



2018

Incident Management Framework – Patient and Staff Stories

Care | Compassion | Trust | Learning



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Patient Stories – “The First Victim”

Patients for Patient Safety is a World Health Organisation initiative inaugurated in 2004 which acknowledged patients and families as an untapped resource and also recognised the patient’s experience of their care as a learning tool. In the intervening years PFPS networks have been formed around the world, including Ireland.

Patients for Patient Safety Ireland (PFPSI) is a group of 16 volunteers whose aim is to promote patient safety in our health care system. They are a collaboration of patients and family members who have experienced preventable harm in our health care system, as well as patient advocates, policy makers and health care workers who are committed to improving patient safety. Each of the group’s members has a story to tell. Some have witnessed preventable harm occur to their loved ones, including death, in our hospitals. Others are dealing each day with the challenge of managing life-threatening and taxing illnesses caused by unsafe practice.

They are committed to using their unique experiences to inform healthcare improvement and the prevention of adverse events. They do this in a collaborative and partnership engagement with healthcare at all levels – education, research, regulation, policy making and especially through presentations at conferences, workshops and in-service days.

The following stories, written from the perspective of members of Patients for Patient Safety Ireland in their words, have been kindly shared to support staff in the application of the principles outlined in the HSE’s Incident Management Framework.

Eve’s Story

During 2010, twelve-year-old Eve had recurring ear infections. A few days before Christmas that year, her mother, Paula, brought her to A&E at the local hospital. The doctor she saw diagnosed an ear infection and prescribed antibiotics. Over Christmas, Eve was very nauseous and experienced 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.

They arrived mid-morning, when A&E had only 4-5 patients, but had a very unsatisfactory and distressing experience with the registrar. Initially he 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, saying aloud, and in front of everyone, *‘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 it seemed 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 very ill as she had to help her from the chair to the bed. The doctor dismissed this, saying, *‘I think a little bit too much television, looking at her phone, and getting a lot of attention from her mum.’*

Although Paula believed that the doctor was negligent in his manner and diagnosis, she didn’t say anything at the time. This was 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.’*

As it was New Year’s, Paula then had to wait until January 2 to get an appointment for Eve with her GP. *‘I was 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.’*

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

Eve's Story (continued)

Luckily, they did. The young registrar 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 next 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. Eve was very ill...a 12 year-old at risk of a stroke that could do damage to the brain. She was transferred back to the first hospital (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 the second hospital where she remained for a month. She also was seeing an ophthalmologist from a third hospital (a university hospital).

Overall, with the exception of the registrar who wouldn't listen, Paula and Eve feel they experienced excellent care and dealings with healthcare personnel. Paula remembers one day during Eve's stay at the first hospital, when she had been particularly upset and crying. A doctor who had been on the rounds earlier that day came back to the ward when he was finished duty. He had taken off his scrubs to go home, but came back 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!

Eve eventually recovered well. She says 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 Year's Eve, us not being able to get a doctor until Jan 2. During that time, she could have had a stroke. When she got admitted to 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.'*

Paula didn't raise the incident at the time – she was only concerned for Eve's wellbeing and didn't 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.

The first hospital (the one that they had been sent away from by the registrar) never mentioned or acknowledged the incident either, despite the fact that the second hospital had to call over their ENT team to help treat Eve. The doctors at the second hospital did indicate that they thought Eve was inappropriately sent home by the registrar in the first hospital, without proper examination. Paula says, *'they were very careful, as of course they would have to be.'*

At the time, Paula did wonder about not being asked by the first hospital why they had ended up in the second hospital. *'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?''*

While they were in the second hospital, a Patient Liaison Officer asked about their experience in that hospital. They told her it was fantastic, but also explained their initial problems in the first hospital. Although not able to officially comment on this, the Liaison Officer said that they were certainly going to learn from it.

And Paula says that's all she wants, that lessons are learned from their awful experience. *'It would be great if something good can come out of it. To change the mind-set of even one person, then you are changing the experience of all the patients that they come into contact with afterwards.'*

For the past five years Eve has had recurring ear infections, and she attends the ENT consultant's clinic at the first hospital about every 6 months for this. Recently, an administration system mix-up led to Eve being inappropriately discharged from the clinic and a difficult battle to get re-instated...but that's another story...

Mark's Story

About fifteen years ago, 15-year-old Mark was brought to an A&E department with a range of psychological symptoms. After some time he was diagnosed as having schizophrenia, and that this was brought on by drug abuse. For his mother, communications were very traumatic. She was told that *'he had paranoid schizophrenia'*, there was a *'75% chance of him committing suicide'* and there was *'nothing that she could do for me'*. Medication was also problematic: *'the first time I brought him out he was so doped up that he was drooling and he couldn't speak. ... I thought that if this was the quality of life he was going to have for the rest of his life, he would be better off dead'*.

Mark sometimes needed A&E services in the last 15 years. Problems occurred: *'Attitudes from some registrars are poor in relation to getting a separate room away from the main area to help in maintaining the dignity of the patient. They could cause disruption while waiting as they are very unwell'*. The *'refusal to admit patients leaves the responsibility for coping with patients behaviour with the carer, often when they have little or no knowledge of medications, for example. This is a danger to all'*.

GP services were also problematic: *'the GP did not know enough about mental health as he said he only had 6 weeks training in psychiatry'*. When she rang the hospital to get him assessed for the first time she was told that *'she was an over-reacting mother'* over the phone. Eventually she got an appointment which ended up as an involuntary admission and Mark was subsequently hospitalised as an in-patient for 6 months.

Psychiatric services provided further difficulties. One issue was the inconsistency between psychiatrists in terms of emphasis on medication. When Mark decided to change his psychiatrist, there were different approaches to him. Every time he became in-compliant it was known as a *'blip'* and no emphasis on finding out the cause of why he was not taking his medication. Psychiatrists *'were more concerned about drug levels than psychiatric symptoms or behaviour'*. On three occasions, Mark went missing from a semi-secure unit. Once he turned up again only through his own initiative. He was not missed by staff for 5 hours, even though he could be a suicide risk.

