality), go to Hospital B instead and get a different team to work for them. So they went to A&E there, hoping they would get somewhere.

### **.... where Eve was diagnosed with a life-threatening condition, and care was excellent**

Luckily enough they did. The young registrar (who looked to Paula like he had just made his Confirmation!) said *'kids don't make up stuff about headaches and double vision, so there is something causing it...an ear infection won't cause that....'* He phoned a consultant and they admitted Eve. The following morning she had an MRI scan and it showed a 3 to 4 inch transverse sinus thrombosis (clot in her head, in the sinuses) which was putting pressure on the optic nerve.

Ironically, the ENT team from Hospital A then came up to Hospital B to see her. Again, Paula didn't mention their awful experience at Hospital A, even though she knew that the particular registrar they had seen at Hospital A had by then gone to another hospital. She didn't want to risk antagonising the consultant as she was trying to get him to help them, relieved that they were in the loop now and had the care.

Eve was incredibly ill....a 12 year-old at risk of a stroke that could do damage to the brain. She was transferred back to Hospital A (as an ENT case) where she had a mastoidectomy (removal of the mastoid bone behind the middle ear). This had completely rotted, probably from infection that had been there for about three months (the doctors thought that Eve must have a high tolerance for pain or that the nerve endings had been affected because of so much pus). After the mastoidectomy, Eve had to have treatment for the clot and she was transferred back to Hospital B where she remained for a month. She also was seeing an ophthalmologist from a third hospital (a university hospital). *'It was horrendous, it was horrible for her ...just, you know, an incredibly sick child...'*

Overall, they felt they had experienced excellent care, with the exception of the registrar who wouldn't listen. For example, one incident that stood out for Paula and Eve was on a day when Eve had been particularly upset and crying during her stay in Hospital A. A doctor who had been on the rounds that day took the trouble to come back in to the ward when he was finished duty. He had taken off his scrubs to go home, but came back out of kindness, just to try to cheer her up. This was a registrar, just like the first doctor in the same hospital's A&E who had originally dismissed Eve and Paula - such a difference! As Paula says, *'...everybody else, except for that guy in A&E, everybody else was exceptional...I mean, it was fantastic care, terrific care ...just this one glitch...and, you know, the fear of what he could have....to think that she was so at risk in those few days...it terrifies me, absolutely terrifies me looking back.'*

### **Luckily, Eve eventually recovered her health...**

Eve eventually recovered well....as she said herself *'all that happens now is that I get recurring ear infections, luckily none of the bad things happened'*. But Paula knows they could have easily...*'in the time from New Years Eve...not being able to get a doctor until Jan 2...during that time she could have had a stroke....you know, in hospital, she was woken up every hour on the hour, asking her little tricks to make sure she understood where she was, what her name was, light shone in her eyes...'*

After discharge from hospital, Eve had dreadful residual headaches from the head trauma and these continued for a number of years. She missed a lot of school from the initial acute episode, follow-up treatment and the ongoing severe headaches.

### **....but not without impacts on school, her confidence, her everyday life and her family**

As a result of her illness, Eve missed 3 months of 6th class in primary school. The following year she had to drop down from Honours to pass in some subjects in secondary school because, due to absences, she didn't have the foundation work done. She kept referring to herself as 'not intelligent' or 'stupid'. Thankfully, Eve is now beginning to get her confidence back...but it took about 3 years. There were other impacts as well. For example, her friends might say something like '*we're going to the cinema, Eve, on Saturday...maybe you can come if you're not sick?*' So this thing of 'you're the sickly one' kept being reiterated in her mind.

During that period Eve would get depressed ... she would be very sad. She couldn't understand why all this bad stuff had to happen...first of all, to her, but also to Paula [who had been treated for cancer two years previously]. '*What is it about us...it's happened to us again, why did we have two lots of it?*'

It was very stressful for Paula and her husband, but also for Eve's brother and for her sister, who, because of the family's health experiences, began to worry about health matters from a young age.

