Potentially catastrophic misdiagnosis: Melissa's story

Worried about risk of miscarriage

In July 2009, Melissa was 5 or 6 weeks pregnant with her youngest child. She had a history of early miscarriages, having had 4 previously. Although she had 2 children already by this stage, she was worried about this latest pregnancy. *'In my panic 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 and see would they check. I went in the following day and had a scan where they said that they couldn't see anything but they asked me to come in again in 2 weeks' time.'*

Immediately prior to this second scan 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 previous 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.

Her husband dropped her off at the entrance to the hospital unit while he went to park the car. Melissa went on in and the scan was performed immediately, even before her husband had re-joined her.

After a scan, told the pregnancy was not going to progress

Melissa could see on the scan that the foetal sac had gotten bigger but then the doctor looked at the midwife and just shook her head and then she was told that: '*Sorry, but this pregnancy is not going to progress'.* Melissa said *'Are you sure – the foetal sac is bigger'*. But the doctor said *'There is no heartbeat there'.* 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. At this stage her husband had still not arrived and Melissa said that they needed to get him to come in. They went out to fetch him, and he came in to be told that Melissa had lost the baby.

'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. I didn't want nature to take its course because I didn't think I could cope emotionally. I had taken the tablet on a previous miscarriage but had found that to be very painful, so we said that we would go for the D&C, because it was quick and it was clean and I had had it before. Lucky for me there wasn't a slot available until 2 days later. They told me to go home and they gave me a drug called Cytotech to be taken on the morning of the D&C to open the neck of my womb and help it contract. '

A chance meeting changes everything

The following day, however, Melissa still felt pregnant. By chance, she met with a friend and discussed the situation with her. As she was talking with her friend some doubt crept in for Melissa. Her friend told her that the local GP practice (unusually) had a scanner and suggested she go along there to get a second opinion. Melissa decided to do this, even though it was not here own GP practice. Melissa's husband was on his way home from work at the time, and was surprised to hear that Melissa was at the GP office. He joined her there.

What a surprise for Melissa 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?' And she said to me 'could you just wait a minute, I want to go and check with the other 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. He said 'I'm afraid the hospital are very wrong'*'. "My husband was elated at the news, but was also very angry".

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.*

Unsatisfactory hospital response

Melissa's husband rang the hospital to tell them that she would not be coming in for a D&C. They informed the hospital at 9am (an hour or so after she was due to have received the D&C) that she had had a second scan and that the foetus had been found to be alive. Melissa was asked to come to the hospital to follow-up. *'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 to see the heartbeat, but eventually she said that she had found a good strong heartbeat. Melissa was given a progestin tablet 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. *'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 asked who would be looking after her for the remainder of her pregnancy and they asked a senior consultant to take over my care. *"I was assured that the original doctor would not be any part of my care".*

Melissa continued the pregnancy and was hospitalised twice during the remainder of the pregnancy 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. During that period, Melissa's husband had been on to their solicitor and had informed him of the situation

'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 and 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! 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".

After the birth of her son Michael, Melissa says *'I was so happy that Michael was now mine to care for and I could keep him and mind him myself.'* But the experience had been a very traumatic one for Melissa and her husband. There was a see-saw of emotions as events unfolded. Firstly, there was anxiety, sadness and confusion at the initial diagnosis of miscarriage. Then there was elation and relief at the good news, followed by confusion and anger at what had happened. Melissa's and her husband's reactions to what happened were compounded by the hospital's inadequate acknowledgement of the events.

The hospital investigated…. but no follow-through

Late in the pregnancy, Melissa's husband found out from their solicitor that the hospital had done an internal investigation and reported on it. But they had never discussed the case with Melissa. They had found that the heart rate monitor was old and subjected to a heavy workload and that this had been known before Melissa's investigation. In addition, the couch that was used in the examination was the wrong kind of couch, and that the person who did the scan wasn't qualified to have done so.

Despite this, nothing had been done at that stage as a result of this investigation. *'They were still using that scanning machine 6 months after my case.'*

Melissa was unhappy with this response, which she felt to be incomplete, uncommunicative and inadequate. She had not been involved in the internal hospital investigation and she was also unhappy that, during the remainder of her pregnancy, no reference was made to the initial difficulties. '*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.*

Melissa decided to publicise the details of her ordeal, which she did initially through the medium of the Irish Independent. This was followed by press interest from other newspapers, TV News and on line media comment. It culminated in a RTE report on Primetime where the details of Melissa's case were presented. This publicity led to questions being asked of the Minister for Health in the Dail and resulted in the establishment of an independent enquiry.

'I went to the Irish Independent and told them my story. I just wanted the recommendations from my report to be implemented and I wanted it to be done sooner rather than later. They carried the story the way that I wanted it – they didn't sensationalise it. The day after publication, another woman came forward in Galway – there were many similar stories that followed, each within different hospitals in Ireland. It then transpired that so many people were contacting their hospitals that both the hospital and the HSE had to set up helplines. I felt very sorry for these women, because they will never know whether their baby was dead or not.

Independent enquiry

The independent enquiry, under the Chair of Prof. William Ledger, covered the entire set of HSE maternity hospitals. It found that there had been as many as 24 similar cases in the previous 5 years. The causes of these problems were also similar – faulty and outdated IT equipment, lack of training, lack of appropriate couches and a lack of appropriate services.

Going forward an important positive outcome of Melissa's terrible experience was the publication of the results of the long awaited National Miscarriage Misdiagnosis Review in April 2012. Since the Review's publication the HSE has been implementing its recommendations through the Clinical Care Programme in Obstetrics and Gynaecology. The implementation of the Report's recommendations will ensure that there are measures in place to prevent recurrence of a misdiagnosis of miscarriage.

National guidelines on the management of miscarriage in the first trimester have been developed and an educational programme for all disciplines is now in place.

The Irish Maternity Early Warning System (IMEWS) has also been successfully implemented in all maternity units since April 2nd 2013. Ireland is the first country in the world to implement a national standardised system. An educational programme for using this system has also been successfully implemented nationally.

A diploma in early pregnancy ultrasound for all disciplines involved in early pregnancy care was also established in UCD.

Lessons that could be learned

Unusually, the events in Melissa's story were the subject of two investigations – one at hospital level and the other at national level. Many lessons were learned and apparently the recommendations were all implemented. However, there are also some other lessons to be learned that are perhaps less obvious.

The hospital investigation identified a fault with the scanner that was used in the hospital, yet it continued to use it even after the failure to correctly identify a foetal heartbeat. It seems that no corrective action was taken in this regard until after the independent investigation.

The initial hospital investigation was conducted without involving Melissa. This came to its own conclusions and these were not communicated to her as a matter of course. It would have been both more proper and more effective to have involved Melissa in the investigation and to have communicated its results to her.

Melissa feels 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, none of the subsequent problems would have happened. Part of this lesson is about enabling women to trust their own feelings in situations like Melissa's.

Melissa also feels that there are other learning points that may not have been acknowledged, even with the two investigations that have taken place. One concerns the response of the health care system to the investigations that took place at hospital level. There appeared to be no communication between the hospital and other maternity hospitals until the second investigation took place, even though it might have been expected that similar problems were occurring elsewhere.

A second issue concerns the role the Clinical Indemnity Scheme might play in identifying and acting on problems. It would appear there is no analysis of data collected for purposes of managing and preventing risks such as occurred in Melissa's case. Given that the Ledger report identified as many as 24 similar cases over the previous 5 years, why was the risk not picked up earlier?