Gaining access to services during relapses was often a challenge, sometimes needing dramatic measures. Once, Mark had to be made homeless before he could receive appropriate treatment – *'I had to put him into a homeless shelter to get service ... They gave him many life skills – they were the life saver'*.

Care plans were also an issue. *'Families should be present with the patients consent, but this was not always the case'*. Care plans were often deficient. Continuity of care was also a problem. *'A lot of team doctors do not read up on notes prior to interviewing the patient. Discontinuous treatment, poor handover between doctors (registrars)'*.

There is a lack of involvement of the family or the carer in the care plans: *'If the person is living within the family, they should be involved in the care plan. If they are living independently, that is a different care plan altogether'*. However, *'If the person refuses to let the family into the care plan while living with the family, now you have a huge problem, and how to get over this is another problem'*.

The carer can have a key role in supporting people, but often they have no formal role: *'Patients should be made aware that they can have a carer with them in the early stages as this would facilitate communication and treatment. We live with this all of the time and we are not educated in how to recognise problems and how to deal with them'*.

Families and carers should be involved in care plans and treatment from the beginning of treatment... *'Education, support and knowledge of how to cope with a crisis – this should be part of a care plan, even where the patient has reached the age of 18...'* *'The patient is the primary service user, but the family unit is the 'secondary service user'*.

Families need to be assessed following the diagnosis of mental illness. They have both needs and potential resources to bring to bear: *'the family could have been assessed, what are their needs and resources in the context of the diagnosis?' ... 'If every carer who has a person with a mental health problem refused to take them back into their house, what would the HSE do?'*

Much of the treatment that Mark has received has been medication oriented. There is a reluctance to reduce medication to a minimum, especially where there is perceived stability in the patient's condition: *'at one stage he was on 7 drugs. Eventually he was being kicked out of the housing services he was receiving until his medication was changed. This took extraordinary efforts'*.

Mark's Story (continued)

Mark has wanted to reduce the drug dosage, but there can be little support for this from psychiatric services: *"your levels are great, and you are doing well so you are better off staying with this dosage, why rock the boat"*. *'Mark wants to get down to the least amount of drugs possible. He knew he was prepared for it ... but dosages have to be discussed first with the team and then they decide to reduce the dosage or not. This should be Mark's choice as who else knows his body better than him – he should be encouraged to do so at safe levels'...* *'Reductions are possible... although complete reduction of drugs in some cases is not an option, a review system on the diagnosis should be put in place every few years'*.

Caroline's Story

In 2005, Caroline (a 39 year-old-nurse) was diagnosed with an 8cm ovarian cyst and scheduled for admission to hospital for routine surgery to have it removed. She is married with one daughter who was aged 5 years at the time. Caroline and her husband were both working full time then. Her daughter was in her first year of national school. Everything seemed to be going well for Caroline and her family – life was good with no major worries or concerns.

In March that year, she went into hospital for the surgery. This was expected to be conducted laparoscopically, with a view to open surgery if any complications arose. It is usually a fairly routine procedure and it was expected that Caroline's hospital stay would be no longer than 5 or 6 days at the most. However, after the surgery on Friday morning she experienced severe pain when she awoke in the recovery room. After review by the consultant and anaesthetist, more analgesia and sedation were administered and Caroline was transferred back to the ward. It wasn't until late afternoon on Monday that the cause was diagnosed – a life-threatening perforation of the bowel.

Over the weekend Caroline's condition deteriorated – she continued to have severe pain as well as difficulty passing urine, difficulty eating and drinking, and felt she could not have a bowel movement. She had spiking temperature and a rapid pulse rate. A doctor who reviewed her thought she might have a urinary tract infection. Nothing abnormal was detected when a urine specimen was tested, but the doctor anyway started her on oral antibiotics for a urinary tract infection.

She felt herself that there was something seriously wrong, but the nursing staff thought she was just anxious. When the doctor came to see her again on Sunday morning Caroline says '*...[he] wrote on the chart "feeling better"(god!), but I wasn't feeling better...*' Her mother and other visitors that afternoon could see how unwell she was '*...but still the staff seemed to think there was not anything wrong with me...it was like nobody listened, no matter what...*' Sunday evening and night Caroline continued to get worse. She was seen by the Registrar, who suspected it could be a pulmonary embolism, and a portable x-ray was taken during the night.

On Monday morning Caroline had a very upsetting experience while her husband was visiting. She recalls '*...one of the nurses came into the room and clapped her hands and said "out of bed, up out of bed" and persisted with this even when Caroline refused because of the pain '...She went out, came back in with a colleague, and they proceeded to drag me out of the bed, to sit me in the chair...to make the bed...when the bed was made, she told me I could get back into it...!*'

The consultant who had conducted the surgery came to see her that morning and said an ultrasound needed to be done to see what was going on, but it was 3.30 that afternoon before Caroline was brought down for the scan. After about 2 hours she was brought back to the ward where, as she says, '*...there seemed to be doctors coming out of the woodwork, I was surrounded – at last they were noticing...trying to find veins in my arms, putting cannulae in, intravenous fluids, pain relief, various doses of IV antibiotics...told me then that I had a perforated bowel and needed to go for surgery...*'

An emergency operation found a perforation of the sigmoid colon with associated peritonitis. She developed septicemia and from theatre went straight to intensive care, where she remained on life support. Her husband was told she had a 50:50 chance of survival, if she made it through the first night, but she was getting progressively worse and her chances went down to 30:70 at one stage. Thankfully Caroline survived and came off the ventilator after about 10 days. But she remained seriously ill '*...developed everything you could possibly...multi-organ failure, acute respiratory distress syndrome...had to have a colostomy...had problems with my blood clotting mechanism, required several blood transfusions...sinus tachycardia...absolutely everything you could possibly think of...*' She also needed a lot of intravenous anti-fungal treatment and developed a deep rooted wound infection, which was compounded by an MRSA infection. '*...had that everywhere as well...*'

Eventually she was moved from ICU to the ward and was in hospital for a number of weeks. Around the end of April Caroline went home in a wheelchair, with a vac therapy unit for the wound. She needed a lot of care at home and was very weak, requiring a daily nurse visit for getting the dressings done, colostomy bags sorted out, and so on. Over time, Caroline was gradually getting better in some ways, but she then developed a large incisional hernia, and the colostomy was still there and giving a lot of problems. Around October she went back to hospital for colostomy reversal surgery and repair of the incisional hernia.