### **....and loss of trust in the healthcare system**

For Paula, the biggest impact was the fear, fear for Eve's health, although she thinks that even if Eve had got fantastic care, that would be normal for a parent. Apart from that, the most negative impact of the incident was because this doctor on New Years Eve was basically someone she could not trust. '*I did not feel that I was able to trust people....and I hate that, because that isn't who I am...I have great respect for people, especially people in healthcare, you know, I really had great respect....and I think it made me look back at my own treatment, when I was going through the cancer treatment and, you know, everything that goes with it ....I look back at that and you go, sometimes you're so grateful to be getting treatment that you're saying 'they're wonderful, they're angels', you know...but I could look back now and say, well, there were kind of faults there as well...so it made me, em, a little bit more negative.....I do hope that I'm getting away from that because I don't like to be that person ...but certainly I had doubts...and I started, you know, when a doctor or a nurse would talk to me I was thinking 'is she really listening or is she fobbing me off, or is she...!....suspicion came in, you know, whereas I wasn't usually a suspicious person...'*

### **The hospital never acknowledged the incident**

Paula did not raise the incident at the time - she was only concerned for Eve's wellbeing and did not want to antagonise anyone providing care for her. She has not raised the matter formally since then either, something which she often feels she should have done, especially if it would have reduced the possibility that the doctor in question might continue with this attitude with other patients.

On the other hand, the hospital in question never mentioned or acknowledged the incident either. Paula says that, at the time, she did think '*why are you not asking me why I went to the other hospital?*'...

*...I wonder, did they look at her chart and say, he made a mistake there, and just stay quiet, you know, don't mention the elephant in the room type of thing...I wasn't mentioning it, but to me, there must have been...somebody must have looked at Eve's chart ....when they got the phone-call from the other hospital...you saw a girl a couple of days ago...she's now presented here...she's got a thrombosis...surely someone, whichever doctor, be it the consultant or medical registrar or whatever, would open Eve's file and say 'oh she was here, we had her here and we sent her home...why did we send her home?'* All this despite the fact that, as Paula says '*...Hospital B had to call the ENT over, so I had to, you know, go to another hospital to get attention from the ENT in Hospital A [the one first visited]....'*

The doctors at Hospital B did indicate that they thought Eve was inappropriately sent home by Hospital A's A&E, without proper examination, although as Paula says '*...they were very careful, as of course they would have to be...*'

Also, while they were in Hospital B, a Patient Liaison Officer came to them with a clipboard and asked about their experience in the hospital. Paula recalls '*...and we were saying Hospital B is fantastic, but, you know, we did have a lot of problems in Hospital A....and we did end up talking about it....she said to me, you know, 'we can't officially comment on it but we are certainly going to learn from it'.....and, you know, that's all I want.....About 6 months later she asked me to join a Patient Focus Group in Hospital B, which I am still a member of...and she also introduced me to Patients for Patient Safety Ireland...*'

### **5 years on.... administrative failures jeopardise Eve's follow-up care**

Paula also mentions something that just happened in January 2016, five years after the original adverse incident. This was connected to Eve's ongoing follow-up care since 2011, although Paula says '*.... it's almost like a second complaint...but, again, it's highlighting something within the system.*'

Eve's ear infections are recurring so she goes back to the consultant's clinic in Hospital A about every 6 months. In April 2015, she had an appointment and Paula was to pick her up from school to go to the clinic. But Eve phoned her about an hour beforehand to say she felt really unwell, had a temperature, just didn't feel great...so Paula phoned the ENT clinic, told them this and said that it might be a virus so she'd like to defer the appointment and not bring a virus into the hospital. The receptionist thanked her ('that's great, we'll send out a letter') but no letter arrived.

Paula didn't bother too much at the time '*...because I know there's kind of a long waiting list for it, I didn't really take notice of it...went off on summer holidays...everything was fine...came back in September and Eve was feeling unwell ...ear was beginning to fill with pus....I felt I should have got a letter by then...so I phoned them but they said 'Oh no, you didn't arrive in April and you got a letter in May and you didn't arrive then either, so she's been discharged'...*

*Now I wasn't told.....and as I say, I absolutely phoned and I absolutely did not get a letter...because I take so much care of her...so paranoid about it, you know, we have in play.....a notice board, it goes into the phone...so we don't miss anything important to us...'*

### **Eve classified as a 'DNA', denied access to the clinic that she needed...**

Because they were (wrongly) classified as a 'DNA' [Did Not Attend], the hospital said they would have to go to ENT casualty, which, as Paula says, means '*...you have to go to your GP, the GP sends in a letter then and you wait for the appointment.*' After following the process they got the appointment, but had a very unsatisfactory experience when they arrived.

