Litany of professional and system failures; needless death of 21-year-old Kevin

The beginnings of the tragedy

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 (3.51 mmol/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.

Kevin's symptoms persist and worsen

After this, Kevin had repeated consultations with his GP, physiotherapist and other services. But Margaret says *'...on each occasion, he was returned to us as seemingly healthy and without explanation for his sometimes unacceptable and erratic behaviour. Only later did we learn that this behaviour was due to the chemical imbalance caused by his undiagnosed medical condition and the fact that, while his bones were being starved and softening, the viscosity of his blood was being altered and putting a huge strain on his heart.'*

Kevin spent the summer of 1999 in the US. On his return, he attended his GP complaining of lethargy, occasional vomiting and continuing bone pain.

Calcium levels become even higher, but not given appropriate attention

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. It was at this point that Kevin's contact with primary care came to an end. Sadly, Margaret says *'our next interaction with his primary care physician was to inform him of his death in the hospital four days later'.*

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. The hospital did not have the benefit of his original blood tests, from almost two years previously, and the more recent *'off-the Richter scale'* calcium levels at 5.73m.mol/l. The absence of complete and integrated records and proper communication between primary and secondary care professionals were significant contributory factors to his needless death.

At this time, even as his condition deteriorated rapidly, no medical personnel seemed to appreciate how ill Kevin was. Margaret recalls speaking with the consultant in the hospital corridor on the afternoon before Kevin was transferred to a tertiary hospital. She asked was he concerned at all about the delay in his transfer, and told him she had this '*desperate sense of urgency* (hand on chest*)'.* Kevin's brother interjected and inquired about what they would do differently in that hospital. The consultant said that they would do nothing differently; perhaps they would take a biopsy on Monday or Tuesday. But Kevin was dead on Sunday, and Margaret says *'You ignore at your peril the concerns of a mother…'*

Despite his continuing decline, no alarm was raised. Kevin 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. '*Two crucial days were lost during his stay in that hospital – further missed opportunities as yet another point of contact failed Kevin...'*

A weekend admission and Senior personnel not alerted to his deteriorating condition

Finally, he was transferred to the 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'.*

Kevin dies needlessly

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.'*

Kevin carried a donor card so Margaret asked about organ donation, but '*...the doctor shook his head - Kevin had been allowed to deteriorate to the point where his organs were of no use to any other human being. That was very difficult to hear...it was almost like Kevin dying twice. The doctor then asked if we would like him to enquire about the possibility of donating Kevin's eyes. So Kevin's corneas were donated and we later learned that two people now have sight, a 42-year-old woman and a 60-year-old man.'*

Margaret says *'...Kevin's death certificate lists multi-organ failure, hypercalcaemia, parathyroid tumour...but stresses that 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.

Lost learning opportunities

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.'*

Many unanswered questions

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 boy 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.'*

'Disappointed and frustrated, we retraced Kevin's medical history over the previous three years. The story slowly and painfully unfolded. Failings and shortcomings were many in number and serious in nature. They were indicative of system breakdown and were compounded by misdiagnosis, inappropriate treatment and management, together with issues of communication and data handling... laboratory results were mishandled – tests provided sufficient data which was ignored and which, if interpreted correctly and acted upon promptly, would have saved his life. In fact, the potential to achieve proper diagnosis and treatment was sabotaged by a combination of filtering of the results and inaction. These errors ranged from his treatment at primary care level right through to that afforded him in a tertiary training hospital. That is why I say - every point of contact failed him.'