Caroline's Story (continued)

Because of Caroline's medical problems her husband had to take time out of work to look after their daughter, and ended up working part-time. Caroline herself tried to go back to work, but even part-time she wasn't really able for this and was then off sick for the best part of four years. This had a major impact on the household income. She was in and out of hospital regularly (and still is) – had a lot of sub-acute small bowel obstructions and then had to have her gall bladder removed.

When she was recovering Caroline started to wonder how something could go so awfully wrong, when she went in for a relatively simple procedure. She had received no explanation or apology for what had happened, so she lodged an official complaint to the HSE. HSE conducted a full root cause analysis by their Risk Management team and a final report was issued in April 2008. The report acknowledged that there was a care management issue in the delay in the diagnosis of Caroline's presenting clinical condition, and recommended a care management review of how this would be preventable in future.

One element of Caroline's complaint was that, when she got a copy of her records from the hospital, she found information about her emergency surgery that had not been given to her before. During the emergency surgery for the perforated bowel it was discovered that she had another cyst (on the same ovary), but nobody had ever mentioned this to her before. The surgical team had not been aware of this and it was inadvertently perforated during the surgery. The HSE review report recommended that full disclosure and explanation of events (including unplanned events) should be part of the post operative consultation with the patient.

But there was no admission of error in the report and Caroline was left without answers. She says there '*... was never going to be an admission of any error on his [the consultant's] behalf...they said that I had a weak bowel – but I had never had a problem with my bowel prior to that... I was left with a lot of questions, like, do I have an underlying bowel condition or not? I needed to know!*' So Caroline had to resort to litigation in order to try to get to the truth. This was a long, expensive and stressful process. Caroline's case was lodged with the court system in March 2007 and was eventually set to go to trial in January 2013. But it was settled at the last minute at a meeting in December 2012, with an admission of liability by the HSE. And Caroline says '*...that's all I ever wanted...for somebody to say, we did wrong here, we caused you harm.*' Even without ever going to court, there were 200,000 euro legal costs just from Caroline's side. She says '*...this is money that could be much better spent on improving patient care...there's got to be an easier way for people to get the truth...not to be putting up a full defense for something that's really indefensible...*'

The recommendations in the HSE's risk management review report on her case address some aspects of care, but Caroline feels there is need for mechanisms to ensure fuller learning from adverse incidents such as hers. Doctors and nurses should listen more to the patient and observe, not rely only on machines. More attention should be given to patient consent (highlighted by the episode where a nurse forced her to get out of bed). It would be good to capture both sides of the story (ideally for herself and the consultant to work together on the story) and the lessons that can be taken from it. Patients should be supported during the review process after an incident (e.g. by Patient Liaison Officer).

Kevin's Story

Kevin's mum, Margaret, recounts the beginnings of the tragedy in 1997, a year and ten months before Kevin died. During that year, 19-year-old Kevin presented on a number of occasions with persistent back pain. Without any improvement, he was referred to an orthopaedic consultant in the autumn. Blood tests revealed high levels of calcium (3.51m.mol/l). This level of calcium causes serious damage to health and is most commonly an indication of primary hyperparathyroidism or a malignancy. Other parameters were also raised. All of these abnormal results were underlined in the laboratory report. When the consultant wrote to Kevin's GP he noted his intention to see him again early in the New Year, but underplayed the high calcium levels and ignored a plasma creatinine level indicative of more than 50% loss of overall renal function. That letter is not on the GP's file and the consultant's intention to see him again was never conveyed to Kevin.

Kevin's file contains a notation by the Consultant's secretary following subsequent contact by Kevin's Mum. *"Telephone call from patient's mother. She is extremely worried about her son. She wishes you to know that she thinks he may be depressed also. Failed his first year exams, repeating and not doing well either, finding it hard to study. He is now remaining in bed a lot. She has arranged an appointment with Dr X (a psychiatrist) tomorrow and would like to have results of bloods, bone scan, etc for the consultation. She wonders if he really has a back problem. What can I tell the mother? She wished to speak to you. Results in file".* The doctor's response was "fax results to Dr. X" ...and there was no direct contact with the mother or the patient.

After this, Kevin had repeated consultations with his GP, physiotherapist and other services, but nobody diagnosed his condition. He spent the summer of 1999 in the US, and on his return attended his GP complaining of lethargy, occasional vomiting and continuing bone pain. Blood and urine samples were taken, with test results being telephoned to the surgery the next day and written on a Post-It note by the practice nurse, who drew attention to the high calcium level (now at 5.73m.mol/l). However, the GP did not mention this in his letter of referral to the hospital, focusing only on those elements of the blood test results which supported his own diagnosis of Leptospirosis, but he did send the Post-It with the letter.

When compiling the file in the hospital, the Post-It note containing those vital calcium results was stuck to the back of the letter and was not seen until six weeks after Kevin's death. The standard blood test in that particular hospital did not include testing for calcium levels. So, throughout his time there they remained unaware of Kevin's dangerously high calcium levels, and a diagnosis of nephritis was made.

At this time, even as his condition deteriorated rapidly, no medical personnel seemed to appreciate how ill Kevin was. He became dehydrated and described muscle pain and neurological problems – his medical notes quote him as saying *"I have crazy thoughts coming into my head"*. These notes also show advancing renal failure. Margaret says *'...Two crucial days were lost during his stay in that hospital – further missed opportunities as yet another point of contact failed Kevin...'*

Finally, Kevin was transferred to a tertiary hospital and it was there that the family first heard concern over calcium levels of 6.1m.mol/l. Kevin's care was left to be managed at Registrar level – senior personnel were not alerted and more aggressive treatments were not available at the weekend. Margaret cannot say if that would have resulted in a better outcome... *'but it would be nice for me, his mother, to know that he was given every chance'*.