Paula says '*...this time I am in the process...I am going to complain...composing a letter at the moment... because the way she was treated was appalling.....I mean, the nurse and the doctor....the registrar and the doctor...both said to Eve, not to me....'you didn't arrive for two appointments'....I interjected and told them the reasons...they said 'no, no there was no phone call...because it wasn't written down for them, so there was no phone call and you got a letter'.*

They were given a follow-up appointment for a week later. When they went back, Eve's ear wasn't clear and the antibiotics were finished. The doctor said it would be ok but Paula requested a follow-up appointment at the ENT consultant's clinic because she was afraid it would flare up again.

Because of the mastoidectomy Eve's ear cannot be syringed by the GP, so it was imperative to have access to the hospital....*'I said this to the doctor and nurse but they still refused an appointment'*. She was told *'no you can't have one because you're a DNA'*. Paula tried to argue the point but Eve became very uncomfortable so they *'took it on the chin'* and were told that if anything happens they would have to come back through Casualty again.

In November, Eve told Paula that her ear had actually been weeping the whole time since they had been on the last visit to Casualty... she didn't want to tell Paula because she didn't want to go back due to the treatment she had received. As a result they had to go to their GP, who sent a note to the hospital on December 14. Paula waited until December 18 and then phoned the hospital because she was getting anxious. She was told it would have to be after Christmas, which she accepted because it was the holiday period.

### **....eventually accepted back after a struggle**

When nothing had arrived by January 4, Paula phoned again only to be told *'she's a DNA'* even though this was a Casualty clinic. So Paula phoned every day (4th, 5th, 6th, and 7th). Eventually she was told she could be seen on February 4, but Paula had had enough and wasn't accepting this. After many more phone-calls she eventually did get an appointment for January 15. Ironically, just as they were going out the door that morning the postman came...there was a letter to say Eve was accepted back into the consultant's clinic. This meant, as Paula says, *'...we do now have a follow-up and we're back in the loop. [But] I don't think we should have had what we had to go through in order to get back in'*. By the time Eve went to the appointment on January 15, Paula says *'...she'd had this massive infection which had probably been going on since September and was allowed to build up simply because these people decided....and, you know, even if they were right, and we didn't arrive, she should have been judged on her health, not on how good she was on attending appointments, you know...'*

Coincidentally, Paula says that *'...within the same hospital, about a week ago I had a sinus problem so I had microsurgery....I didn't get a letter telling me I was having the surgery but I got a phone-call from a nurse who just takes pre-op notes...and that's how I found out...so there is something within their mailing system, to me, that's wrong...'*

*...so, as a result of the previous experience at the hospital.... I am going to follow through...not in an angry manner because it's not about being angry, it's about educating them..."...there is something here...can you do something about it?".....I will complain.... even though we're back in the loop and everything is ok for us...because I don't want to just say "ok, that's the end of it", and walk away....I want to complain and I want to say "but you know, we're all human...I know that there's problems...none of the people are bad people...but there's something in that system that isn't working..."*

## Lessons that could be learned

Paula feels that the healthcare system could learn a number of things from the incident. She says it isn't just about complaining '*...in a way it's educating...you know 'there's a problem here...potentially this is what you could do, or you're the experts and know better than I what can be done....'*'

### **Education for medical students**

She thinks that one valuable approach would be to present their story to medical students. '*Originally... when I joined Patients for Patient Safety...my first thing, to me, was I'd love it to be presented to medical students, you know, and tell them 'there can be huge ramifications of you having an off day, this is a huge responsibility for you and one that needs to be taken very seriously'....I'm sure that there are probably people that constantly go to the emergency dept. when they don't need to, I'm sure there are...but I still think, sorry but that's your job...and, yes you're human and of course you're not going to feel the same....but this was only her second trip...I mean, you have a child, you know, you can't have an off day...you need to be focused, you need to listen...*

*... if there's just a tiny little seed set in medical students' minds...that would say, you know, I really do need to listen, I really need to listen and not jump ahead of things, and decide ahead of time, I need to listen...because the difference between the two registrars we saw....the one in Hospital B called me aside and said straight out, you know, 'kids don't come up with that kind of stuff' and he was able to see it, but the other guy just said 'she's looking for attention'...so, they were poles apart in the way they viewed the same child within three days of each other, you know....people may have problems outside of work, family problems, and they're going into work with that....but you need to listen, you need to look at the bigger picture...and not presume...'*

