



At a loss

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Deborah Crawley

Losing your parents is sad but acceptable because they've lived a long and happy life, but losing a baby is unacceptable. It's just not what you expect.

Ala Maniatakis

Seeing your child who looks a bit like you, a bit like your husband then you feel this surge of love immediately, so kind of sending her away to mortuary, that was the hard bit. Because I didn't want to let her go.

Nick Maniatakis

Your mind has to be quite ordered and you have to speak to the relevant people, even register the death, organizing the funeral, speaking to the funeral directors, picking the cemetery. I think when something like that happens, you don't know what to think and actually having decisions to make almost gave me something to do and something to focus on.

NARR:

Losing a baby is every parent's worst fear. At a time of shock and overwhelming grief they have to make a whole range of difficult and important decisions that can seem totally bewildering; one of them is whether or not to have a post mortem. or not. The decision can often divide parents. Dr. Philip Cox is a perinatal pathologist. He is actively involved in training and educating hospital staff who approach families for consent.

Philip Cox

I wouldn't argue that all babies should have a post mortem, but I would argue that every family who loses a baby should have the opportunity to make a decision over a post mortem. So I would say that there is value in any pm that is undertaken whatever the circumstances. One in 200 babies dies as a stillbirth. Stillbirth is 10 times as common as cot death. In many of them we don't really fully understand what has happened but information from pm can help to bring us some better understanding of what is going on. It's only by looking at large groups of babies who have died, the background to the deaths and the placenta and everything else around that that we can possibly come to an understanding of really what is happening in many of those babies and prevent at least a proportion of those deaths happening.

NARR:

Nick and Nick and Ala Maniatakis noticed that their daughter Eleni had stopped moving the night before they were due for a routine routine ante-natal appointment at 29 weeks.

Nick and Ala Maniatakis

Fairly quickly the doctors and midwives were sitting us down to tell us our options. I had presumed that we would probably do a cesariancesarean to get the baby out immediately I thought that would just be the norm. But they said you have to go home for two days and come back in two days to give birth, which at the time I was horrendous and with hindsight was probably the best thing we could have done because I think had Ala given birth immediately – we were so emotionally all over the place at the time that I don't know how we would have felt when we'd see our baby and the two days at home where we cried, we saw family, we saw friends. aAt least I was mentally prepared two days later that, obviously I didn't have to do anything physically but I knew that I was kind of ready to be there and to be supportive.

Ala Maniatakis

I think it only took six hours between induction and giving birth and I was quite grateful for that. At home we were given all these information packs. SANDS brochure if you want to see your baby, if you want to take photographs, what do you want to do about the burial and post mortem as well. So in those two days we tried to discuss what we want to do and we decided just to everything, whatever was there, to see your baby, have photographs to have post mortem, just pretty much everything.

NARR:

C was admitted to the day assessment unit at 28 weeks because her son J's had slowed down his movements had slowed. The condition she refers to is associated with a higher rate of fetal death.

C

I had a reversed end-diaostolic flow through the umbilical artery which meant that they wanted to get him out very quickly. It was a very shocking out of body experience to be whisked into theatre at 28 weeks when you're not expecting it and have him taken away and then eventually seeing a tiny, tiny baby in an incubator with wires. I think it's very difficult to feel like a mother in that situation when you're being told they're very, very sick and you've got careful about even touching him. I certainly wasn't able to hold him until he was dying. After J died we had a lot of contact with his neo-natologist who was superb and the option for post mortem was discussed. Our neonatologist felt quite strongly that that would be a sensible option for us, given the multitude of issues that J had had with his kidneys and his clotting issues and the extent of the bleeding in his brain. And I felt we had built up a strong trust relationship with our neo-natologist and really felt that if he felt that was important

to explore further, then we'd like to do that, partly to find out what happened to J, partly to – we weren't at the stage of thinking about other children but it was put to us that if we did want to have other children it would be important to understand the underlying causes and also for future research for other families. So really all of those things, for me, combined to thinking that's why we wanted to have a post mortem.

NARR:

After the post mortem on their daughter Eleni, Nick and Ala met up with the consultant to discuss the results.