Margaret tells how Kevin tragically passed away at the hospital *'...during Sunday, Kevin was lucid but very sleepy, giving a thumbs-up to his father before he left his bedside. At 3.30 p.m, just as the young SHO came to check on him, Kevin suffered a heart attack as his sister and I sat at the bedside. Sadly, attempts at resuscitation failed... Kevin had died right before my eyes.'*

Margaret says *'...Kevin's death certificate lists multi-organ failure, hypercalcaemia, parathyroid tumour... but adverse events happen to real people. Kevin was more than a statistic, he was more than a medical condition. He was a real person, a young man, full of life. But above all, he was my beautiful boy – handsome, strong and carefree...'* And that was the end of Kevin's patient journey, a journey which could and should have been much less prolonged, and with a happy ending...if only the obvious had been properly flagged and appropriate interventions made during his various contacts with GPs and Consultants over the two years before he ended up in hospital.

Kevin's Story (continued)

Even worse was the apparent lack of learning from the tragic events. Margaret recalls a chance meeting with the SHO, six weeks after Kevin's death. *'He said "Kevin was very unlucky" – that was all he brought away from the tragedy. What a waste of an opportunity for learning and self-growth for that young man. The organisation took the easy way out and left him with a superficial perception of what had happened.'*

This is despite the fact that the family have a special memory of that young SHO on the afternoon of Kevin's death. As Margaret recounts *'...Kevin's friends started to arrive at the hospital – they were confused, bewildered and in a state of shock, many of them sitting on the hospital corridor floor with their backs to the wall, heads in hands. That SHO passed by, stopped, took off his white coat (the barrier), rolled it up, placed it on the ground and, saying nothing, he just sat with them – a most wonderful spontaneous demonstration of solidarity. He showed himself to be a decent, empathic and insightful young man. He deserved better than a superficial explanation.'*

Margaret and her family were in shock and left with so many unanswered questions. *'Nothing or no one had prepared us for this – we had no warning, we never considered his life to be in danger and no one had intimated that this was the case. We had questions and we needed answers. How can a twenty-one year old young man be admitted to hospital on Thursday and die on Sunday? What went wrong? What we encountered was closing ranks, lame excuses, muddying the waters and protestations of loyalty to colleagues.'* In the immediate aftermath of Kevin's death Margaret says *'...there were initial honest and humane reactions from individuals, especially the nurse, for which I will always be grateful.'* But this was soon replaced by a process of damage limitation. One doctor described his dilemma as an issue of *"loyalty to colleagues"*.

Because their confidence in being able to find the truth through honest dialogue was shattered, Margaret and her husband were forced to go the litigation route. *'For ordinary people, like ourselves, it is a David and Goliath experience. Until the 11th hour every effort was made by the defendants to settle without admission of liability – a wearing-down strategy that lacks compassion and consideration for heart-broken people.'* Still, Margaret and her family stuck with it. Almost five years later, they were vindicated in the High Court where medical experts stated (and the judge agreed) that Kevin's condition should have been clearly evident and, properly treated, *'...Kevin would have had surgery to remove the over-active parathyroid gland. He would have been cured and would still have been alive today.'*

There was a financial provision, but Margaret says *'...monetary compensation was never an issue for us as a family... we donated the settlement figure to two charities.'* Two GPs, a private consultant, a hospital consultant and a hospital all admitted liability. They expressed their regret at Kevin's death and sympathised with the family. Sadly, this was done through legal representatives and not in person, something that would have provided credibility and acceptance of individual and corporate responsibility for the tragic outcome.

Margaret's call for open disclosure, her call for reporting and learning are all grounded in the fact that: *'I was present at Kevin's birth. I know every detail of that birth. I was also present when he died. As his mother, I needed and deserved to know everything relating to how that came about. Over and above that, it is essential that I be assured that lessons will be learned, that those lessons will be disseminated – all in the hope of preventing recurrence.'*

Melissa's Story

In 2009, Melissa was five or six weeks pregnant. She had a history of early miscarriages and was worried about this latest pregnancy. *'I went to the doctor even though I was showing no signs of miscarrying and she said to go to the early pregnancy unit at the hospital. I had a scan the following day where they said that they couldn't see anything but they asked me to come in again in 2 weeks' time.'*

In the intervening time Melissa had been on holiday in the West of Ireland and had felt many of the signs of early pregnancy, including sickness. She didn't have that feeling on the 4 pregnancies that she had lost, but she did on the pregnancies of her 2 children, so she thought this was going to be OK. When she returned from holiday, Melissa attended the early pregnancy clinic at the hospital for the scheduled follow-up scan.

She could see on the scan that the foetal sac had gotten bigger, but the doctor looked at the midwife and just shook her head. The doctor said: *'Sorry, but this pregnancy is not going to progress'*. Because she was still only 8 weeks pregnant and had not displayed any of the signs of a miscarriage, Melissa asked again were they sure. But they said that there was no heartbeat there, and that they needed to discuss the options. *'It was pretty devastating. Our options were that we could let nature take its course, they could give me tablets, or I could have a D&C... we said that we would go for the D&C, because it was quick and it was clean and I had had it before.* There wasn't a slot available until 2 days later and Melissa says *'...they told me to go home and gave me a drug...to be taken on the morning of the D&C, to open the neck of my womb and help it contract.'*

The following day Melissa still felt pregnant. On a friend's advice, she went to a local GP for a second scan, and what a surprise when she got this scan! *'She [the GP] put the probe on my stomach and I could see a heartbeat, I could see it. My initial reaction was pure joy. And I said to her 'is that my baby's heartbeat?'* The GP wanted to check with another doctor *'... He came in and flipped a switch on the machine, and all you could hear was 'bump, bump, bump', of my baby's heartbeat, and he said 'I'm afraid the hospital are very wrong'*. They were so fortunate to have got the second opinion when they did. *'Luckily they [the hospital] didn't have a slot on the Wednesday or Thursday or I would have had the D&C and I would never have known.'*

Melissa's husband rang the hospital to tell them that she would not be coming in for a D&C. *'They wanted to see me again so that they could clarify what had happened, and it was at that point then that I began to feel very nervous.'* Melissa and her husband went to the hospital and she was seen by the doctor in charge of at-risk pregnancies. It did take her a while, but eventually she said that she had found a good strong heartbeat. Melissa was given medication to help the pregnancy along and she was told to book herself in for her next appointment.