Struggle for acknowledgement and the truth

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"*. In relation to the Post-It, another doctor suggested that, even if it had been seen by his consultant colleague, it would not have meant anything to him. He said this was because it was not written as they would write it, in scientific notation. Margaret found this implausible *'...the suggestion that Cal might not mean Calcium and Sod might not mean Sodium, and they all in each other's company...and it was at that point that I lost faith'.*

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. This proved to be a difficult journey. Their experience was of a legal system that favours the defendant in these cases, especially in finance and resources. *'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 when a High Court judge declared "*it is very clear to me that Kevin Murphy should not have died*". Medical experts stated that: *"The combination of bone pain, hypercalcaemia and renal failure in a young patient points either to a diagnosis of primary hyperparathyroidism or metastatic malignancy and these ominous results should have been investigated as a matter of urgency...All the evidence indicates that the patient was suffering from a solitary parathyroid adenoma at that time and removal would have been curative with a normal life expectancy...Kevin would have had surgery to remove the over-active parathyroid gland. He would have been cured and would still have been alive today."*

Margaret says *'...it is clear that the orthopaedic consultant failed to fulfil his duty of care by not responding to the elevated test results and making a referral. It becomes all the more poignant when research tells us that the procedure - to remove what was discovered at autopsy to have been a benign tumour - has a 96% success rate with a 1% complication rate. Our family experience also bears this out. Three months after Kevin's death, his father successfully underwent this surgery. Wonderful odds in Kevin's favour, but we now know that every point of contact failed him...The necessary referral to an endocrinologist did not happen, the diagnosis of primary hyperparathyroidism was not made and hypercalcaemia was allowed to progress for a further year and ten months, by which time the calcium level was higher than any ever recorded in the tertiary hospital and was described as "inconsistent with life".'*

'It is also clear that primary care failed Kevin by filtering test results and communicating only what supported the GP's differential diagnosis, depriving the patient of the benefit of a second pair of eyes seeing the complete results.'

As a result of the five-year litigation process, 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.

There was also a financial element of the settlement, but Margaret says *'...monetary compensation was never an issue for us as a family. The truth is that the sum of money does not exist which would equate to Kevin and neither could we imagine any circumstance in which we would derive benefit or pleasure from that money. Consequently, we donated the settlement figure to two charities.'*

Lessons that could be learned

Kevin's needless death prompted Margaret to become active in the pursuit of safer healthcare systems. She is External Lead Advisor of the WHO Patients for Patient Safety Programme (PFPS), which advocates for a culture of safe care that is more inclusive of patient and family, and was a prime mover in the establishment of the PFPS group in Ireland. She identifies two key factors as motivators for this: '*Every point of contact within the Irish medical system failed Kevin. That grave injury was compounded by the very real fact that learning opportunities were frustrated by damage limitation efforts after his death. I would contend that the duty of care to the patient does not end with the death of that patient.'*

Margaret's journey and reflections have identified many shortcomings and contributory factors to the tragic outcome, at both primary and secondary levels:

Primary Care

- Inability to recognise seriousness of Kevin's condition
- Appropriate and timely interventions not taken
- Selective and incomplete transmission of laboratory test results
- Non-receipting of vital information – duty of care
- Absence of integrated pathways
- Link between his uncharacteristic behaviour and test results not made, despite the textbook *'moans bones groans'* symptoms
- There was absolutely no tracking of his deteriorating test results – no longitudinal approach
- Serious absence of direct communication with the patient.

Secondary Care

- Treatment management left at Registrar level
- The team dynamic – why did nobody in that team, junior or senior, speak up on his behalf?
- The impact of a weekend admission
- Patient asked to accommodate system – opposite of patient centred care
- Expectations of a Tertiary Training Hospital not met.

Margaret emphasises the importance of primary care in preventing treatable conditions from escalating. *'Kevin's case history clearly illustrates that people who become acutely ill often have a long antecedent period where successful intervention is possible. The optimum location for those interventions, either to be delivered or initiated, is often at the level of primary care as the GP plays a key role in determining the future care path of their patient.'*

Ensuring test results are noticed and acted upon

Failure to properly flag and act upon Kevin's test results was a key factor in his needless death. Margaret says '*...it is also significant that, throughout Kevin's care, only one set of clinical eyes saw those particular test results – at no point in his care was the hard copy forwarded and neither did it travel with Kevin as part of a patient-held record - no one else, patient or clinician, had an opportunity to revisit them or question them. The opportunity to initiate best practice was thwarted by: (i) not recognising the seriousness of his condition; (ii) the absence of a system to flag the high calcium readings in a way that insisted on immediate referral ; and (iii) not communicating the test results in their entirety and thus preventing the patient from benefitting from that "second pair of eyes".'*

Importance of Open Disclosure and Non-adversarial systems

Margaret says '*...as patients, we cannot give permission for error. However, we do understand that the practice of medicine is a complex and risk-laden endeavour. I accept unreservedly that no one intended any harm to Kevin.'* She feels that Open Disclosure has to be part of the culture of each organisation if learning and improvement are to be achieved. Disclosure is not about blame. It is not about accepting blame, nor about apportioning blame. It is about integrity and being truly professional.