Nick Maniatakis

Obviously there's a huge amount of medical terms, you know, we're not medical people so it's not the easiest thing to understand but the overriding impression - and I got confirmation at the meeting - was that there was no reason. And we'd read obviously - the age of the internet and there's lots of experts out there - I think we were quite prepared for it, I can't remember what the stats are now but, whether it was 50 or 60 or 70 percent, there was a very high percentage where you just don't know what happens. So we were semi-ready for it and in my mind I was hoping that if they did find it, it wouldn't be something serious and next best would be to find nothing because then we'd know it was not some serious genetic issue. It not being anything major was reassuring in itself. We still want to know why and we still ask why and that will never be answered, I don't think.

NARR:

Many parents feel frustrated when they receive an inconclusive result to their child's post mortem, but as Dr. Philip Cox points out that a negative result is still a very important one.
Phil Cox

Yes, we don't always find the cause of death but that in itself is important in the future management of pregnancies for the mother. Depending on what classification you use of still births anything from 60% are negative or unexplained is the term that's used, or if you use more modern classifications 10 or 15 % are unexplained but even that unexplained group are a group and in effect it's a diagnosis similar to sudden infant death syndrome in that it's an unexplained natural death in a child and that does inform the obstetricians and the families for future pregnancies so whilst it is "negative" quote unquote that is actually a useful piece of information.

NARR:

Fetal growth retardation, or failure to thrive, is now thought to explain 43% of stillbirth. One of the many questions parents may be asked to answer when they consent for to a post mortem, is about might also be asked to give permission to for retain an organ or tissue sample to be retained in the hospital for a particular period of time.

C

It was felt very necessary to look at his brain very carefully so we were advised that it might anything up to 8 weeks to fix his brain, to look at it and then to return it to his body which we specifically said that we wanted prior to his funeral. So he was actually away for 4 weeks. It was almost 4 weeks to the day when we had his funeral.

For us it was very important to have everything put back more or less where it should be. So to have his brain returned and his other organs returned was very important although we did give consent for blocks and slides to be retained for the future and for research purposes so we didn't reunite those.

NARR:

Consent for post mortems dropped significantly after the scandal surrounding Alder Hey children's hospital in Liverpool in the 1990ies, when it was found that hundreds of organs had been removed and retained without authorization from parents. It led to the creation of the Human Tissue Act in 2004 which changed the legislation surrounding the handling of human tissue. Philip Cox was a perinatal pathologist at the time.

Philip Cox

In the few months following Alder Hey, I was here at this hospital, and the number of PM dropped from 30, 40, 50 a month down to 10 or 15 but only for a few months actually. After that initial period the rates recovered and since then the number of post mortems have been growing almost year on year. The rates of PM aren't as high as they once were. There were hospitals where 90% of babies would have a post mortem. And I don't think we'll ever achieve that and I don't think that's a problem. But we are now for a lot of hospitals at around 30-40 % of the cases will have a full post mortem and a proportion of the others will have at least some form of examination.

NARR:

But the time it takes for the results of the post mortem to be processed can be very difficult stressful for families.

Nick and Ala Maniatakis

I think the most difficult thing around the whole thing was that it took us weeks to have a burial. We lost Eleni in August and I think that's when the summer holidays are because it took a while for the post mortem to get the results back. She was born on the 6th of August and I think the funeral was on the 13th of September so it was about six weeks later.

Ala Maniatakis

:Yes, I think the waiting to get the body of Eleni back just to have a burial was awful. I wish it could be a bit shorter. It's irrational in a way, but if you think of your baby in some cold, dark

room, you just want to lay her to peace you know.

NARR:

It is important for parents to know that their baby will be treated with care and respect while it is at the mortuary. Sarah Davis is a deputy mortuary manager who assists the pathologist with the Post Mortem and looks after the baby until it is released back to the family.

Sarah Davies

How the babies are presented to us in the mortuary is that there is notes attached to the clothing asking that specific requests from the family. Can this teddy stay with baby, can these clothes be redressed on the baby and we always follow those requests. All types of possessions are definitely logged here. So whatever comes with the baby is released with the baby. We take special notice of that. We are conscious that there are families at the end of a telephone anxious about their babies and so all babies are definitely treated with respect and dignity at all times. That's a major part of our job really.

NARR:

The majority of parents whose loose a baby dies opt NOT to have a post mortem. Deborah Crawley's son Michael was diagnosed with a serious heart condition at 24 weeks. He had to have open heart surgery after he was born, but he didn't survive the operation.