But Melissa wasn't really satisfied. *'I said 'is that it? I need to know what happened and why this happened.'* The doctor asked would Melissa like to speak to the Head of the Department, which she agreed to do. *'They brought us into someone else's office and apologised for what happened, and said that this had happened once before. I said that, given that I had a history of miscarrying, should they not have given me another scan the following week instead of writing the baby off? They didn't listen to me.'* Melissa also asked who would be looking after her for the remainder of her pregnancy and they asked a senior consultant to take over her care. *'I was assured that the original doctor would not be any part of my care'*.

Melissa continued the pregnancy and was hospitalised twice before giving birth. But there was no further mention of the incident by the hospital; its seriousness seemed not to have registered with the system. *'Nobody else spoke to me about what had happened. Nobody else came near me. At one point during the pregnancy the doctor who had done the initial scan came along to do another scan! I didn't believe that they would let her near me...we had to tell the senior staff what had happened and what we had been assured of. They had no knowledge of the incident and, incredibly, had to read through my notes!'*

Melissa's Story (continued)

During that period, Melissa's husband had been in touch with their solicitor and had informed him of the situation. In October 2009, they found out from the solicitor that the hospital were conducting an internal investigation. But they had never discussed the case with Melissa. *'All throughout my pregnancy and my three hospital stays, not one member of management or staff spoke to me about my experience, which I found upsetting. I felt that if I hadn't gone to my solicitor I would never know why I was misdiagnosed and what the hospital planned to do about it'. In January 2010 the hospital reported on my case.* The hospital had found that the heart rate monitor was old and subjected to a heavy workload and that this had been known before Melissa's misdiagnosis. In addition, the couch that was used in the examination was the wrong kind of couch, and the person who did the scan wasn't qualified to do so. Despite these findings, nothing had been done as a result of the investigation. *'They were still using that scanning machine 6 months after my case.'*

Melissa was left feeling very unhappy and unsatisfied. *'When I found out all of this, I just felt that it was my duty to go public with it. I needed to go public with it and to let women know to trust their instincts in these matters. I didn't believe that I was the only one that this had happened to. I needed changes put in place to prevent it happening again.'*

The story was covered in the press and on TV, and the publicity eventually led to the establishment of an independent enquiry covering all HSE maternity hospitals. This found 24 similar cases in the previous 5 years, with similar problems of faulty and outdated equipment, lack of training, lack of appropriate couches and a lack of appropriate services. The National Miscarriage Misdiagnosis Review was published and the HSE has been implementing its recommendations since through the Clinical Care Programme in Obstetrics and Gynaecology.

Publicising her story has helped to reduce the likelihood of similar incidents occurring again. Melissa also emphasises that it would have been both more proper and more effective for the hospital to have involved Melissa in its investigation in the first place, and to have communicated its results to her. She also feels that one of the root causes of the problems she encountered was that she wasn't listened to during the initial scan. She feels that if she had been listened to, none of the subsequent problems would have occurred, and that women need to be enabled to trust their own feelings in situations like the one she encountered.

Sinead's Story

Anna tells the story of her sister Sinead who developed kidney problems which needed dialysis for all of her life. Anna became Sinead's primary carer. Eventually, Sinead's health had deteriorated to the extent that she was reaching the end of her life. But some problems with occurred – *'One day she did a dialysis exchange after which she got MRSA – she was in hospital for nearly 5 months'*. After this, Anna feels that some of the health care team could not face up to the issues. *'Sinead died steadily between 2003 and 2008. And she died hard. By 2007 I could see she was failing. They could not talk to us about end of life. I think that they just did not want to lose her because some of the team had worked with her since she was a child'*. This failure continued – Sinead moved to a high dependency unit in 2008 where Anna had a confrontation with a consultant *'I said to the consultant she's dying... The consultant asked "Well you tell me what she is dying of [because it didn't show up on the tests]". But I said "I'm her sister not a doctor. You tell me what she is dying of..."'*

Anna says there were other distressing incidents *'for instance one night a confused old man climbed into her bed – she was terrified because she couldn't move physically... we refused to leave her alone in the hospital then, and I think that maybe we were regarded as being the 'bad (awkward) family.'*

The attitude of some staff left a lot to be desired. Once, Anna was publicly criticised for gaining entrance to the ITU – *'When I went in, the nurse saw me and came across the ward...and she raised her voice to me and was quite aggressive about coming in without permission, [even though a doctor had invited her in].'* There were other examples. *'One evening Sinead was actually bending over in pain. The nurse was trying to support her to cope with another half hour of dialysis.'* Sinead said to Anna *'I can't do this anymore'*. Anna said *'It was too late – we were saying she can't take it – we are saying no – what part of no don't you get?'* Anna was very concerned at this lack of listening and the failure to recognise the gravity of her condition – *'I was looking at a potential suicide. Sinead did not want to end her days hooked up to machines, but this is what happened. Nobody could talk to me about palliative care. She is facing end of life and no one is talking to her (or me) about it.'*

The end was coming close – *'She was getting sicker and sicker and then she plateaued for a while. I had to go to abroad but then I was told to get home fast. She had slipped onto a coma by the time I arrived, and we never saw her again. I then had to make the decision about withdrawing treatment and this happened without her own consultant being there. He would not talk about Sinead dying.'*

Anna felt that interaction with her at the very end was insensitive. *'When they were turning down the noradrenalin the nurse who was doing it was chewing gum as she spoke across Sinead... then they asked me to step outside to discuss a post-mortem while she was still alive. When I was outside with the consultant, one nurse was discussing what she was doing that night. Also while my sister was still alive they were talking about a post-mortem in the middle of this busy ward. The discussion about a post-mortem should have been done after her death and not in an open hospital ward.'*

When Sinead eventually died, there was little sensitivity around family needs. *'It was very, very hard. Lucky it was a Saturday, because there was a 2 day delay in doing the post-mortem and that was the only time we had to come to terms with what happened. Sinead was at the heart of the family and, quite apart from direct family, we had a load of foster kids who had seen Sinead as a key part of their lives. They didn't get to say goodbye.'*

Anna feels that end of life treatment was not handled professionally. *'This is their bread and butter every day, but to us it is one of the most traumatic experiences of our lives. I had to pick up the pieces for my family afterwards and no one ever came to ask us how we were.'*

Sinead's Story (continued)

Lessons to be learned ...