### **Responsibilities of other staff (and other healthcare services involved)**

But she also feels that there are other aspects warranting attention...'*you know, there's more to it than that...the nurse involved, although very well intentioned, her actions were wrong... Even though she was very nice, I still think she was unprofessional, saying "ah do it for me..." '...She was a lovely person, but to me she was accepting that "I'll get around him now, butter him up..." and you'd wonder does she always do that...so people who are behaving badly are being cajoled rather than being told he must, its your job.'*

*'...I wonder as well should there be a role there for her as a 'whistleblower', to say to the consultant or to a supervisor or someone appropriate...'well, I had to cajole this doctor into seeing patients today and its not right"....It would be interesting for me to know...are nurses allowed to come out and say these things, you know...are they allowed to say or do they just have to accept it?'*

Paula also talks about responsibilities across all of the institutions involved '*...when we ended up in the second hospital [Hospital B], flags should have been raised, little warning flags 'why, what happened, what was the follow-up here, why did she go to this hospital?...'and I should have been asked why did we go there and it should have been investigated in some way...how they would do that I don't know, but a lot of it is just common sense, you know, that you should ask questions....but I think, because of litigation they are afraid to bring something up to a patient ...I wasn't saying anything because I didn't want to make enemies...so everybody was backing away from it, you know...so the communication...but I understand that people are just so worried about litigation that it becomes the first thing for the health service in their mind.'*



### **Receptionist and appointments services are central, and need to be improved**

There are also lessons to be taken from the failures of the administrative and mailing systems that recently affected both Eve and Paula. Apart from causing significant inconvenience and stress, these can often impact on important elements of continuity of care. Paula is not sure whether being 'discharged' as a 'DNA' (Did Not Attend) is purely an administrative decision or what level of clinical involvement there is, if any. This is something she would like to find out more about - in Eve's case it seemed the discharge was not on medical grounds but due to 'DNA'. Paula has also heard of a 7-year-old patient being declared a 'DNA' in similar circumstances and having to go through the same rigmarole. There is a need to review and correct a system that automatically discharges a patient from a consultant's clinic because of being classified, rightly or wrongly, as a 'DNA'.

Paula feels that it would also be useful for the hospital to make phone-calls to patients who are due to come in two days time, to check they are coming. This could free-up appointment times that people are not arriving for, and make sure they are not discharging someone who may have got a letter 12 months ago and has mislaid it or forgotten the appointment date.

### **People should speak up, report adverse incidents**

Paula thinks that people should speak up more and report adverse incidents, and feels she should have done more in this regard herself.....*'I didn't, I should have....we did say at the time that when its over I'll complain...but it took so much out of us...for the full month I stayed with her...whether it was sleeping on mattress on the floor or on a chair or whatever, all my energy went into her...'*

*I know that it was only a few days between the incident with the registrar and when she was diagnosed....but it was complete negligence and it should never have happened...and if I could just use that story to say to some med student or doctor, you know, whatever, that you can't afford to have an off day....I can have an off-day in my work because I won't affect somebody's health...but you cannot afford to have an off-day...when you get in there you have to switch it on, no matter what your mood is, you know....I would like if the story was used for that...when I hear about other incidents in the news...I wonder has this guy...are we just one small link in the chain or was it just one bad day and that was it, he never made a mistake again?...*

*...and I know Eve would absolutely like there to be follow-up...she has always said I should have, should have said it...she resented this guy so much...but she's also very interested ...much stronger feelings than me about it, I'd say she has put more thought into it...., said it again this morning...'we don't know did he go on to do more damage'...and by us keeping quiet, did we kind of help him...in the same way that I'm, I suppose, suggesting that the nurse kind of enabled him, did we (my husband and I) do the same thing because we said, right, he's not dealing with her anymore, he's someone else's problem...let him go up the country...did we enable someone potentially to do harm?'*

### **Every hospital should have a Patient Liaison Officer**

Paula thinks that having a Patient Liaison Officer is terrific '*... every hospital should have one... if you have a problem she tries her best, instantly if possible, she tries her best to do it within 3 days....she will tell you when, she'll give you a timeframe and follow it up....I think its fantastic that the HSE and the hospital (Hospital B] have used this...its one position that would be just fantastic if it was rolled out...'*

### ***"It would be great if something good can come out of it..."***

As a final remark, Paula says, '*...it would be great if something good can come out of it [their story]....to change the mindset of even one person... then you are changing [the experience] of all the patients that they come into contact with afterwards.'*