Deborah

After Michael died and we were given permission to hold him and take him, the nurse came and said she could take the breathing tube out and we could have a post mortem or not. But my husband and I both said that surely, he'd been in open heart surgery all night, that they could see that he only had half a heart so why would he need to have anything more intrusive done to him. So we said we didn't want to have a post mortem. If I hadn't known the cause of my son's condition I don't know if I would have had a post mortem or not. I know that probably my husband would have said yes. He's an engineer and he needs answers so that he would have wanted to know the answer. But I do know that the post mortem doesn't always give an answer and that's really hard because everyone is searching for answers and closure and things like that.

I don't think that in all the time we were diagnosed that I don't think that anybody mentioned that he would die, and I think that was a bit of a failure really. But I don't know how you mention it to be honest, you don't think your baby is going to die, you don't think of it as an option.

NARR:

Penny Robertson is another mother who opted against a post mortem. Her daughter Lily Mae died in the womb at 36 weeks.

Band:

I was offered a PM by the midwife but me and my partner turned it straight down as we don't like the thought of Lily Mae being cut. That was our choice. The hospital did try and change our mind to try and get some results. When she was born we found out she had a short cord and that was what caused her death so we didn't need a post mortem to tell us that. I felt Lily Mae had been through enough.

NARR:

But having something tangible to remember their children by was extremely important, whether the parents decided to have a post mortem like C or whether they didn't like Penny and Deborah.

C

When J had died, at that stage the neo natal unit didn't have a dedicated room to take parents who were receiving difficult news or any kind of bereavement suite so it was very awkward. I was only 2 and a half days post cesarean. I couldn't sit comfortably, I couldn't get down on the sofa at all because it was very low so in terms of the actual time we spent with him after he died it was very confused and it was not ideal. The nursing staff unfortunately the very experienced nurse who was looking after J that evening went home and we were left with some very inexperienced nursing staff. Who didn't talk to us at all about memory creation. they just whisked him off, dressed him in something I would never have put him in and handed him back and said they'd taken some hand and footprints, but we weren't part of that process at all.

Penny Robertson

I got handprints, footprints and hair and a piece of skin. They just did it. I asked for the hair and my partner asked for the bit of the skin that fell off. And I asked for getting her dressed and wrapped up. All the things, the hair, the handprints, the skin and the footprints all went into my memory box on Lily Mae's shelf in my bedroom. I went on holiday quite soon after losing Lily Mae and I had a bag done with her picture on and I had some tattoos done with her name and a baby and wings in memory, so I could have her with me all the time.

Deborah

I think we had the handprints and the footprints to take home with us. I don't think they asked us. I think they just gave it to us as a package and I definitely didn't ask for them. But they are some of the most important things that we've got. His hand prints and his footprints and a tiny

little bit of his hair. – When we'd laid him down he looked different from than he did when he was alive and we decided that his spirit had gone if you like and we didn't see him again. But I don't think I knew that I COULD could and I think my husband was uncomfortable. But you see because we hadn't talked about it, because we didn't know what you could do, what your options are, I didn't know that I could go, that I could go back and spend time with him. I don't think I did. I knew that he was at the undertakers and I know that we drove past the undertakers and I thought I should have gone in to see him, but I didn't . There's always regrets. One of my biggest regrets is that he didn't get to meet his brothers and sisters. Because everything happened so quickly. We didn't know what was going to happen and then he died and then the opportunity was gone.

NARR:

If you, or someone you know, has been affected by any of the issues raised in this podcast, you can get more information from SANDS, the Stillbirth and Neonatal Death Society, at uksands.org, or the SANDS helpline, 0207 436 5881.

End it here because it is not about the post mortem and Sam and I prefer for Deb to have the last word.

NARR:

Meanwhile Nick Maniatakis is grateful that the circumstances surrounding his daughter Eleni's death allowed him the time he needed.

Nick Maniatakis

I'm very glad that out of a horrendous situation I've got some good memories and I can take solace that we spent time with her. We know that years ago this wasn't the case. Mothers from 20/30 years ago, I don't know how many years ago, never saw the children. But I think I've got some happy memories of the day, of the birth and the hours that we spent with her. And I'm happy that we've got those, I know that whatever happens in the future, I've got a child and that memory can never be taken from me.