- Some parts of the system and some people were very helpful – *'Not all of it was awful. For example, the dialysis nurses that came down to our home for the funeral were wonderful. Anna also feels that MRSA is a complex issue and she doesn't harbour blame for it. 'The MRSA that Sinead got, I'd say that it was waiting to happen and that it is a global issue. The MRSA just finished her off.'*
- End of life care was slow to happen and was handled badly. *'When she died there were brochures for ocean cruises with dialysis services! She was a ... woman who loved life and it seems that, no one actually thought that she might die. What did they think, that someone with an illness like Sinead's was going to live forever? There is a failure to deal with issues relating to dying. 'There needs to be a more open attitude about terminally ill patients ..., and not have a fear of failure, or whatever it was.'*
- Anna feels strongly that palliative care should have been made available. She says *'First of all it should have been in a palliative care setting. The difficult conversation had to be had and no one recognised it except me that she was dying. We missed the last few weeks of her life as a result.'*
- For Anna, insensitivity was at the heart of the negative experiences that she had. *'They need to have awareness all the time of the patient and family. And death has to be handled more sensitively. After Sinead died I got her stuff back in a yellow bag. I know that this has changed since then.'*
- Anna also notes the failure of services to listen to her about the severity and nature of Sinead's illness. *'I wasn't listened to, I think because they are so busy. I don't think they are unkind people, I think they would have sat down if they had the time to do it. But if you have 10 people doing 20 people's work this is what you are going to get.'*
- Another point Anna raises is that many clinicians do not face up to the issues of death and dying. *'The consultant did not want to see that she was dying. He thought that he should do everything to keep her alive, that this was his role, but now it was time to let go.'* More generally, Anna thinks that *'every hospital should have a hospice ward for a start. Politeness and courtesy are not an add-on. It is a part of the culture that we are supposed to care.'*
- Structural problems need to be addressed. *'In ICU, we have to be very careful of burnout. We have high octane situations with high octane workers. I see this with some of my own students. Some of them have to be in on the drama. We do need people like that, dynamic people who will not collapse under the pressure and we need those workers.'*
- There is a need to have a pastoral role and perspective in the care team: *'We need to have someone else on the team, but someone who is involved all of the time who can stand back and soften the situation. We need someone to oversee the pastoral care.'* She goes on *'There is a disjointed system – maybe we need a patient advocate, or someone who has been through it, or we need a new role. It is an issue of the balance of the clinical team. It needs someone who is being human about it.'*
- Anna also feels there is a need to improve how the system deals with mistakes. *'The system doesn't learn from its mistakes, because they are afraid. There is a fear of negative consequences if they admit mistakes.'*
- Another issue for Anna is the almost exclusive emphasis on the patient. She feels that a more holistic approach is needed – *'the treatment is focused mainly on the person who is ill, not on the family or carers or significant others. However, the person who is ill is relying on the family or the carer to take them where they need to go, whether it is out of hospital or to let go.'*



Staff Stories – “The Second Victim”

What is meant by the term ‘Second Victim’?

The term Second Victim was first coined by Albert Wu, MD, MPH, Professor of Health Policy and Management at the Johns Hopkins School of Public Health in a 2000 British Medical Journal article. He is a leading expert on disclosure and the psychological impact of medical errors on both patients and caregivers. In this article he recognised that when a patient is seriously injured by health care, there are

almost always two victims and one of those victims is obviously the patient. A second victim is the health care professional involved in the incident that feels in some way responsible and is emotionally traumatised by what happened.

A May 2011 study¹ identified that one of the most striking findings was how every second victim participating in the project described their respective unanticipated clinical event as a life-altering experience that left a lasting impression on them. One healthcare professional described his second victim experience as an “emotional tsunami,” unlike anything he had ever experienced before in his professional career.

Numerous variables contribute to the severity of the second victim response. A patient that ‘connected’ the healthcare professional to his/her own family (such as a service user with the same name, age, or physical characteristics as a loved one), the relationship between the service user and caregiver, length of professional relationships, cases that involved paediatric service users, and the healthcare professional's past clinical experiences influenced the severity of the second victim's response to the safety event.

Although each case was unique and the healthcare professionals involved developed individual coping skills they in common described a similar recovery path. The study identified six stages that described the second victim recovery process: (i) chaos and accident response, (ii) intrusive reflections, (iii) restoring personal integrity, (iv) enduring the inquisition, (v) obtaining emotional first aid, and (vi) moving on. The sixth stage was unique in that it led to one of three potential outcomes: dropping out, surviving, or thriving.

Though the six stages were common, the research found that similar to the stages associated with grieving, each individual, though not necessarily following the six stages in a linear sequence, does have a unique support requirement i.e. that no one intervention will meet everyone's support needs.