Cases like theirs need to be heard in a non-adversarial environment, where the focus is not on blame but on honestly arriving at the truth, acknowledging what happened, and identifying ways to prevent a recurrence – in short, learning from the tragedy. For Margaret it is very obvious that the current adversarial system does not serve anybody well. *'I am convinced that proper disclosure and dialogue with us as a family would have been far more beneficial to all parties, would have avoided almost five years of trauma and uncertainty brought about by the litigation process and the inappropriate responses which forced us down that route.'*

Changing systems and cultures

Margaret also points to the need to change systems and culture. *'Taking personal responsibility seems to be a taboo, and error, in particular, is often attributed to system failure. A combination of factors is nearer the truth - in most cases there is a personal and individual component and we have to take responsibility for that...'*

'... It is also very certain that something called a "system" did not walk through the front doors of our institutions and say "from now on I'm running the show around here". Systems are designed by people, they are maintained by people and they can certainly be changed by people...what's needed is transparent and open handling of critical incidents, coupled with supporting patient, family and staff – a combination of acknowledging error, achieving learning, preventing recurrence, allowing staff to recover and be more effective in the future...'

Listen to patients and their families

Recalling her anxious phone call to the doctor's office, recorded in the notes but not acted upon, Margaret emphasises the importance of really listening to patients and their families. '*Carers and family members are often dismissed as being "over anxious". I would say that you ignore at your peril the concerns of a mother…The patient and family are critical components to the integrated care process. My understanding is that one of the aims of the integrated care pathway is to improve clinician-patient communication and patient satisfaction. Sadly, the missing link in the process is, more often than not, the patient [and family]*'.

Caring for the medics as well

Margaret also accepts that there can be a great burden for healthcare professionals as well when tragedy occurs. *'To this day I am concerned for the Registrar who clearly found the outcome so difficult. At a chance encounter, I identified myself as Kevin's mother, he looked shocked, blurted the words: "I didn't think he'd die" and fled the scene. Clearly no one had taken care of him either.'*

Final words from Margaret, as a mother

Margaret tells us that the motto of the British Medical Association says of healthcare: With head, with heart, with hand. She says her call for care that is delivered with those three elements, her 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.'***

A wish list...

When thinking about what she has learned from all of this, Margaret says '... *I have my own wish list, a patient and family wish list...'* and feels that much of this would resonate with what would be found in a structured patient-safety investigation of a tragic healthcare failure such as this. The list would include things like:

Individual Practitioners

- Observe existing guidelines, best practice and SOP's; be prepared to challenge each other in that regard
- Listen to and respect patients and families
- Know your personal limitations. You do not own the patient; your duty is to respond to his needs by making appropriate and timely referrals.
- Keep impeccable records and refer constantly to those records.
- Communicate effectively and completely within the medical community and with patients.

For the System and Individuals

- Following adverse outcomes, undertake "root cause analysis" and "system failure analysis"/"critical incident investigation", and include patients and families in that process
- Replicate what is good and be constantly vigilant for opportunities to improve
- Learn and disseminate that learning by putting in place a fully compliant and just reporting and learning system.
- Practice dialogue and collaboration – meaningful engagement with patients and families.
- Create a coalition of healthcare professionals and patients.
- When things go wrong, be honest and open and seize the opportunity to give some meaning to tragedy.
- Acknowledge error and allow learning to occur.
- Do not allow yourself be seduced by the notion that such things could not possibly happen in your organisation – anything can happen to anyone, anywhere and at any time – 5 most dangerous words.
- Above all, accept that to err is human, to cover up is unforgiveable and to refuse to learn is inexcusable.