Supporting the ‘Second Victim’

The first and most important source of support to staff who are involved in an incident is the person's line manager and their colleagues. They need not to feel isolated and alone, rather they need to feel a sense of empathy and support. This response in many instances, especially in the immediate aftermath of an incident, does not need to be complex, it can be as simple as acknowledging the event and the impact on them and enquiring about how they are feeling, whether they would like to take a break or to go home early. The impact of such an immediate response cannot be overestimated and can greatly assist in framing the next steps. We need to see the offering and acceptance of assistance and support as a positive human response to what can be an emotionally distressing experience rather than a sign of professional/personal weakness and vulnerability. In addition to providing an appropriate support response at the time of the incident and following this up with an offer of more formal support options to staff (such as employee assistance programs [EAPs], social workers, clinical psychologists, or counselors), the next relevant support of or when available relates to ensuring that they have a positive experience in contributing to the incident review process and a chance to participate in any identified system redesign to reduce the risk of a similar incident recurring in the future.

¹ The Second Victim Phenomenon: A Harsh Reality of Health Care Professions <https://psnet.ahrq.gov/perspectives/perspective/102>

Without such support the impact of incidents on staff can be so devastating that it can have a bearing on their future practice and often in their personal lives. In some cases this can lead to those staff not feeling able to continue to the extent that they leave practice. In the same way as the Incident Management Framework places emphasis on the need to support service users and their families it must also seek to support staff. Our objective is to ensure that health care services have comprehensive systems and support structures, including training programmes, in place to

- (i) assist staff in preparing for and quickly responding to an incident including engaging in open disclosure discussions with service users and their families,
- (ii) aid staff who are experiencing normal stress after experiencing abnormal/highly abnormal events/incidents and
- (iii) to help staff to manage this stress so that they can better care for their patients, so healing can occur, and so that staff can comfortably return to the work environment with normal productivity.

The following stories illustrate the phenomenon of the “Second Victim” and have been kindly and courageously shared with us by staff. They both relate to nurses but there is a desire to broaden the repository to include other healthcare professional groups.

Caroline's Story

On 21st May 2013 I was sent on relief to a 31 bedded surgical ward. The ward was very short staffed and it was a busy theatre day as well. I was working with a Nurse Manager, a Pre-Reg nurse, an agency staff nurse and an attendant. The student and I took handover on 3 six-bay rooms and 2 side rooms while the manager organised the rest of the ward.

I allocated the student to look after the patients who needed breakfast while I quickly ran around checking the observation sheets. I checked that the patients for theatre were ready and then turned my attention to my post-op patients.

Mary was Day 1 post abdominal surgery. She was on intravenous fluids, patient controlled analgesia and oxygen. She said she was comfortable at rest but did have shoulder pain on coughing. I encouraged her to use the PCA and after checking her vitals I moved along to see the other post – ops. The Consultant reviewed Mary while I was attending to another patient. Mary informed me that he reassured her that her shoulder pain was to be expected, he encouraged her to mobilise and advised her that she could commence sips.

She mobilised to the bathroom with assistance for a wash and on return to her bedside sat in an armchair. Her Early Warning Score was 3 at that time but I was not alarmed as she had mobilised and was on 2L oxygen.

Late morning she had routine bloods taken and after physiotherapy she returned to bed for a rest. When I checked on Mary she looked uncomfortable and she felt she may have overdone it. I checked her pulse noting she had a slight tachycardia so I encouraged her to use more analgesia.

Just after lunch, the Physiotherapist informed me that Mary was light headed so she didn't take her out for a walk. She had used a lot of analgesia and had pin point pupils. We got her back to bed as she felt unwell. At this point she was hypotensive and had a tachycardia. I contacted the surgical team, did an ECG and increased her fluids.

I continued to keep her under observation while I managed 2 other patients who had returned from theatre as well as giving 2pm medications. About an hour later the student called me to say Mary was nauseated. When I went to give her an anti-emetic I noticed she was very clammy. She said she was dying and asked me to get her husband in. I reassured her that it was probably the analgesia that was making her feel poorly and that she'd be fine.

Caroline's Story (continued)

The Intern arrived after 4pm. He reviewed Mary and said the Registrar was on the way. It was about 5pm when the Registrar and Consultant came to the ward. I went to get her blood results while they reviewed her. I was alarmed to see that her urea and creatinine were extremely raised. Mary told the Consultant that her shoulder pain had gotten steadily worse throughout the day. He asked for an urgent x-ray and increased her intravenous fluids.

The nurse manager arrived and questioned why I had not documented more frequent observations in the Early Warning Score sheet. This was done in front of the consultant and patient who looked even more apprehensive. I was told to write up my notes and another nurse would take over from me. I completed my nursing notes on all the patients, and left the ward after 6.30pm.

I returned to work in my own ward the next day and was called into the manager's office. She said that Mary had died at 11pm that evening and that there was criticism of my records and the care I had given. My manager was sympathetic but advised me to jot down what happened as the risk manager wanted to interview me.

I was devastated for Mary and her husband who had joked with me that afternoon about Mary liking her morphine. I remembered telling her she'd be fine when she said she felt something bad was going to happen. I also remembered the nurse manager telling the consultant that I hadn't recorded the observations enough and was distraught that perhaps I was somehow to blame. It was so unfair as I hadn't stopped running all day and stayed back after my shift had finished because it was the right thing to do and I couldn't just walk away when it was so busy.

Later that day I met the risk manager who asked if I was ok. I burst into tears when she tried to be nice to me – it was as if she had opened the flood gates – a patient I had cared for died, I couldn't cope with someone being nice to me!

She asked me why I was so hard on myself and I told her about the conversation I had overheard and how I had left the ward that evening totally deflated but this was nothing now that the patient had died. She explained that she would carry out a review of Mary's care but not to worry. How could I not worry; a patient died and I was being asked to account for my actions.

I was so angry, I had never had any training on the Early Warning Score but I was a bloody good nurse and I may not have recorded every single thing I did with Mary that day but I did the best I could when the ward was short staffed and the manager never came near me.

The risk manager was soothing but I knew someone would be held to account and it would be me. She offered me support but I just wanted to get away from her, she asked if I wanted Employee Assistance and I felt my world was falling apart.

We arranged to meet the next day to finalise my statement. I phoned my partner and he told me that I shouldn't have given a statement without getting advice. I didn't sleep that night with worry. The next day when I was on duty the consultant was on my ward and he approached me. He asked me what had gone wrong the day I looked after Mary and why hadn't I called his team sooner. He was told that not completing the Early Warning Score sheet was a fitness to practice issue but this was something he wouldn't share with Mary's husband who wanted answers.

I felt sick; I didn't know who to turn to. I contacted my friend and she tried to reassure me but I couldn't even listen to her. I felt I was going to be physically sick and couldn't concentrate on anything. Eventually my manager told me to go home but to let the risk manager know as we were to meet up in the afternoon. I called her and she said she'd come to see me. When she arrived she didn't say a word she just hugged me and I felt my heart burst. I vividly remember that moment thinking I had never felt so crushed before – this is what devastated sadness feels like.

The risk manager took me to her office. I told her about the conversation with the consultant. She could see I was destroyed and kept telling me that it wasn't my fault, that I was good at my job and my line manager totally trusted me. It didn't help, Mary had died on my watch!

I gave my statement and was told to keep my chin up. She gave me her number and told me to call her anytime. She couldn't see that meeting her would be painful and so I kept it all inside and returned to work on my ward half the person I had been.

Caroline's Story (continued)

I had been planning my wedding but I felt my light had gone out and felt it was wrong to be planning my wedding in the aftermath of this awful event. Some weeks later I met the Intern who had reviewed Mary and he asked me how come I hadn't noticed the patient had deteriorated. I couldn't even answer him – I knew then I had to move to another hospital. That evening as I was leaving the ward the manager called me aside saying she was worried about me. I had lost weight and was drawn – Did she think I was made of stone!

The next day the risk manager came to the ward and I felt sick with worry. She took me for coffee and asked me to tell my story again as if it was for the first time. She jotted down some notes. She read out the statement I had given her 5 weeks earlier and then read out the notes she had just written. I was shocked at just how different they were. My statement was an account of my care and observations and the notes she wrote were ones of self-doubt and self-criticism.

She reminded me that Mary's death was subject to a Coroner's Case and we didn't know the cause of death and I was doing a disservice to every other patient in my care. She asked me what exactly I was taking the blame for. Did I order the bloods? Did I neglect to call the doctor? Did I falsely reassure Mary knowing her fate was to die!

She made me promise to phone the Employee Assistance Programme and I did.

The risk manager phoned me when the Coroner's Case was scheduled as I was called to give a statement and she came with me. It brought it all back, that sick feeling in my stomach that I'd have to meet Mary's husband again and see the anger in his eyes.

I answered the questions asked of me by the Coroner, he was very formal but his questions were very clear and there were no catches. He noted that my care was exemplary. Mary had sustained a perforation during surgery. She needed antibiotics and surgery to save her life.

That was over three years ago, a time in my life I will never forget. I did get married but it was a very different person who walked up the aisle. I did leave my job and went to work for an agency while I sorted my life out.

I am strong now and I care for my patients zealously, perhaps too intensely at times. I can never let go of the feeling that Mary might be alive if I had done more.

Sean's Story

I was a nurse manager in an Accident and Emergency Department in another country.

The department was experiencing one of its busiest ever days for emergency admissions. An inter-hospital/ ambulance service overflow emergency plan had been instigated but the neighbouring departments were also full and the ambulance service continued to bring patients to my department. Having got in early at 7.30 that morning I decided to stay on after my shift finished as there were several ambulances "stacked" outside, all cubicles were full and the floor area was full of patients on trolleys. I took over the triaging of ambulance patients to try and get these people into the department from the ambulances waiting outside. I triaged one patient who had fallen and sustained a limb injury. The patient was conscious, alert and orientated. Having had the handover from the ambulance crew I allocated this person a "yellow" category (to be seen by a doctor within one hour) I asked a nurse to do a baseline set of observations. I moved another patient out of a cubicle and this patient was taken in and transferred to a hospital trolley. I did not see this person alive again. I left the department later that night – it was still extremely busy. I returned the following morning at 07.30. I was immediately informed that a patient had been "found dead" in a cubicle. It later transpired that this was the individual I had triaged and this person had not (to our knowledge) been checked subsequent to having had initial observations on arrival.

All of us who worked that evening and night were shocked and upset at this death. The fact that this person died alone behind a curtain, without being checked for several hours, was particularly distressing.

An external review was commissioned and all those involved were assured it would be a systematic review looking at all the operational aspects of that evening, night and morning. In the event it felt like an exercise in apportioning blame. In the immediate aftermath and during the review there was little or no support for those involved. None of us was asked if we were needed help or support – we were expected to get on and cope. There was significant media and political interest; it felt that there was a clamour to have the report completed and fingers pointed at the nursing staff in the department. Staff were kept in the dark about the outcomes of the review; we were informed that the report would be anonymised and focus on the issues of overcrowding, understaffing, medical and managerial support and bed management. In the event all these significant factors were given little if no credence and on the morning of publication we were told that the report would not be fully anonymised before release to the media by press conference.

This felt like a second blow to those involved. Each of us wanted a full but fair disclosure of events on that night but this was not to be. To those involved it felt like we had been hung out to dry. We acknowledged and fully accepted certain failures but the absence of support following the event and then during and after the review have had lasting effects on me and several of my former colleagues. The feelings of distress, failure, anger and something akin to grief never leave. They are suppressed but can resurface at any time, triggered sometimes by the most innocuous event or recollection.

It is a cliché but none of us came to work that day to give anything less than our best. An individual died alone in noisy A&E Department having been left for several hours without anyone checking their wellbeing. That tragedy can never be reversed nor erased.

The Health System, particularly Emergency Departments, is under incredible stress and strain. An event like this could happen again. I hope it doesn't but if it should I would ask that if you are a Senior Manager you remember that the concept of the "second victim" is a real phenomenon. A cursory "are you OK?" is not enough. There are at least three former colleagues who, following traumatic events, have left nursing and are scarred by the experience of the event and the lack of support in the aftermath. Supporting staff and caring for their welfare is a tenet of basic humanity let alone a managerial function. Not everyone wants to be cuddled, counselled or comforted but if you don't ask, how can you know?



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